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# SEX, YOUNG PEOPLE AND CHLAMYDIA: REDUCING THE IMPACT

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## STATEMENT OF ORIGINALITY

I hereby declare that this submission is entirely my own work, with due acknowledgement given to colleagues and co-authors given as appropriate, throughout the thesis. I also verify that no part of this work has been used for the award of any other degree or diploma.

Melissa Kang

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#### PUBLICATIONS FROM THIS RESEARCH

Kang M, Rochford A, Mindel A, Skinner SR, Webb M, Hillier L, Usherwood T. Young people get clued up about chlamydia: an internet based randomised controlled trial [abstract]. *Sexual Health*, 2007; 4:289.

Kang M, Rochford A, Skinner SR, Mindel A, Webb M, Usherwood T. Getting Clued Up in cyberspace about chlamydia: a randomized controlled trial of an internet-based intervention [abstract]. *Journal of Adolescent Health* 2009; 44(2) Supplement:S22.

**Kang** M, Skinner SR, Usherwood T. Interventions for adolescents and young people in Australia to reduce HIV and sexually transmitted infections: a systematic review. *Sexual Health* 2010; 7:1 - 22.

**Kang** M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Facilitating chlamydia testing among young people: a randomised controlled trial in cyberspace. *Sexually Transmitted Infections* 2012; 88:568-573.

**Kang** M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Sexual behaviour, sexually transmitted infections and attitudes to chlamydia testing among a unique national sample of young Australians: baseline data from a randomised controlled trial. *BMC Public Health* 2014, 14:12.

Kang M, Hillier L. Medieval wenches and other icky connotations: how young people's constructions of sexually transmitted infections deepen our understanding of their sexual health [abstract]. *Journal of Adolescent Health* 2014; 54(2) Supplement:S65.

Signed statements from all co-authors for the above publications verifying my contribution can be found in the Appendices.

The following prize was also awarded:

Victorian Society for Sexual Health. Best poster in Clinical/ Epidemiology research. Australasian Sexual Health conference, 7 – 9 September 2009, Brisbane Convention and Exhibition Centre, Brisbane, Queensland, Australia.

#### ABSTRACT

Genital chlamydia infection is a highly prevalent condition across the world and disproportionately affects young people. In Australia chlamydia has been the most common notifiable disease for fifteen years, with the overwhelming majority of notifications being among young people aged 15 to 24 years. The sequelae of untreated genital chlamydia infection include pelvic inflammatory disease, tubal infertility and ectopic pregnancy in women, and epididymitis in men. The asymptomatic nature of chlamydia, its population prevalence, curability and the availability of a cheap, sensitive and specific diagnostic test make it an ideal candidate for screening. Chlamydia screening has become the major strategy for chlamydia control in developed countries.

The Commonwealth Department of Health released the first National Sexually Transmissible Infections (STI) Strategy in 2005, which prioritised chlamydia control. The strategy included funding for a range of pilot interventions to evaluate chlamydia testing among priority populations, including young people. These pilot interventions were designed to help inform a national chlamydia screening program.

The research presented in this thesis arose out of a successful application for a chlamydia targeted grant as part of the first national STI strategy. The research includes two separate and linked studies, aiming to reduce the impact of chlamydia in Australian young people by increasing chlamydia testing. The first study is a randomised controlled trial (RCT) and the second a qualitative study using in-depth interviews and discourse analysis.

The aim of the first study was to evaluate the impact of an internet-based intervention on chlamydia testing among young people 16 - 25 years residing in Australia. The second study aimed to enquire about the experiences of young people who participated in the RCT to gain deeper insights into the quantitative findings, and also to explore how young people understand chlamydia and STIs more broadly.

For the RCT, recruitment, delivery of the intervention and follow up all took place online, via a purpose-built website about chlamydia and chlamydia testing. The intervention was personalised email interaction over six months between the young person and a nurse or doctor who

identified themselves and provided contact details. Young people in the control group received monthly impersonal emails from the 'research team'. The primary outcome was self-reported chlamydia testing at six month follow up. Secondary outcomes were changes in reported condom use, knowledge about chlamydia and attitudes to chlamydia testing. Intention to treat and per protocol analyses were conducted, because only a proportion of young people in the Intervention group engaged in email interaction (by responding to a personalised email at least once). Since interaction was the intended intervention, but did not always occur, outcomes for the whole intervention group and for the 'engaged' group were compared with the Control group in separate analyses.

Seven hundred and four young people (16 - 25 years) completed baseline information, 40 were excluded and five withdrew prior to follow-up. The completion rate was 47.3% overall. In the intervention group, 40.6% (95% CI 30.7% to 51.1%) reported having had a chlamydia test at follow-up compared with 31.0% (95% CI 24.8% to 37.2%) in the control group (p=0.07). A perprotocol analysis found that those who engaged in email interaction were more likely to report chlamydia test uptake compared with those in the control group (52.5%, 95% CI 39.3 to 65.4% vs 31.0%, 95% CI 24.8% to 37.2%, p=0.002). There were no differences in secondary outcomes between groups.

Emails received from young people who engaged in email interaction were subjected to content analysis. The tone of their emails was polite, friendly and/or grateful and many were also humorous without being flippant. The topics covered in their emails were much broader than chlamydia and included a range of sexual and reproductive health issues.

In addition to the 704 young people enrolled in the RCT, 152 young people who had never had sexual intercourse completed baseline data. We analysed the baseline data of all 856 young people who completed baseline data and compared sexually active and non-sexually active young people. Sexually active young people were more likely to smoke regularly or daily, to drink alcohol, or to have binge drunk or used marijuana or other illicit substances recently. Among the sexually active group, risk factors for having a history of any STI were 3 or more sexual partners ever, 6 or more partners in the past 12 months, condom non-use and being 20 years or older. Almost all sexually active participants said that they would have a chlamydia test if their doctor recommended it.

At the end of the follow up questionnaire in the RCT, young people were asked if they would be willing to participate in a secondary qualitative study involving face to face interviews. The interview guide included questions about the young people's experiences of receiving emails (personalised and impersonal, depending on their allocation in the RCT) and about their understandings of STIs. Seven young people (5 female, 2 male) participated in in-depth interviews. Interviews were digitally recorded and transcribed, and subjected to thematic and discourse analyses. Young people found regular emails from the research team acceptable, but six out of seven were from the Control group. There were three dominant discourses about STIs: the safety-risk (medical) discourse that emphasised condom use and STI testing; the morality-shame discourse that related to sexual activity and being young regardless of STI status, and the contamination discourse. Participants produced subject positions for individual STIs. Not all STIs were equally negative. Different STIs had different meanings including 'gross' 'disgusting', 'serious', 'scary', a 'medieval wench' and 'having icky connotations'.

This research found that for some young people, online engagement with a health professional did increase the likelihood of getting a chlamydia test. It was not clear from the subsequent study what factors might facilitate or prevent online engagement. Discourse analysis of interview transcripts suggested that young people strongly uphold a medical discourse about STIs and see themselves and others as being responsible if they are safe (ie use condoms or get tested). Further research into young people's understandings of STIs and the ways in which they position themselves within different discourses could help to find ways to engage young people in sexual health self-care. As digital technologies continue to rapidly evolve, understanding the ways in which young people engage with them in relation to sexual health care will be important.

#### PREFACE

The structure of my thesis, while conventional, lends itself to a brief prologue. You will find a long introductory section, comprising six chapters, before reaching the chapter outlining the aims of my research. I wanted my research to tell a story that is not only about data and interpretation, but that invites thinking about how and why we interpret any subject of investigation the way we do.

This body of work is about young people, sex and chlamydia, with a specific exploration of how the impact of genital chlamydia infection can be reduced among sexually active young people via screening. Yet over my years of working as a clinician, researcher and educator I have found that, just as you believe you have understood something, another way of understanding the same topic will present itself. To borrow from my favourite author, 'It is a truth universally acknowledged...' that there is no universal truth. I was pleasantly surprised and relieved to find, for example, that debate still rages about what a bacterium is... (Chapter 4).

To attempt to do justice to the approach I wanted to take, in studying the impact of chlamydia screening, I needed to step right back in time and place. Not only did I want to place chlamydia screening in a contemporary Australian context, I also wanted to ask myself, continuously, what alternative understandings of chlamydia, sex, and screening, have been and might be.

My six introductory chapters therefore were deliberately organized to take me, and I hope you, on a journey through a range of seemingly different, but ultimately interconnected subjects, to arrive at my very specific research questions. Chapter 1, Understanding adolescent sexuality, presents an overview of the history of modern, western theories about both sexuality and adolescence, in order to describe the evolution of ideas about adolescent sexuality. Chapter 2, Sexual health and young people, presents population health approaches to young people's sexuality and the inherent biases in sexual health research that arise from how we construct understanding. Chapter 3, Young people's understandings of sexually transmitted infections (STIs), is a literature review of research that has examined knowledge, meanings and /or discourses about STIs and seeks to make us ask ourselves not what, but how, we understand what we think we know. Chapter 4, *Chlamydia trachomatis*: biology, clinical features and epidemiology, dwells for a long time on the history of this organism. The bacterium eluded scientists for decades, and although medical technology has advanced sufficiently to make population-wide screening viable, the organism, its pathological effects in humans, and the

benefits of screening, remain somewhat elusive. Chapter 5, STI screening, discusses chlamydia screening in the context of medical screening and its history more generally, with an attempt to understand the sociology of screening on the whole. Chapter 6, Access to sexual health care for young people in Australia, begins to outline the context in which the first part of my research, the randomised controlled trial, takes place. In Chapter 7 I state the aims of my research which, while modest, relate to the breadth of topics and methods of enquiry that have been described in the preceding chapters.

My research consisted of two separate, linked studies, using very different methodologies. Because of this the thesis is then divided into chapters that describe the randomized controlled trial and the in-depth interviews separately – with Methods and Results of the former presented first, followed by Methods and Results of the latter.

The final chapter brings together both studies, describing the strengths and limitations of both, weaving their findings into the literature and proposing implications for policy, practice and further research.

# CHAPTER 1 UNDERSTANDING ADOLESCENT SEXUALITY

Sexuality is one of the ways that we become enlightened, actually, because it leads us to self-knowledge. - Alice Walker, CNN Sunday Morning, 1998

What is a youth? Impetuous fire. What is a maid? Ice and desire. The world wags on...

- Nino Rota, "What is a youth?" from Romeo and Juliet, dir. Franco Zefferelli, 1968

One of the mysteries of the universe is the way in which the human species deals with its own sexuality. Ordinary and natural as a cloudy day, sexuality has the potential to divide and marginalize human beings, sometimes brutally, ravaging lives like a wild storm. Our modern, Western understandings about human sexuality continue to evolve in parallel with the major philosophical and cultural movements that date back to the Enlightenment. Seminal works in the modern period on human sexual behavior shifted western concepts of sexuality into a scientific paradigm, and described, categorized and medicalised human sexual expression and behaviour. In the post-modern era, sexuality came to be understood as socially constructed, with individuals adopting and resisting dominant (often medical) discourses on sexuality, identity and behaviour. In the current post-modern (also called trans-modern and pseudo-modern) age, the 'virtual' world created by internet technology has ushered in a cultural milieu whereby the user, or recipient, of cultural products is as important as the creator, or producer. The user becomes creator, shifting from passive to active and back again, in the production of cultural texts, leaving them, and their users' identities, fluid and impermanent. In this cyberworld, a new term, wikisexuality, has been coined that 'highlights the constant formation of sexual identities...reflect[ing] the nonlinear, postmodern, and chaotic formation of sexuality...[and]...evoking the notion of sexuality as constantly shifting with every encounter'.1(p.588)

The first modern text about sexuality was published in 1896 in German by English physician, psychologist, teacher and writer, Havelock Ellis (1859-1939). In 1897 it was published in English, the first of six volumes on *Studies in the Psychology of Sex*. In these works, Ellis described among many things, homosexuality, children's sexuality, transgender psychology, masturbation and other auto-erotic practices, and advocated for sex education among young people.<sup>2</sup> Despite his mother's evangelical Christianity and his classification of many sexual practices as abnormal, Ellis largely removed the moral dimension previously associated with them.<sup>3</sup> Ellis was a contemporary

of, and cited in his chapter on Sexual Education, G. Stanley Hall (1844-1924), who is accepted by western psychologists to have been the founding father of our modern, scientific understanding of adolescence.<sup>4</sup> Hall, an American psychologist, published his two-volume text, Adolescence, in 1904.5 He coined the term storm and stress, describing this experience as universal and necessary among adolescents, and noted characteristics such as an increase in depressed mood, delinquent behaviour, peer group and media influences, brain changes, the growth spurt and of course sexual development. Much of Hall's theory still resonates today, though his views on adolescent sexuality were ambiguous at best. Hall normalised adolescent sexual desire and supported sex education and more open dialogue about sex between parents and children. On the other hand, he condemned masturbation and pre-marital sex as morally wrong, although attempted to do so by using biological and medical arguments.<sup>6</sup> Sigmund Freud (1856-1939), an Austrian Jew, was the other thinker of the late 19<sup>th</sup> and early 20<sup>th</sup> century who contributed to the shift in discourse on human sexuality. His ideas are thought to have been influenced by Havelock Ellis, and he was invited by Stanley Hall to speak at Clark University in Massachusetts, where he was President, and this became Freud's only visit to America.<sup>7</sup> Freud introduced the concept of the unconscious as a driving force in human behaviour, as well as the three-tiered structure of personality involving primitive instincts, decision-making capacity and a moral 'regulator'. The significance of his theories to emerging understandings about human sexuality was the underpinning belief that personality in adulthood was influenced by the negotiation of several psychosexual stages beginning at birth.<sup>8</sup> Freud's emphasis on erotic stimuli of infants, children and pubertal adolescents made sexuality central to understanding personality development, human behaviour and psychological disorders. These three men, from different cultural backgrounds, lived and wrote during the time of Charles Darwin and the theory of evolution, a rapidly advancing technological age, Victorian sexual repression, women's suffrage movements and World War One. Their combined, enduring legacy for our current understanding of adolescent sexuality is in both the foundation they laid for a developmental approach to adolescence, and, up to a point, their normalisation of sexual desire.

As the field of psychology grew into the 20<sup>th</sup> century, so did the scientific study of adolescence. Anna Freud (1895 - 1982), daughter of Sigmund Freud, applied the theory of psychoanalysis to explore child development. Anna Freud also regarded adolescence as 'a biologically based and universal developmental disturbance'.<sup>9(p,3)</sup> Her work extended the theories of her father in that she wrote about the ability of a child's social environment to interact with their development, and influence personality.<sup>10</sup> Another of the 'grand theorists' of adolescence was Erik Erikson (1902 – 1994), whose work, published in the 1950s, 60s and 70s, on the specific challenges of each life stage and the individual's need to negotiate these successfully, still informs current thinking. Erikson focused on the importance of identity formation (which includes sexual identity) during the adolescent phase and on the importance of the interplay between biological, psychological and social factors throughout the lifespan.<sup>9</sup> Jean Piaget (1896-1980) described a developmental theory that focused on changes in cognition. The crucial change that occurred in adolescence was the increased cognitive capacity for abstract thinking, which Piaget described in 1958 as *formal operations*.<sup>11</sup> This was, according to Piaget, the final, most advanced stage of cognitive development, and was reached around the age of 11 or 12, although by 1972, Piaget was beginning to postulate that intellectual development did not abruptly stop during adolescence, that the timing of formal operations varied and that different social contexts influenced cognitive development.<sup>12</sup> The central tenet of his theory was the capacity of the adolescent to 'think about thinking', a concept that has relevance today.<sup>11</sup>

The field of sexology also expanded during the first part of the 20<sup>th</sup> century, mainly in Europe, with works published on homosexuality, prostitution, 'transvestism' and sexual urges, but more importantly seminal work by Iwan Bloch (1872-1922), the 'father' of sexology, that broadened the field of sexual science. Bloch insisted that anthropology and the humanities, and not just medicine and pathology, needed to be incorporated into the study of human sexuality.<sup>13</sup> The expansion of this academic field remained modest, in part due to the two world wars and rise of Nazism in Europe. It was not until after World War II and the work of Alfred Kinsey (1894-1956) that sexology had a renaissance. This was partly due to the sheer scale of his work but also his background as a zoologist and taxonomist and the broad, multidisciplinary approach to his research on sexual behaviour in humans. Kinsey's sample sizes of over 5000 males and almost 6000 females and his non-clinical background allowed the world to see that the sexual practices among adults, including homosexual and bisexual behaviour, were diverse and so prevalent as to be normal.<sup>14,15</sup> Kinsey's research largely reported only on white American participants and his samples, while large, were far from random, being self-selected volunteers. Like sexological works before him, including Havelock Ellis', Kinsey's publications saw periods of criticism, banning and censorship. It was to be another four decades before similar, national surveys were conducted in either the USA<sup>16</sup> or other parts of the world. By this time, there were an estimated 9,000,000 adults worldwide infected with the human immunodeficiency virus (HIV) and perhaps one million with acquired immunodeficiency syndrome (AIDS).<sup>17</sup> The study of sexual behaviour came to be considered then, as it is today, an essential component of pandemic control.

Michel Foucault (1926-1984), French-born social scientist and historian, was an early victim of AIDS, dying at the age of 57 in the year that his final two (of three) volumes on the history of sexuality were published. In the first volume, The Will to Knowledge, published in 1976,<sup>18</sup> Foucault swept into history a perspective on understanding sexuality that focused on how, rather than what, that understanding came to be. Foucault argued that new discourses on sexuality began to emerge in the modern era (18<sup>th</sup>-19<sup>th</sup> centuries) that met a socio-political need for the transfer of power from the aristocracy to the burgeoning bourgeoisie. To shift social attitudes away from pleasure-seeking and create a strong work ethic in order to grow power in the middle classes, sex became a human activity unsuitable for anything other than reproduction. However, rather than silencing sex, (the 'repressive hypothesis') its discourse was moved into specific social structures that held power: what became important was not just what was being said, but who was saying it. This 'will to knowledge' is linked to power, with the institution of marriage claiming the discourse on sexuality in the 19<sup>th</sup> century, although Foucault points out that psychiatry and prostitution became alternative outlets for non-reproductive sex that brought their own discourses. Foucault argued that by the end of the Victorian era, rather than any radical shift in knowledge and power that lifted sexual repression, the discourses on sexuality remained strongly dominated by science, particularly medicine, and that the scrutiny of sex increased so much as to saturate society. Foucault essentially believed that sex and sexuality had become entities that were entirely constructed by society; even concepts such as desire arose from the idea of repression rather than any essentialist 'truth' about human beings. Sex and sexuality became the 'inventions' or constructs through which knowledge and power could be created and maintained.<sup>18</sup>

As post-structuralism and social constructionism, *vis à vis* the ideas of Foucault and others, were gaining ground in the latter half of the 20<sup>th</sup> century, and which could be applied to understanding sexuality, so too were advances in biomedicine and technology. Masters and Johnson's pioneering work on the human sexual response described physiological changes during sexual arousal, orgasm and resolution, dispelled myths about female orgasm and sexual responses in older people,<sup>19</sup> and offered clinical interventions for common sexual problems such as premature ejaculation and vaginismus.<sup>20</sup> The oral contraceptive pill was first marketed in 1960, a technology that has impacted the lives of millions<sup>21</sup> and that has revolutionised sexual behaviour and relationships. Recent advances in fields as diverse as reproductive technology, neuroscience and cosmetic surgery have the potential to shape the sexual lives of individuals and populations.

The scientific field of adolescent development through the first half of the 20<sup>th</sup> century had largely fallen into the realms of psychology and psychiatry. By the 1970s the 'mind-body split' appeared to have left psychiatry the inferior relative within other fields in medicine, with its interest in social environments limiting its scientific rigour as a discipline. George Engel (1913-1999), a psychiatrist at The University of Rochester, New York, challenged the reductionist view of the biomedical model, and described a biopsychosocial model of health and illness,<sup>22</sup> an approach that 'became the watchword of progressive unification of the medical and behavioural sciences, including psychiatry, in a search for etiological and preventive factors in human health and disease'.<sup>23(p,2039)</sup> Adolescent medicine, as a medical sub-specialty arising out of paediatrics in the late 1960s, embraced the biopsychosocial approach from its outset. Research into adolescent sexuality over the last 20-30 years has been dominated by studies of sexual behaviour and its biological, psychosocial and cultural influences.

The onset of puberty as signalled by external markers - breast development, testicular growth and pubic hair - currently defines the beginning of adolescence. One body of research has explored the influence of the sex hormones on adolescent sexual behaviour, and concludes that the increases in serum testosterone levels in both males and females over time does influence sexual interest (desire) and initiation of sexual intercourse: this is an independent predictor in girls,<sup>24</sup> but in boys pubertal development (considered a social, rather than biological, factor) is predictive, while testosterone alone is not.<sup>25</sup> Sexual desire however is difficult to clearly define and may have at least two separate components. Proceptivity, the urge to seek or initiate sexual activity, is what has been studied in relation to the effects of testosterone on adolescent desire. Receptivity, or arousability, is the capacity to respond to stimuli, and is present in pre-pubertal children.<sup>26</sup> Indeed, pre-pubertal children from a very young age exhibit a range of sexual behaviours. It appears however that the complex cascade of hormones that stimulate rapid growth and physical sexual maturity at puberty, although incompletely understood, plays an important role in sexual expression and behaviour in adolescence.<sup>27</sup>

Neuroscience has also altered our understanding of adolescent development over the past two decades. Two important shifts in thinking have occurred that change our previous beliefs that cognitive development stopped in mid-adolescence, and that risk-taking was simply a matter of immature pre-frontal cortices and would eventually settle down. The first is that the pre-frontal cortex continues to develop into the third decade of life. This development involves 'fine-tuning' of cortical connections through processes such as synaptic pruning, myelinisation and dendritic

arborisation.<sup>28</sup> The second is that there are two separate brain development processes occurring during adolescence that explain the non-linear nature of adolescent risk-taking. In adolescence, subcortical regions of the brain that lead to sensation-seeking mature in a non-linear fashion, and do so earlier and relatively faster initially than cortical maturation at this time. The ventral striatum is the subcortical region implicated most in this function, and sensation-seeking has been explained in evolutionary terms as necessary for the individual to separate from, and leave the safety of, the parental/ adult environment to become independent. This function is separate from impulsivity, which is greatest in children, and declines throughout adolescence and into adulthood. Functional connectivity between the subcortical and cortical regions strengthens with ongoing development and experience during adolescence. Thus, the hypothesis is that adolescents have capacity to make rational decisions and to understand the consequences of risk-taking, but in emotionally salient conditions, the relatively more developed subcortical system that seeks sensation will override the less developed 'control' cortical system.<sup>28</sup> Sexual sensation-seeking, whether 'risky' or not, can thus be understood in this context of brain development for many adolescents.

These most recent advances in technology may now shed different light on the foundational theories of Hall, Anna Freud, Erikson and Piaget. Nevertheless, what all these forms of knowledge have in common is the construction of adolescence through a particular lens which might be labelled developmental, medical and/ or scientific. The word adolescent, which comes from the French adolescere (to grow to maturity), first appeared in the English language in the 15th century and is defined as 'a youth'.<sup>29</sup> The word 'youth' is older, with its earliest appearance in English being in the 12<sup>th</sup> century. In all definitions of 'youth' the word 'adolescent' does not appear, rather, it is defined as 'the fact or state of being young'.<sup>30</sup> It is clear from the medical and psychological texts beginning with Stanley Hall until the present day that adolescence has long been tied to a biological, developmental understanding of being young, while the word youth is broader both in terms of an age range and cultural meaning. A recent review of the sociological interpretations of 'adolescence', 'post-adolescence' and 'youth' argues that although these terms are often used interchangeably, they come from different sociological analyses dating back to the first half of the 20<sup>th</sup> century. 'Adolescence' is characterized by the biological changes of puberty and, in western cultures at least, includes an implicit understanding of dependence or physical connection to parents or a family. Youth includes this period of adolescence but is broader, and represents a continuum from childhood through to adulthood.<sup>31</sup> This understanding is reflected in the age-based definitions adopted by the World Health Organisation of adolescents (10 - 19)

6

years), youth (15 - 24 years) and young people (10 - 24 years).<sup>32</sup> In the chapters following this one, the term 'young people' is favoured, but, where appropriate, age ranges are specified.

Much, if not most, of the literature on adolescent sexuality however has studied epidemiological associations between various types of sexual behaviour (including the initiation of sexual intercourse) and a range of variables that can be labelled risk or protective factors. Some of this has included longitudinal research, but much has been cross-sectional. In addition to the biological variables of puberty and brain development, there are psychological factors (attitudes, intentions, self-efficacy, emotions) as well as social factors (family structure, relationships and norms, parenting, peer behaviour and norms, relationship factors, school, educational and socioeconomic factors), and all of these operate within broader cultural and sub-cultural contexts.<sup>33,34</sup>

Social science research on adolescent sexuality has occurred in parallel with epidemiological research and has examined adolescent sexual behaviour from the perspectives of sociological theory, such as socialisation theories (how young people learn, socially, to become sexual) and social constructionist theory (which examines the discourses that young people adopt and resist, as they make decisions, behave and/or come to understand themselves, sexually).<sup>35</sup>

Cutting across all these forms of knowledge is the issue of gender. Whether a particular research study takes an overt feminist approach or not, gender, and particularly gender inequality, matter. Epidemiological research examines gender as an independent variable that can predict risk or outcome, and to date has almost invariably found that young females are at higher risk for a vast range of poorer sexuality-related outcomes, including sexual violence, abuse, sexual and reproductive ill-health<sup>36</sup> and poor body image.<sup>37,38</sup> Social science research emphasises the sexual double-standard that remains alive and well<sup>35</sup> and describes paradoxes for young women who are offered empowerment through an increasingly sexualised world and media, but who are simultaneously made victims of 'neo-liberalism, neo-conservatism and globalisation' in a 'pervasive...ruthless sexism in mainstream culture'.<sup>39(p.60)</sup>

The impact of media on adolescent sexuality has long been a subject of interest to researchers from both epidemiological and social science perspectives. However the expansion of digital technology even in the past decade *or less* has been so rapid as to leave us reeling. Young people have always interacted with many forms of media, rather than remain passive recipients. But internet and digital technology have created a whole new dimension where young people are not simply interacting, but can find simultaneous, multiple ways of being. The study of old and new media and their influence on adolescent sexuality nevertheless conforms to the same theoretical frameworks as research that has gone before:- there are those who study associations and/or causal links between media and sexual behaviour, and those who are interested in the discourses on sexuality that arise out of these new technologies. It remains to be seen whether and how our conceptualisation of both sexuality, and adolescence, evolves in this new era. The movie Her,<sup>40</sup> about a man (Theodore) who falls in love (and has a sexual relationship) with his computer operating system (Samantha), captures this post, post-modern vision:

Theodore: Well you seem like a person, but you're just a voice in a computer. Samantha: I can understand how the limited perspective of an un-artificial mind would perceive it that way. You'll get used to it.

The world wags on, indeed.

# CHAPTER 2 SEXUAL HEALTH AND YOUNG PEOPLE

Health is the state about which medicine has nothing to say.

WH Auden, 1970

#### 2.1 Global developments and definitions

Not long after Auden wrote these words, the World Health Organisation (WHO), which had been constituted in 1948, published its first-ever technical report relating to sexuality. This followed a meeting in 1974 of a group of experts to discuss the training needs of health workers and other appropriate personnel in the realm of sexuality, because of its relevance to sexual health. The technical report listed the importance of understanding sexuality for practitioners in clinical fields such as family planning, sex therapy and sexually transmitted diseases, and emphasised the importance of sex education, the socio-cultural context and the interdisciplinary nature of sexual health practice.<sup>41</sup> The technical paper defined sexual health as:

The integration of the somatic, emotional, intellectual, and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication and love.<sup>37(p.6)</sup>

Over the ensuing two decades, the HIV pandemic seized the attention of all those concerned with sexual health. Reproductive and maternal health were also advancing on the global agenda, impacted significantly by HIV, but also as a women's rights issue.<sup>42</sup> The International Conference on Population and Development in Cairo in 1994 was an international 'call-to-arms' to consider reproductive health and sexual health together in a social justice framework and also emphasised gender and social discrimination.<sup>43</sup> The WHO had defined reproductive health as:

Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes,<sup>40(p,1)</sup>

and clearly articulated the relationship between reproductive health and women's health.<sup>44</sup> The Cairo conference adopted a Programme of Action<sup>45</sup> and its follow up and implementation was designated to the United Nations Population Fund as the lead United Nations agency.<sup>46</sup>

In 2002, the WHO convened a meeting that attempted to further synthesise concepts and strategies that could address sexual health, incorporating the definition of reproductive health, and bringing together the perspectives of the World Association of Sexology, the WHO Regional Office for Europe and the Pan American Health Organisation. The definition that emerged from these discussions, and which is still cited today, is nevertheless considered by the WHO as a working definition. It is:

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.<sup>47(p.5)</sup>

A dominant theme in this technical paper is the centrality of adolescence to healthy sexual development: '*Adolescence sets the stage for sexual health in later life*'.<sup>47(p.6)</sup> The Department of Child and Adolescent Health within the WHO became one of three WHO departments that worked together to carry forward the recommendations in a medium-term workplan.<sup>47</sup> The WHO's work in adolescent sexual and reproductive health has rapidly expanded over the past few years, and also takes a rights-based approach, citing the United Nations Convention on the Rights of the Child that underpins its approaches and the importance of focussing on adolescents to reach several of the Millennium Development Goals.<sup>48</sup>

Despite the breadth and depth of the universally-accepted definition of sexual health, at a population level both nationally and internationally, indicators and surveillance data which provide some measure of sexual health remain narrowly focused on sexual and reproductive mortality, morbidity and disease and the behaviours that predict them. These indicators are nevertheless critically important, because their outcomes remain unacceptably high, particularly in developing countries and particularly among young women. For example, a recent analysis of the global and regional burden of disease as measured by disability-adjusted life years (DALYs) among young people found that for 15 - 19 year-old females, abortion, maternal sepsis and chlamydia ranked 4th, 6<sup>th</sup> and 9<sup>th</sup> respectively in the top 10 causes of DALYs; for females aged 20 - 24 years, HIV/AIDS became the 2<sup>nd</sup> highest cause of DALY, abortion and maternal sepsis maintained the same ranking and chlamydia dropped out of the top 10. For young men aged 20 - 24 years, HIV/AIDS ranked 8<sup>th</sup>. Unsafe sex ranked second among risk factors to which

DALYs could be attributed for males and females aged 10 – 24 years.<sup>49</sup> Maternal conditions and HIV remain leading causes of death for adolescent females worldwide, with the highest rates being in Africa and South-East Asia.<sup>50</sup> Other sexual health indicators in many countries include, variously, teenage birth rates, abortion rates, teenage pregnancy rates, and sexually transmitted infection and HIV incidence, prevalence or notification rates. Included as health indicators are behaviours considered risk factors for these health outcomes, such as prevalence of sexual intercourse among young people and/or age of sexual debut among unmarried teenagers, number of sexual partners and condom and contraceptive use.<sup>51</sup>

At the global level, the approach to understanding adolescent sexual health has nevertheless been one that pays close attention to the social determinants of health, the availability and accessibility of sexual and reproductive health services and education, and the importance of youth engagement and participation in programmes. In 2012, the 45<sup>th</sup> session of the United Nation's Commission on Population and Development was devoted, for the first time ever, to Adolescents and Youth. Despite the broad terms of reference of the Commission,<sup>52</sup> it is notable that at the 45<sup>th</sup> session, access to sexual and reproductive health services and education, preventive programs against HIV/AIDS and sexually transmitted infections, and elimination of discrimination against girls and women that can lead to early marriage and childbirth, were highlighted.<sup>53</sup> Active consultation with leading academics in youth health and youth development helped shape the resolution to reach the breadth it did with regard to sexual and reproductive health, but also other aspects of adolescent health such as mental health, nutrition and obesity, and violence including sexual violence (George Patton, Professor of Adolescent Health Research, University of Melbourne, email communication, 10 November 2014).

A recent review of worldwide, country level ecological analyses of health data for 10 - 24 year olds to determine social determinants of health found that structural factors such as national wealth, income inequality and access to education, as well as more proximal determinants such as connectedness to school, family, community and peer group influences all impact on sexual health outcomes.<sup>54</sup> The availability and accessibility of sexual and reproductive health services and education are widely acknowledged as crucial to young people's sexual health. These include access to antenatal and postnatal care, contraception, STI diagnosis and treatment services and to evidence-based sexuality education programmes.<sup>51</sup>

A recent synthesis of worldwide data to describe the current state of adolescent health found that indicators and their accompanying data were most developed and complete respectively, at a global level, for sexual and reproductive health. The indicators selected for this synthesis relevant to sexual and reproductive health were: maternal deaths, HIV, sex by age 15, early childbirth, early marriage, condom use, HIV knowledge, HPV vaccination, health service use, and education, parental understanding, unemployment and self-rated health.<sup>55</sup>

In Australia, the health indicators for young people (12 – 24 years) have been determined using a three-tiered framework: health outcomes; determinants of health and health system performance,<sup>56</sup> which accord with the multi-level and multi-factorial nature of understanding adolescent health. These were last updated in 2010, and are summarised in Table 2.1. Table 2.1 shows the indicator framework and its components, and lists under each subheading, where applicable, the indicators that specifically relate to sexual and reproductive health, their social determinants as described by the above literature and relevant aspects of health system performance. It should be noted that of the three health outcome indicators, genital chlamydia infection is the most prevalent condition among Australian young people.<sup>57</sup> A review and revision of young people's health indicators in Australia is currently being considered, a process that is hampered by a lack of Commonwealth funding (George Patton, Professor of Adolescent Health Research, University of Melbourne, email communication, 10 November 2014).

These definitions of sexual and reproductive health, their evolution and the definitions of key indicators are important for understanding programmatic and policy responses at global and national levels. Yet the focus remains at the 'pointy end' of sexual health: mortality, morbidity and disease and the factors that contribute to these. What is unavailable at population levels is information about young people's wellbeing in relation to sexuality, including their experiences of pleasure, emotional and social safety in sexual encounters, and freedom from discrimination. A systematic review of factors that shape sexual behaviour was able to sift beneath and between the more 'structural' social determinants described earlier to identify that issues such as reputation, social penalties and rewards for sexual activity, social expectations and gender stereotypes have an important influence on sexual behaviour and sexual risk behaviour, across countries and cultures.<sup>58</sup>

# <u>Table 2.1:</u> Australia's key sexual health indicators for young people 12 - 24 years

adapted from the Australian Institute for Health and Welfare.<sup>56,57</sup>

Tier 1: Health status	
<ul> <li>1.1 Wellbeing (1 indicator)</li> <li>1.2 Human function (2 indicators)</li> <li>1.3 Deaths (1 indicator)</li> <li>1.4 Health conditions (5 subgroups (Sub-group 4 of 5):</li> </ul>	3)
Communicable diseases	• Hepatitis A, B and C notification rate
	HIV infection notification rate
	Incidence of notifiable STIs
Tier 2: Determinants of health	
<b>2.1 Health behaviours (7 subgroup</b> (Sub-group 7 of 7): Sexual and reproductive health	<ul> <li>Proportion of young people in Year 10 and 12 who have had sexual intercourse</li> <li>Proportion of young people in Year 10 and 12 who used a form of contraception at their most recent sexual</li> </ul>
	<ul> <li>Age specific birth rate for 15 – 19 year old women</li> </ul>
2.2 Community and socioeconomic	
Subgroup 1 of 13: Family cohesion	Indicator/s under development
Subgroup 4 of 13:	Indicator 1 of 2:
Community and civic participation	• Community participation rate among young people aged 18–24 years
Subgroup 7 of 13:	Indicator 1 of 2:
Victims of violence	• Rate of young people aged 15–24 years who have been the victim of physical or sexual assault
Subgroup 8 of 13: Homelessness	<ul><li>Indicator 1 of 1:</li><li>Proportion of young people aged 12–24 years who are homeless</li></ul>
Subgroup 10 of 13:	Indicator 2 of 3:
Education	• Apparent retention rate from Year 7–8 to Year 12
Subgroup 11 of 13:	Indicator 2 of 2:
Employment Subgroup 12 of 13: Income	<ul> <li>Unemployment rate for young people aged 15–24 years</li> <li>Proportion of young people aged 15–24 years receiving government income support</li> </ul>
	<ul> <li>Proportion of young people aged 15–24 years who experience financial stress</li> </ul>
Subgroup 13 of 13: Socioeconomic status of parents	• Proportion of young people aged 12–24 years living in jobless families
2.3 Environmental factors (2 subgr Tier 3: Health system performance	
Subgroup 4 of 9:	<ul> <li>Cervical screening rates among women aged 20 – 24</li> </ul>
Cervical cancer	<ul> <li>Cervical servering rates among women aged 20 21 years</li> <li>Cervical cancer vaccination rates among women aged 12 – 24 years</li> </ul>
Subgroup 6 of 9: Delivery by Caesarian section	<ul> <li>Caesarian sections as a proportion of all confinements of young women aged 15 – 24 years</li> </ul>
Subgroup 7 of 9: General practice consultations	<ul> <li>Rate of general practice encounters for young people aged 12 – 24 years</li> </ul>

The issues about which young people themselves feel concern in relation to sexuality and health are difficult to fully appreciate, since the concerns expressed will depend not only on questions they are asked, but who is doing the asking. Sexual health research is inherently biased towards shaping questions that reflect researchers' interests in particular topics. Research that takes a broader approach to understanding any concerns of young people might not be able to probe deeply enough to capture more detailed or specific sexual health related issues. For example, in Australia, national surveys on the issues facing teenagers aged 15 - 19 years have been conducted annually by Mission Australia, since 2002. These surveys ask participants about a broad range of issues including education, employment, their aspirations for the future, the issues they believe are important to the country, what they value and the issues of personal concern. In this latter category, body image has featured consistently as one of the most important concerns, as have stress and mental health, but whether and how these might relate to sexuality or sexual health is not known. There were no concerns that could be more specifically labelled as sexuality or sexual health concerns reported in the most recent published survey of over 14,000 young Australians.<sup>59</sup> By contrast the 2013 annual report of Kids Helpline, a national Australian telephone and webbased counselling services, found that of over 233,000 contacts in 2013, sexual development was among the top ten concerns for children aged 5 - 12 years; for those aged 15 - 19 years, body image, sexual orientation, sexual activity and pregnancy were common and among 20 - 25 year olds, dating and partner relationships emerged as major concerns.<sup>60</sup> Mental health concerns, school issues, emotional wellbeing and abuse were also prominent, but as with the Mission Australia surveys, any association with sexuality or sexual health is unknown. Focus group research enquiring into school-aged young people's general health concerns have found that sexuality/ sexual health topics are mentioned, often in the context of relationships, and are sometimes specifically about sexually transmitted infections and safe sex.<sup>61,62</sup> Various analyses of unsolicited questions sent by young people to youth-targeted websites,<sup>63,64</sup> and popular media<sup>65-67</sup> have found a broadening of sexual health concerns. The proportion of concerns about pregnancy, contraception use or sexually transmitted infections (common sexual health indicators in Australia and elsewhere) is small relative to concerns about relationships, physical appearance (especially genitals and breasts) and attractiveness, sexual arousal, practices, performance or function and whether these observations are 'normal'.

The sexual and reproductive health of young people has the support of international agencies such as the United Nations and several of its subsidiary organisations. Social justice, gender inequality and discrimination, and an understanding of social determinants of sexual and reproductive health are incorporated into strategic approaches to improve sexual and reproductive health at a global level. Maternal mortality in young women, teenage childbirth and sexually transmitted infections including HIV are key indicators for measuring sexual and reproductive health across many countries. Yet, while the engagement and participation of young people themselves is accepted as crucial to policy and programmatic responses to sexual and reproductive health issues, the breadth of issues of concern to young people in relation to their sexual health might need to be more fully incorporated into approaches to sexual health services, education and promotion.

#### 2.2 Sexual behaviour and sexual health

Partnered sexual activity begins almost universally in the mid to late teenage years. The age of sexual initiation, defined as first vaginal intercourse, is generally accepted as an indicator of sexual health because of what is considered its 'public health implications'. These include unplanned pregnancy and sexually transmitted infections (STIs), but also the increased likelihood that early initiation is non-consensual.<sup>68</sup> Patterns of partnered sexual activity vary within and between countries and regions and are shaped by social, economic and political factors. In some parts of the world, first sex mainly happens within marriage, and for girls this can be at a very young age and can be coercive and traumatic as well as unprotected (from pregnancy and STIs). In some developing regions, sex differences in context of first sex are prominent, whereby young men are much more likely to have sex outside marriage than young women.<sup>51</sup> In many developed countries the age of marriage has increased substantially, while age of first sex remains at around 16 or 17 years, meaning that there has been a secular trend toward high rates of pre-marital sex. In other regions, the ages of marriage and of first sex (within marriage) have both increased. Monogamy remains the dominant pattern of sexual relationships, but there are sex differences where multiple partners are more common for men than women.<sup>68</sup>

Condom and contraception use by young people also vary enormously around the world. There has been a general trend however, towards higher rates of condom use, in the developed and some parts of the developing world, particularly sub-Saharan Africa. The use of hormonal contraception is much more common in developed than developing countries, but remains between 42% (USA) and 69% (UK) at last sexual encounter for teenage girls.<sup>51</sup>

### 2.2.1 Data on Australian young people's sexual behaviour

Australia has been systematically collecting data on young people's sexual behaviour since 1992. As with most countries in the world, this was a direct response to the HIV/AIDS threat. There have been five- to six-yearly surveys of secondary school students across Australia that enquire about HIV and STI knowledge, attitudes, sexual attraction and a range of sexual behaviours including condom and contraception use. In 2002, Australia also conducted the first-ever national household survey of sexual behaviour, attitudes and knowledge on a representative sample of adults aged 16 - 59. The second Australian Study of Health and Relationships was launched on 7 November 2014 in Sydney with key findings published in a special issue of *Sexual Health*.<sup>69</sup>

Although there was some inter-survey variability in the national school surveys, overall many findings have remained similar over twenty years. For example, about half of Year 12 students (age 17 - 18 years) at each survey report experience of sexual intercourse, and the majority of students across the samples (Years 10 - 12) report some sexual experience. Condom use has remained fairly steady, with over two-thirds reporting condom use at last intercourse. Knowledge about HIV has always been high, whereas knowledge about viral hepatitis and STIs has been relatively low. Same-sex attraction has been consistently reported by a small but significant minority. Further, while the majority have consistently reported having positive feelings after sex, about one quarter reported an unwanted sexual experience, often in the context of alcohol intoxication.<sup>70</sup> A summary of key findings from the most recent secondary school survey appears in Box 1.

The two national household surveys conducted ten years apart have found that the median age of first vaginal intercourse for both men and women declined for those born between the 1940s and 1960s but with no further decline since. Among young women and men currently aged 16 - 19 years, the median age of first vaginal intercourse is 17 years.<sup>71</sup> Among 16 - 19 year old men who had had vaginal intercourse in the past six months, 60.1% reported always using a condom; for young women 16 - 19 years this was 55.3%.<sup>72</sup> Just under five per cent of 16 - 19 year olds reported a non-heterosexual identity.<sup>73</sup>

## Box 1: selected findings from the 2013 secondary school survey of sexual health<sup>70</sup>

Total sample size = 2136; 'sexually active cohort' = 713 (reported vaginal or anal intercourse)

- Twenty-three percent of Year 10 students, 34% of Year 11 students and 50% of Year 12 students had experienced sexual intercourse

- Fifty-nine percent of sexually active students (those who answered 'yes' to having either vaginal or anal sexual intercourse) reported using a condom the last time they had sex.

- Twenty-three percent of sexually active students had sex with three or more people in the past year

- Approximately one quarter of sexually active students reported an experience of unwanted sex.

- Eighty-three percent of young men and 76% of young women reported sexual attraction only to people of the opposite sex

- Eight per cent of young men and 4% of young women reported sexual attraction only to people of the same sex.

- Five per cent of young men and 15% of young women were attracted to people of both sexes.

- Around 4% of young men and 5% of young women were unsure about their sexual attraction

## 2.3 Same-sex attraction and sexual health

Sexuality incorporates an individual's sexual attraction, orientation and identity, as well as their gender role/s and identity/ies. All of these are fluid, dynamic and predominantly socially constructed. Language and labels also vary between countries and cultures as well as over time. This is a brief summary of the main health outcomes for young people who experience same-sex sexual attraction or who are gender-questioning, and/ or who identify as gay, lesbian, bisexual, or transgender (LGBT). Most of the research into this 'composite' group of young people comes from Australia and the USA.

Concerns about health and wellbeing of young people who experience sexual or romantic attraction to people of the same sex, who are gender-questioning, or who identify as gay, lesbian, bisexual, or transgender, have centred around their mental health. Increased levels of depression, suicidality, substance use and other mental health problems have been reported in the literature for several decades.<sup>74</sup> However it seems artificial to separate negative mental health outcomes that some same-sex attracted or gender-questioning young people experience *as a result of sexuality-related discrimination* from our broad understanding of sexual health. There is compelling evidence from Australian and international research that many, if not most, young people who

are same-sex attracted or gender-questioning experience victimisation because of their real or perceived sexual orientation or gender expression.<sup>75,76</sup> The level of acceptance by parents and carers of their sexuality has a profound impact on their mental health outcomes as well as sexual risk behaviour,<sup>74</sup> self-esteem and general wellbeing.<sup>77</sup> There is some evidence that same-sex attracted and gender questioning young people are overrepresented in out-of-home care placements and in juvenile justice systems.<sup>76</sup>

In Australia there have been national surveys every six years since 1998 among same-sex attracted and gender-questioning young people specifically enquiring into their sexual health and wellbeing. Levels of homophobic abuse have been high in all three studies. In the most recent survey, 61% reported verbal abuse, 18% physical abuse and 26% other forms of homophobia. Most of the abuse (80%) occurs at school.<sup>75</sup> There has been a trend for same-sex attracted and gender questioning young people to come out at younger ages,<sup>75,76</sup> which (paradoxically, perhaps) reflects perceived greater tolerance of gender and sexual diversity.

Sexual risk behaviours, sexually transmitted infection rates and unplanned pregnancy are also higher among same-sex attracted and gender questioning young people.<sup>75,78</sup> In national Australian research, same-sex attracted and gender questioning young people had higher prevalences of all sexual behaviours compared with heterosexual peers (deep kissing, touching genitals, oral sex, penetrative intercourse), were twice as likely to report an unplanned pregnancy and more likely to report a diagnosis of an STI.<sup>75</sup>

## 2.4 Conclusion

Health disparities around the world due to macroeconomic factors such as national wealth and income inequality give different emphases to sexual health priorities in different regions, countries and communities. At a global level, HIV, maternal mortality and unsafe abortion are the most pressing sexual and reproductive health problems facing young people, and more specifically young women. By recognising that social and cultural factors such as gender discrimination and homophobia impact on young people's sexual health and wellbeing and that the medicalisation of sexuality can affect the way we understand and measure sexual health, we realise that current health indicators cannot capture the breadth of the definition of sexual health. If we approach sexual health from a human rights perspective, and sexuality as a social construct, then we begin to appreciate the fuller picture of the sexual health of young people and what else needs to be done to realise it.

# CHAPTER 3 YOUNG PEOPLE'S UNDERSTANDINGS OF SEXUALLY TRANSMITTED INFECTIONS (STIS)

These young things for the most part fell into a trap which Nature had baited with her most fascinating lure; they were usually ignorant; not seldom they were deceived by an attractive personality; often they were overcome by passion; frequently all prudence and reserve had been lost in the fumes of wine. From a truly moral point of view they were scarcely less innocent than children.

- Havelock Ellis, The Conquest of the Venereal Diseases, Volume II, Part III in Studies in the Psychology of Sex, 1928.

# **3.1 Introduction**

Havelock Ellis is describing the high proportion of syphilis and gonorrhoea infections in Europe among young people relative to older people. He emphatically states that young people are at higher risk for venereal diseases, he advocated strongly for education of adolescents, for systems of disease surveillance through notification and for accessible treatment. Despite his efforts to remove notions of immorality and judgement from treating individuals with syphilis and gonorrhoea, this chapter, published in 1928, is imbued with moral references such as innocence, female chastity, young men being victims of prostitutes, and the 'fallen person'.

The term 'venereal disease' or VD was the medical term for sexually transmitted infectious diseases for several centuries until the late 20<sup>th</sup> century. Derived from the Latin *venerens* (of the goddess Venus, meaning 'of sexual love'), the 'venereal diseases' included syphilis, gonorrhoea, chancroid, Donovanosis and lymphogranuloma venereum. As sexually transmissible conditions were increasingly recognised in the latter part of the 20<sup>th</sup> century to include genital warts, genital herpes, trichomoniasis, hepatitis B and others, the term sexually transmitted disease replaced venereal disease. In Australia, the term sexually transmitted infection is now preferred, since many sexually acquired pathogens are asymptomatic and do not cause obvious disease. The distinguishing feature of sexually transmitted infections is that they are pathogens which can be sexually acquired or transmissible. They represent a wide range of microorganisms, including bacteria, viruses, fungi and protozoa and cause a variety of clinical syndromes and sequelae.<sup>79</sup>

This chapter is concerned with current understandings that young people have of sexually transmitted infections (STIs). Having explored ways of understanding adolescent sexuality and sexual health in the modern and post-modern eras, the intention now is to focus on sexually transmitted infections. From an epidemiological point of view, STIs remain a relevant health issue for young people now as in the past, but the ways in which they are experienced and understood by young people adds meaning to any clinical, public health and programmatic efforts to address STI burden of disease. Although the focus of this doctoral research is on genital chlamydia infection, how young people distinguish between chlamydia and other STIs is unknown, thus the scope of this chapter includes any STIs including the human immunodeficiency virus (HIV).

## 3.2 Young people's understandings of STIs: a literature review

In this literature review, young people's 'understandings' of STIs is defined as a composite of knowledge, meanings and discourses. The literature searched has therefore included research that has measured knowledge of STIs or HIV among young people and (mainly qualitative) research that has sought to explore or describe the meanings and/ or discourses relating to STIs and/ or HIV.

## 3.2.1 Knowledge of STIs and HIV among young people

The literature on young people's knowledge of STIs and/ or HIV has grown exponentially in the past 15 years. Initial studies focused on HIV knowledge while in the past five to 10 years, chlamydia knowledge has become the main STI of interest in developed countries, and many studies explore both, as well as some other STIs. This review summarises the most salient findings only, and focuses on studies conducted in countries where chlamydia, rather than HIV, prevalence among young people is of much more concern.

In 2014 the Guttmacher Institute reported on several indicators concerning the sexual and reproductive health of young people, by exploring data from 30 countries in most regions of the world, with the great majority being developing countries. The authors found that 'comprehensive knowledge' of HIV ranges from 3% in females aged 15-24 years in Pakistan to just over 50% in two countries in Sub-Saharan Africa for females and in Kenya and Moldova for males 15-24yrs.<sup>80</sup> A national, representative survey of young people in the USA published over ten years ago found up to one-fifth of respondents had misconceptions about HIV, such as not knowing that condoms are protective.<sup>81</sup> Smaller studies published since then report variable

levels of HIV knowledge, with young African-American males, for example having low levels of knowledge<sup>82</sup> and an intervention study in high schools in Baltimore finding an increase in HIV/ STI knowledge that was greater among females, but with reasonably high baseline knowledge scores (80%).<sup>83</sup> A systematic review that explored the impact of peer-led HIV/ STI prevention interventions published between 1998 and 2005 reported that all studies in their review showed an increase in HIV/ STI knowledge, but did not report on actual knowledge scores.<sup>84</sup> By contrast, a systematic review of studies in Europe of school-aged adolescents' knowledge found extremely high knowledge of HIV, including that it is a virus, is sexually transmitted but can also be transmitted by sharing needles, and that condoms are protective.<sup>85</sup> Knowledge of HIV among Australian school-aged young people has also been consistently high since regular surveys began in 1992.<sup>70</sup> In all these reviews and studies, 'HIV knowledge', where reported, consists mainly of correct responses to simple yes/no questions about the different means of transmissibility of HIV and the protectiveness of condoms.

Studies that report on knowledge of other STIs show interesting variability. In Australia we have seen a gradual improvement in knowledge about STIs between 1997 and 2008, among both females and males, although HIV knowledge has always remained better.<sup>86</sup> In the most recent survey conducted in 2013, again HIV knowledge was high, but knowledge about chlamydia was only moderate, and knowledge about viral hepatitis and HPV was poor.<sup>70</sup> The Australian Study of Health and Relationships is another representative survey that includes young (and older) adults over 16 years. The first study was conducted in 2002 and the second in 2013. The survey includes eight knowledge questions about chlamydia, gonorrhoea, hepatitis C, herpes simplex virus, hepatitis B and genital warts. Females aged 16 - 29 scored slightly higher than males, and knowledge improved between 2002 and 2013.<sup>87</sup>

The systematic review (of studies published between 1990 and 2010) by Samkange-Zeeb<sup>85</sup> of HIV/STI knowledge among European school-aged young people found that HIV knowledge was consistently highest in all studies reviewed and human papillomavirus (HPV) knowledge was lowest, while knowledge about chlamydia, gonorrhoea and syphilis was moderate. A study in Denmark and Germany among high school students that explored HIV and chlamydia knowledge using a 'sexual knowledge and education space' model to analyse (among other things) relationships between knowledge and sources of information, found that HIV knowledge was much greater than chlamydia knowledge, attributable to prevention campaigns and concepts at a societal level.<sup>88</sup> A study among university students in Sao Paolo, Brazil, found very high

levels of knowledge of sexual transmission of HIV, syphilis, herpes and gonorrhoea, moderate knowledge about HPV, low knowledge about trichomonas but the lowest levels of knowledge were about chlamydia.<sup>89</sup>

There have been several studies mostly published within the past five years that specifically explore knowledge of chlamydia, and all have been conducted in western, developed countries. Knowledge about chlamydia (including its asymptomatic nature, prevalence among males as well as females, the process of testing, curability and prevention) has been studied among school and university students and other young people. Knowledge among females has been consistently higher in several studies.<sup>90-94</sup> Of particular interest were two studies that explored 'confusion' between chlamydia and other STIs. A small US study using a clinical sample of 119 young people (14 – 22 years) found that almost half did not know that there were differences between chlamydia and HIV and that correct knowledge about chlamydia (eg that it was curable) was more likely with increasing age of participants.<sup>95</sup> Another small US study of 60 women aged 18 – 25 years visiting a gynaecology clinic found considerable confusion between cervical cancer screening and chlamydia.<sup>96</sup>

The development of effective HPV vaccines and subsequent roll-out of adolescent HPV vaccination programmes in many developed countries since the mid-2000s has led to interest in and concern about young people's (especially young women's) knowledge about HPV and cervical cancer. A systematic review published in 2008 identified 39 studies that measured HPV knowledge, most were from the USA. There was a wide variability in awareness among study participants, from 13 – 93%, and knowledge overall was poor, but higher among women than men. This review also found that knowledge increased steadily with year of study. However, in some studies in the review, confusion existed between HPV and either HIV or HSV (herpes simplex virus).<sup>97</sup> A more recent study among young women in Victoria, Australia in 2010 and using social media to recruit participants, found both higher levels of awareness and of knowledge compared with previous Australian and international studies. Women who were aware of chlamydia were more likely to be aware of HPV.<sup>98</sup>

In summary, despite the fact that many of the young people who were surveyed in recently published studies were born after the peak of the HIV pandemic in western countries, knowledge of HIV is high, and often significantly higher than knowledge about chlamydia and other STIs, including HPV. The confusion surrounding differences between HIV, chlamydia, HPV and other STIs is of interest. While its significance is yet unknown, it raises the question about how young people understand STIs in general, and what contributes to their confusion.

### 3.2.2 The meanings of STIs to young people

The literature is sparse on the meanings, understandings and/ or discourses that young people hold regarding sexually transmitted infections. The overwhelming majority of published articles retrieved in a search for 'meanings' OR 'stigma', AND 'sexually transmitted infections' (without limiting the search to 'adolescents' or 'young people') were about HIV/ AIDS-related stigma, mostly in African countries or among gay men in various communities.

It might be useful to try to understand this absence of knowledge by exploring what has been described as 'the erasure of adolescent sexual subjectivity'.<sup>99</sup> Angelides describes a new 'moral panic' that occurred in the Anglophone west in the 1960s, during the decade of the sexual revolution, about adolescent sexual activity. In the United Kingdom, North America and Australia, the apparent increases in premarital sex, 'illegitimate births' and 'venereal diseases' among young people were constructed by many as 'social problems' and 'moral problems' although there were voices of resistance that reconstructed adolescent sexuality as normative and young people's need for information to be free of 'moral admonition'. These 'humanists', in contrast to the 'moralists' were re-orienting the concept of morality from being a public to a private entity. Angelides also argues that this reorientation was representative of a broader societal shift after World War II that rejected the public morality of religion in favour of a secular liberal humanism that promoted concepts such as scientific rationalism, equality and secular ethics.99 As a response to this 'revolutionary' behaviour among young people, calls for comprehensive sex education were made, and in Australia, New South Wales (NSW) was the first state to introduce a curriculum. Of interest here is that a group of about 200 school students from 150 government and private schools in NSW was consulted and reportedly presented their recommendations regarding their preferences for content and delivery. Dominant themes that emerged from this consultation included the desire for factual information free of moral judgement and respect for young people's autonomy and decision-making capacity. The views of these students were not acknowledged in the State Government's report by the advisory committee on sex education, and the students report was never made available upon request to the National Library to the Department of Education, effectively silencing young people both actually and symbolically.<sup>99</sup>

Most of the literature about STI meanings has studied the role of stigma as a barrier to a range of health-promoting behaviours, such as seeking advice, testing, treatment for HIV / STIs as well as disclosure of STI/ HIV status to partner/s and in negotiating condom use. Analytical methods used range from content and thematic analysis, to ethnographic methods, grounded theory and discourse analysis, with thematic analysis being the most common.

#### 3.2.2.1 Stigma and STIs

In a recent review of the literature on stigma and STIs (including HIV), Hood and Friedman found that sources of STI stigma come from sociocultural norms, where sex itself is a stigmatised behaviour; health education efforts that reinforce stigma through the creation of the 'responsible' versus irresponsible person; mass media that tend to reinforce notions of individual blame; and through health services where people experience judgemental reactions from staff and/ or STI services and are isolated and marginalised from mainstream services.<sup>100</sup> In a slightly older review, a metasynthesis of qualitative data on the research on stigma among women living with HIV/AIDS in the USA examined 93 published and unpublished studies. This review described three key findings: (1) that stigma is both felt and enacted and is pervasive among women living with HIV/AIDS, and that perceived and actual stigma is blurred, probably due to women's 'internalisation of negative cultural views' of HIV; (2) the intensification of stigma due to being women which was in large part due to their capacity to have, and therefore to infect, children and (3) the 'unending work and care of managing stigma' which involves ongoing efforts on the part of HIV positive women to reduce stigma and normalise HIV infection.<sup>101</sup> In keeping with the findings of these reviews, several other studies from a range of countries have found that stigma impacts in very real ways on young people's ability to acknowledge their own sexuality, disclose STI or HIV status, or seek information, support and help or medical advice and treatment. For example, among Vietnamese young people, strongly-held negative beliefs about premarital sexual activity of any kind, has led to very low levels of sexual activity; but also to extremely high levels of stigmatisation and silencing or denial of adolescent sexuality. Among those who were sexually active, the young people with high sexual stigma scores also had low self-efficacy scores for condom access and use: stigma silences, and is more powerful than health risk, which was evident in this study from young people's discourses about morality and danger.<sup>102</sup> A study of adolescents living in the UK with perinatally acquired HIV found that stigma was constructed and contextualised in a variety of ways, including its impact on identity as being someone with a chronic condition. However, the sexually transmissible nature of HIV added to stigma during adolescence because of emerging sexuality, potential associations with

'promiscuity' and difficulties around negotiating sexual relationships. Young people in this study appeared to be both adopting discourses of fear and stigma while resisting them and finding new discourses that allowed them to see HIV as a small part of their life.<sup>103</sup> Another qualitative UK study among patients attending a STI clinic found stigma and shame to be prominent themes when exploring the underlying reasons for anxiety among participants. The underlying source of stigma often came from the perception that having a risk for STIs was linked to having multiple partners, which was socially unacceptable.<sup>104</sup> A qualitative study among low socioeconomic African-American young men and women to explore barriers to HIV testing found that stigma associated with being HIV positive was a barrier; although anxiety regarding testing was probably also equally due to fear of death or illness.<sup>105</sup>

Several studies have explored 'meanings' relating to chlamydia testing using qualitative methods, mainly to try to understand barriers and facilitators to testing and/ or partner notification, and most of these have been published only in the past eight years. One of the earliest studies to be published took place in Victoria, Australia and found that fears about stigma, confidentiality, denial, lack of knowledge and pragmatic factors such as time and cost were barriers to seeking chlamydia testing.<sup>106</sup> Several studies published since then report similar findings, and while factors such as awareness, knowledge, time and cost are common barriers, so too are stigma, shame, embarrassment, and concerns about one's identity.<sup>107-113</sup> Some studies found that stigma affects women more than men, since STI stigma has implications for a woman's identity in ways that are more negative than for men.<sup>111,114</sup> Stigma is explored in more depth in some studies, referring to Goffman's stigma framework, and the way in which stigma resides in social interactions, such that stigmatising creates identities of 'other' versus 'normals'.<sup>115</sup> Balfe and colleagues found that the act of having a chlamydia test among young adult women risked accepting one's identity as 'promiscuous', 'irresponsible' or 'risk-taking' and that such identities would be marginalising and therefore needed to be avoided.<sup>116,117</sup> Several of the studies that identified stigma as a major barrier to seeking testing for, or notifying partners of, chlamydia or other STIs found that alternative 'meaning' or identity could act as facilitators: the notion of the 'responsible' person or partner, or one who sought reassurance about health status (rather than avoiding diagnosis).110,112,118,119

#### 3.2.2.2 The social construction of stigma

One of the shortcomings of this body of literature is that it accepts the social construction of stigma as its starting point, rather than exploring how the stigma discourse is adopted or resisted

by the research participants. If stigmatisation itself is understood as a process that 'creates and maintains power' and that any individual might be caught or held within multiple and interlocking systems of power, then the concept of 'intersectionality' can help understand multiple systems of oppression where none is given priority over another.<sup>120</sup> In such an analysis of HIV risk among impoverished Latina women with mental illness living in New York, the intersectional nature of multiple 'axes of differentiation' such as gender, race, poverty and mental illness needs to be understood. These multiple stigmatising factors do not necessarily have an additive effect and can be contrary to each other, so that interventions and services that aim to reduce HIV risk need to address each of these axes at various levels (community, clinic, individual).<sup>120</sup>

Discourse analysis is one such research tool for attempting to understand the social construction of stigma and identity, and has been used, for example, to provide insights into young people's (hetero)sexual subjectivities,<sup>121</sup> how same sex attracted young people position themselves within and resist dominant discourses on sexuality,<sup>122</sup> and in how young women construct their sexual subjectivities within discourses of risk and danger.<sup>123</sup> These insights are invaluable for informing the design of sexuality education programmes and sexual health interventions, including STI prevention. There has been relatively little research that uses discourse analysis to examine the construction of meaning related to sexually transmitted infections directly. As Shoveller and Johnson point out, public health approaches to managing STIs in young people using sound theoretical frameworks such as the Health Belief Model and Social Cognitive Theory could unwittingly be making assumptions about young people's degree of agency and control.<sup>124</sup> Shoveller and Johnson trace the shifting discourses that began in the 1980s with the HIV/ AIDs epidemic with the concept of belonging to 'risky groups' (eg gay men, injecting drug users). Partly as resistance to the discourse of the 'risky group' and partly due to the spread of HIV into the heterosexual community, 'risky behaviour' came to be a new discourse. Because 'risky behaviour' included anyone who had sex without a condom, this encompassed many or most young people: young people themselves became a 'risky group'. To address the ability of young people to distance themselves from the discourse because it was created by adults and health professionals, peer-led education was introduced to embed the discourse among young people themselves, and did so successfully: young people themselves came to take on Foucauldian 'dividing practices' by promoting and perpetuating the safe/risky discourse.<sup>124</sup> In their study on barriers to STI testing among young women in Toronto, Canada, Wong and colleagues found that morality discourses prevailed in relation not only to the young women's sexualities, but also

applied to the biomedical approach to STIs. They found that school-based sex education about STIs emphasised individual responsibilities, which could act as a barrier to help seeking since the need for STI testing implied irresponsibility and, by extension, immorality. The implications of an STI diagnosis on relationships also highlighted power imbalances between young women and their male partners, and young women may choose not to risk their reputations or relationships by seeking a test or disclosing a result.<sup>125</sup> An interesting ethnographic study conducted in remote and rural Australia among indigenous young people noted that young people 'distanced' themselves from STIs, reinforcing the notion of 'other'. Further, the study found that STIs are stigmatised while pregnancy is not, and a hypothetical young woman who loses her relationship due to pregnancy might have a broken heart, but if due to an STI, she automatically assumes an identity as a slut (or other similar labels). Stigma and reputation were also clearly associated with gender, with young women being much more disadvantaged and disempowered compared with young men.<sup>126</sup>

#### 3.2.2.3 Meanings of different STIs

Most studies explore stigma or meaning in relation to one STI (such as HIV, or chlamydia, or HPV) but very few have tried to tease apart meanings associated with different STIs among the same individuals participating in studies. A small study into perspectives on chlamydia screening among young male university students in the UK found that chlamydia for these young men was not a stigmatised condition when they compared it to HIV, syphilis and gonorrhoea.<sup>90</sup> Among disadvantaged Canadian young people living in Toronto, HIV was compared with chlamydia (and other curable STIs) and seen as the infection much more to be feared.<sup>125</sup> Some recent studies have explored beliefs about HPV, in light of the availability of an HPV vaccine. There appear to be different levels of stigma associated with HPV infection, as well as different notions of fear. Among adolescent girls and their parents in Australia, knowledge about HPV was very low, such as knowledge about its prevalence among males as well as females, its link to cervical cancer, and the potential protective effect of the HPV vaccine, and there was much confusion about how all these were interrelated. The researchers hypothesised that lack of knowledge could contribute to stigmatising women due to perception that it is a women-only infection<sup>127</sup> and this lack of knowledge was one factor linked to fear and anxiety associated with HPV vaccination in schools.<sup>128</sup> A study among young men and women with genital warts found significant stigmatisation associated with factors like infectiousness, visibility and labelling ('unclean') and to a lesser extent, the association with cervical cancer.<sup>129</sup> A study exploring meaning of HPV and Pap testing among young women found that HPV infection was more stigmatising than an

abnormal Pap test, and that lack of knowledge about the link between HPV and cervical cancer could in fact serve to protect against social rejection and stigma.<sup>130</sup>

## 3.3 Conclusion

In summary, young people tend to have much higher knowledge about HIV than about all other STIs. It appears universal that STIs and HIV are stigmatising conditions, and that stigma relates to young people becoming identified as promiscuous or unclean, but that these meanings are highly gendered, with young women being more likely to be stigmatised than young men. The most dominant discourse surrounding STIs is a morality discourse, either in relation to young people's sexuality itself, or in relation to the morality of taking responsibility for protecting oneself from STIs by using condoms or by seeking testing. Yet these morality-producing protective behaviours would paradoxically lead to revelations about sexual activity, which would be seen as immoral. Finally, there do appear to be different levels of stigma and discourse surrounding different STIs, but these have been studied very little.

# CHAPTER 4 GENITAL *CHLAMYDIA TRACHOMATIS* INFECTION: BIOLOGY, CLINICAL FEATURES AND EPIDEMIOLOGY

If I had a world of my own, everything would be nonsense. Nothing would be what it is, because everything would be what it isn't. And contrary wise, what it is, it wouldn't be. And what it wouldn't be, it would. You see?

- Adapted from Lewis Carroll's Alice's Adventures in Wonderland and Through the Looking-Glass for Alice in Wonderland, Walt Disney Productions, 1951.

This seemingly facetious quotation from Lewis Carroll captures the challenges, complexities and controversies surrounding not only the taxonomy of the bacteria kingdom but also the dizzying rapidity with which advances in molecular biology and genomics are enhancing the understandings of, yet adding to the confusion about, the evolution, classification and clinical implications of many important bacterial human pathogens. As recently as 2009, a review paper in *Science* stated '...*we still do not understand what a bacterial species is*'.<sup>131(p.741)</sup> This chapter briefly describes the development of current understandings about the biology of *Chlamydia trachomatis* and a history of methods of detection of the organism in humans for clinical application, followed by its clinical features and epidemiology.

# 4.1 The biology of Chlamydia trachomatis

*Chlamydia trachomatis* is a species of the genus Chlamydia, family Chlamydiaceae, order Chlamydiales and of the class and phylum Chlamydiae. The chlamydiae are Gram-negative bacteria that are unique among microorganisms in having a life cycle with two distinct morphologic forms – one intracellular and one extracellular. They are obligate intracellular parasites that require a eukaryotic cell host and can only be cultured in tissue (ie non-artificial media).<sup>132</sup>

*Chlamydia trachomatis* comprises two biovars. The trachoma biovar causes eye and urogenital disease through infection of the epithelial surface of conjunctival and genital mucosae. The lymphogranuloma venereum or LGV biovar causes genital ulceration and bubonic disease, having the ability to spread via the lymphatic system.<sup>133</sup> Within the trachoma biovar, several serotypes have been identified. Serotypes A – C cause trachoma while serotypes D – K cause urogenital disease. Serotypes L1, L2 and L3 are associated with LGV.<sup>132</sup>

The primary surface antigen of *Chlamydia trachomatis* is the major outer membrane protein, or MOMP. The gene encoding this antigen is the *ompA*. Serotyping techniques previously involved using monoclonal and polyclonal antibodies directed against the MOMP, with greater refinement becoming possible after the development of sequencing of *ompA*, giving rise to the identification of many serovar subtypes.<sup>134</sup> Molecular methods such as 16S ribosomal RNA analysis, multilocus sequence typing and single nucleotide polymorphism analysis have also contributed to understanding of the evolution and recombination potential of the various serotypes.<sup>133,134</sup> Very recent whole-genome analysis of a diverse sample of *Chlamydia trachomatis* strains suggests that genetic recombination between the ocular and urogenital strains occurs more readily than previously thought. This might explain mixed infections with both serotypes as well as having implications for immunity from reinfection.<sup>133</sup> Whole-genome analysis also showed that the trachoma strains appear to have descended from ancestors that cause urogenital disease.<sup>133,135</sup>

Although human diseases caused by different *Chlamydia trachomatis* infections have been recorded historically and can be traced back to ancient times, technical challenges in isolating the organism made it difficult to identify and categorise. Earliest visualisations of the organism occurred in 1907. Halberstaedter and von Prowacek detected large intracytoplasmic inclusions as well as smaller extracellular particles in the ocular scrapings of orang-utans, using Giemsa staining<sup>136</sup> and a light microscope. These were originally thought to be protozoa and were named *Chlamydozoa*.<sup>137</sup> Similar inclusion bodies were subsequently detected in human infants, and genital tracts and urethras of mothers and fathers of infected infants. When it was realised that it could only be cultivated within cells, it was assumed to be a virus. The organism was first isolated in the 1930s from people with lymphogranuloma venereum (LGV), while genital tract chlamydia isolates did not occur until the late 1950s and 1960s. It was not until the 1960s that it was identified as a bacterium.<sup>132,137</sup>

The organism was initially isolated through tissue cultures, using yolk sac inoculation. In the late 1960s and early 1970s new culture techniques using irradiated McCoy cells enabled much more rapid isolation (48 – 72 hours instead of six weeks). This diagnostic advance enabled larger epidemiological studies to determine the association between chlamydia and non-gonococcal urethritis and other clinical syndromes. The 1980s saw the development of commercially available antigen detection and nucleic acid hybridisation tests, and the 1990s the introduction of nucleic acid amplification tests. Detection methods for *Chlamydia trachomatis* will be described later.

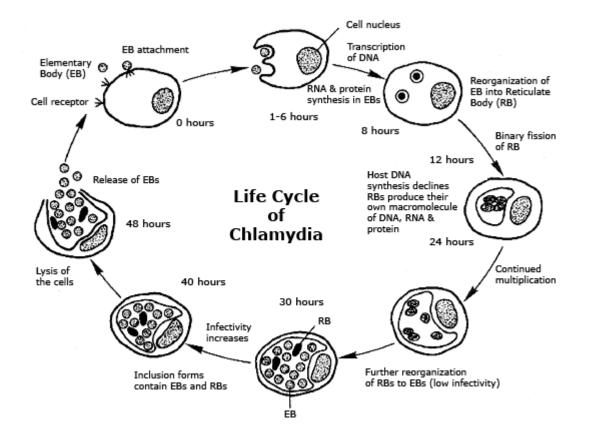
## 4.1.1 The developmental cycle of Chlamydia trachomatis

All chlamydia species appear to have the same developmental cycle that consists of:

- 1. Attachment to the host cell of the infectious particle (elementary body)
- 2. Entry into the cell
- 3. Morphologic change of the elementary body into the reticulate body with subsequent intracellular growth and replication
- 4. Morphologic change of reticulate bodies into elementary bodies
- 5. Release of infectious particles

The elementary body (EB) is a small, metabolically inactive particle about 350nm in diameter. It is resistant to the extracellular environment and attaches to the host cell wall through poorly understood mechanisms, but which might involve a specific receptor-ligand interaction. EBs are rapidly and preferentially ingested by susceptible host cells, including non-professional phagocytic cells; ie they induce phagocytosis. Once inside the cell, the organism inhibits phagolysosomal fusion, the other property that contributes to the organism's virulence. If large numbers (~100) of EBs are ingested, cell death can occur, although the organism does not produce an extracellular toxin.<sup>132</sup>

Chlamydia particles stay within endosome-like structures (inclusion vacuoles) once they have been ingested into host cells. The organism interacts with the host cell such as to foster its survival and replication. It secretes proteins that control metabolic and membrane-trafficking processes within the cell, including the initial inhibition of mitochondrial apoptosis which prevents cell death.<sup>138</sup> About eight hours after cell entry, EBs are transformed into reticulate bodies (RBs). These particles are much larger than EBs, measuring 1 $\mu$ m in diameter and they have a more permeable border that allows uptake of adenosine triphosphate (ATP) and nutrients. RBs undergo binary fission within the host cell for 20 – 24 hours, however by the end of this time some have transformed back to EBs while others continue to divide, such that there are intermediate forms found within an inclusion throughout this process. The mature inclusion body may contain hundreds or thousands of EBs. Figure 4.1 depicts the life cycle of the Chlamydia organism.



## Figure 4.1: Life Cycle of Chlamydia

Source: http://homestdtestkit.org/what-is-chlamydia/ [viewed 10 April 2013]

Much of the current understanding about the molecular mechanisms of survival and replication within host cells has come from genomic studies over the past 15 or so years. This is because its obligate intracellular life has made it technically difficult to extract the organism without causing contamination or inactivation, and also because it is very difficult to manipulate genetically. In addition, *Chlamydia* has one of the smallest genomes of all bacteria, making genome sequencing relatively easy. Genome sequencing has thus provided much of the recent information about the metabolic capabilities and pathways of the organism.<sup>139,140</sup> Whole genome sequences have now been analysed for five *Chlamydia* species.<sup>133</sup>

It is hypothesized that the organism secretes a contact-dependent Type III secretion (TTS) which generates a range of signals including inhibition of lysosome fusion, diversion of nutrients into the inclusion vacuole, differentiation of RB into EB via intermediate initiation bodies and finally detachment from the inclusion.

The EB has a complex, rigid cell wall. The outer membrane of the cell wall contains highly crosslinked, cystine-rich proteins and an additional hexagonally-arrayed protein layer on its inner surface. The EB wall is unusual in bacteria in that peptidogylcans (PG) have not been detected either by electron microscopy or biochemical methods,<sup>140</sup> yet genome sequence analysis has found that the chlamydiae have the codes for PG synthesis as well as some of the enzymes required for synthesis, a phenomenon called 'the peptidoglycan anomaly'.<sup>141</sup> PG are the molecules in cytoplasmic membranes that protect the integrity of bacteria. The cell wall outer membrane described above appears to function in the same way as PG in other bacteria to provide such structural integrity. The EB surface has hexagonally organised projections extending about 30nm thought to be TTS system 'needles' that deliver protein signallers to the host cell upon entry.

The process of cell entry is thought to take place in two stages. The first is a reversible, electrostatic interaction while the second is irreversible and temperature-dependent.<sup>142,143</sup> This binding to the cell probably occurs at host cell receptor sites, although they have not yet been identified. It is then likely that signals are triggered that lead to the internalisation of the EB, probably via the TTS mechanism.

Once inside the host cell, it is thought that the TTS system triggers the release of other proteins. These serve two main functions: the acquisition of energy and the prevention of lysosomal fusion. The *chlamydiae* are able to modify the inclusion vacuole environment through the secretion of proteins, mostly *Inc*s, which are associated with the inclusion membrane.<sup>132</sup> It is believed that *Inc* secretion occurs via the TTS system and is contact-dependent – the greater the contact between the RB and the membrane of the inclusion, the greater the TTS activity. When the EB first differentiates into the RB, there is maximal contact between the RB surface and the membrane. As the RB divides, the surface area contact between RB and membrane decreases until TTS activity reaches a minimum. It is hypothesized by some that this decrease of TTS activity continues until a trigger is reached that signals the initiation of differentiation from RB back to EB.<sup>144</sup> This theory departs from the previous one about a strictly temporal relationship from RB to EB differentiation but appears to be gaining popularity.<sup>139,142</sup>

## 4.1.2 Pathogenesis and immunology

The pathways by which infection with *Chlamydia* lead to disease in humans remain unclear, but it appears that there are two contrasting hypotheses: an immunopathogenic pathway and a cellular

pathway. It had long been thought that a delayed-hypersensitivity type reaction or an autoimmune response was the pathogenic mechanism that leads to tissue damage and long term disease sequelae. Histopathology of acutely infected ocular and genital tissue shows intense infiltration with neutrophils and lymphocytes, while later infection is characterised by plasma cells and macrophages, with the formation of lymphoid follicles containing macrophages and B cells at the centre with T cells at the periphery. Epithelial cell damage and proliferation eventually lead to scarring.<sup>145</sup> The delayed-hypersensitivity reaction theory proposes that chlamydia-specific heat-shock proteins (HSPs) are the antigenic factors but there has not been conclusive proof that this is the role they, or any other potential antigenic factors, play in pathogenesis.<sup>132</sup> An alternative hypothesis, the 'cellular pathogenesis paradigm'145,146 proposes that Chlamydia infection causes tissue damage through the activation of cytokines and growth factors induced by nonimmune infected epithelial and endothelial cells. This hypothesis has been generated by findings that there is a sustained release of pro-inflammatory responses throughout the chlamydial life cycle (rather than just at cell entry). Immune cells become recruited to the sites of infection and in turn produce their own series of immunologic responses that augment the cellular responses. This explains the nature of re-infection pathogenesis by proposing that adaptive immune cells augment this process more rapidly.<sup>145</sup>

#### 4.1.3 Detecting Chlamydia trachomatis: a potted history

#### 4.1.3.1 Isolation and culture

*Chlamydia trachomatis* was first observed microscopically through the direct examination of smears of clinical specimens, initially conjunctivae and later genital tracts. The object of detection was the inclusion body, and several staining methods have been used in the past to optimise accurate visualisation and minimise confounding by other cellular structures.

Table 4.1 summarises the most commonly used staining methods for direct observation of *Chlamydia trachomatis* (from conjunctivae +/- genital specimens).

	History	Applications	Chlamydia features	Advantages	Disadvantages
Giemsa <sup>136</sup>	Developed by Gustav	High quality staining of	Cell nuclei stain red,	Cheap, easy	Time-consuming, other
	Giemsa in very early 1900s.	chromatin and nuclear	cytoplasm stains blue,		cell structures may be
	Initially used in the	membrane of all cells led	reticulate bodies stain		confused with
	identification of malarial	from its application from	blue and elementary		inclusion bodies
	parasites.	microbiology to histology	bodies stain purple		
Iodine	Described for detecting	Was useful for more	Inclusion bodies (the	Fastest of	Least sensitive of the
staining	inclusion bodies by Rice in	rapid detection of	glycogen-like	the three	three methods
	1936, improved for rapid	inclusion bodies in	carbohydrate matrices)	methods	Not applicable for
	detection in field work by	conjunctival specimens	stain brown against		genital specimens due
	Gilkes <sup>147</sup>	, r	pale yellow cells		to the large number of
					other glycogen-
					containing cells
Immuno-	Widely used in 1960s and	Direct fluorescent	Bright green mass	Rapid results	Technically demanding
fluorescence	1970s, became method of	antibody staining has	inside the inclusion	-	· –
	choice of all the staining	been used in the past for			
	methods at that time. Both	genital and ocular			
	indirect and direct methods	specimen staining			
	were used <sup>148</sup>	. 0			

Table 4.1: Staining methods for direct observation of Chlamydia trachomatis

Culture of the organism was first described in 1944 by Machiavello using embryonated hen's eggs although original isolation by culture is credited to T'ang in 1957.<sup>149</sup> Almost a decade later, Gordon and Quan, using gamma-irradiated McCoy cells, described a technique where isolated organisms could be inoculated into the cells and grown, having been taken directly from clinical specimens.<sup>149</sup> Subsequently other cell lines have been used including monkey kidney, HeLa (an immortal human cell line derived from Henrietta Lacks) and HEp-2 (human epithelial Type 2).<sup>150</sup> The clinical samples are centrifuged onto a monolayer of cells and incubated for 24 – 72 hours, depending on which staining method will be used to detect the inclusion bodies. While Gordon irradiated the cells and found that the organism's growth was enhanced, chemical treatments of cells have since been developed that have more widespread utility in laboratories.<sup>148</sup> Culture of *Chlamydia trachomatis* became the gold standard for detection until the advent of nucleic acid amplification techniques. Although the specificity of culture is 100%, its sensitivity is significantly lower, cited as being on average 85%.<sup>150</sup>

### 4.1.3.2 Non-culture antigen detection

Although highly specific, chlamydia culture is a time-consuming procedure, and by the early 1980s, studies using non-culture antigen detection by direct immunofluorescence and monoclonal antibodies were being published.<sup>145,151</sup> This method was very rapid and had a specificity of about 80 - 85% but required experienced microscopists and is no longer used.<sup>150</sup>

Enzyme-linked immunoassays (EIA) and enzyme-linked immunosorbent assays (ELISA) were developed in the late 1980s and became the most widely used detection method before

molecular tests. These used a monoclonal or polyclonal antibody to detect *Chlamydia* lipopolysaccharide. Direct EIA uses an enzyme-linked antibody that binds to lipopolysaccharide from the elementary bodies of all species of Chlamydia. The indirect EIA is a two-stage process involving an IgG detector reagent that binds to the lipopolysaccharide followed by an enzyme-linked anti-IgG antibody which forms the antigen-antibody complex that will change the colour of the substrate. This process takes three to four hours.<sup>152</sup> Several EIAs became commercially available and compared with culture had varying sensitivities from 53% - 75% with high specificity, but since molecular tests have become regarded as superior to culture, these sensitivities have been revised down.<sup>150</sup>

#### 4.1.3.3 Antibody detection

Serologic tests for *Chlamydia trachomatis* have used a range of methods, including microimmunofluorescence (MIF), complement fixation (CF) and enzyme-linked immunoassay (EIA), and other techniques have been described such as indirect haemagglutination, neutralization, precipitation, gel diffusion, enzyme-linked fluorescence, immunoperoxidase and immunoelectrophoresis.<sup>153</sup> Microimmunofluorescence (MIF) became the superior antibody detection method compared with complement-fixation (CF) after it was demonstrated to have higher specificity and sensitivity and was able to show some type-specificity.<sup>154</sup> MIF is useful for detecting neonatal chlamydial infection<sup>153</sup> and has also been used in population studies for pelvic inflammatory disease and tubal factor infertility.<sup>150</sup> The antibodies detected were against structural antigens, especially the major outer membrane protein (MOMP).<sup>155</sup> Recently, and with the advancement of genomic and proteomic technology, antibodies against non-structural antigens have become detectable. These are antigenic proteins secreted by reticulate bodies into the host cell and antibodies directed against them have been showing promise as a screening technique for predicting tubal factor infertility.<sup>155</sup>

#### 4.1.3.4 Nucleic acid techniques

Nucleic acid technology has become the most important development in recent years for the detection of microorganisms. It also has application in non-infectious disease and genetic testing, forensic medicine and other biological research. It involves the direct detection of genetic material, which is stable, in constrast to all the previously mentioned detection methods which rely on organism phenotypic characteristics that might be influenced by in vitro conditions.<sup>156</sup> Nucleic acid detection techniques fall into two categories: amplified and non-amplified.

The first nucleic acid test approved for microbiological testing appeared in the mid-1980s which used a DNA probe (for Legionnaire's disease).<sup>157</sup> This 'nucleic acid hybridisation' technique involves the single strands of nucleic acid from two different sources to 'hybridise' one another: one source is the DNA probe (made from cloned DNA or produced synthetically) while the other is the target, more complex and heterogeneous nucleic acid population. The DNA probe is an homogeneous group of molecules. These two single strands might need to undergo treatment (usually by heating or alkalinising) if they are originally double-stranded, to be separated into single strands. When the two nucleic acid sources are mixed, complementary base sequences 'find' each other and associate, or hybridise.<sup>158</sup> This technique, while highly specific, requires a large number of target cells to achieve high sensitivity.156 The introduction of nucleic acid amplification techniques (NAAT) thus paved the way for both sensitive and specific detection methods for Chlamydia trachomatis which have now replaced culture as the gold standard.<sup>159</sup> NAAT involves the amplification of the nucleic acid sequence up to a billion fold<sup>150</sup> which, in practice, means that a positive signal on a DNA probe can be elicited from as little as one nucleic acid sequence.<sup>159</sup> The actual methods of amplification include polymerase chain reaction (PCR), ligase chain reaction (LCR), strand displacement amplification (SDA), and transcriptionmediated amplification (TMA). The other practical advantage of NAAT technology is its high sensitivity using non-invasive specimen collection methods, such as urine or self-collected vaginal swab samples.<sup>160</sup>

#### 4.1.3.5 Rapid testing

New rapid, or point-of-care, tests for chlamydia are still in trial stages, including a world-first cluster randomised controlled trial in remote and regional Aboriginal communities in Australia.<sup>161</sup> Early rapid tests which relied on antigen-antibody interaction were developed in the late 1990s and early 2000s and used optical immunoassay and magnetic immunochromography. They were found to have very low sensitivity, especially compared with NAAT.<sup>162</sup> There is currently a rapid test that uses real-time PCR which detects both *Chlamydia trachomatis* and *Neisseria gonorrhoeae* in about 90 minutes, directly from endocervical and self-collected vaginal swabs and from urine samples in men and women, and has been reported to have near-perfect sensitivity and specificity.<sup>162</sup> Two other rapid tests are under development also utilising DNA amplification technology.

# 4.2 Genital chlamydia infection ('chlamydia')

Chlamydia trachomatis serovars D - K are responsible for genital chlamydia infection. The organism infects columnar and transitional epithelium of the urethra, the endocervix and the rectum. Infection can extend to the epididymis in men, the endometrium, salpinx and peritoneum in women and, rarely, may produce systemic disease.

Chlamydia began to be recognised as a significant genital infection in the 1970s, causing a range of syndromes similar to gonorrhoea, whose organism had been identified a hundred years earlier.<sup>163,164</sup> By the mid-1980s, chlamydia was attributed to at least 50% of all cases of non-gonococcal urethritis in men and up to 50% of all recognised cases of pelvic inflammatory disease in women.<sup>165</sup> At this time, chlamydia was described as 'the silent epidemic', being asymptomatic or having subtle or subclinical syndromes especially in women.

The incubation period for chlamydia is one to three weeks. Uncomplicated infection can be asymptomatic in the majority of women and men, with a recent review paper citing that at least 50% of men and 70% of women do not have symptoms.<sup>166</sup> Vague or non-specific symptoms also occur: dysuria, intermenstrual bleeding, abnormal vaginal bleeding and pyuria in women and meatal tingling or dysuria in men.

## 4.2.1 Chlamydial infection in women

Clinically apparent cervicitis may be detected in up to one-third of women who have chlamydia isolated from the cervix.<sup>164</sup> When symptomatic, women may notice abnormal vaginal discharge or intermenstrual or postcoital bleeding.<sup>166,167</sup> On examination there may be a mucopurulent discharge or hypertrophic ectopy associated with oedema, bleeding and congestion.<sup>164,167</sup> On colposcopy, mucopus, oedema, immature metaplasia and erythema can be seen, and cytological examination shows greater than 30 polymorphonuclear leucocytes per 1000x field as well as plasma cells and histiocytes.<sup>164,168</sup>

Urethritis can occur in women without cervicitis, as can cervicitis alone, but more frequently both occur. Urethritis in women is often asymptomatic, or it can cause dysuria +/- frequency without bacteriuria (urethral syndrome). In women with urethral syndrome symptoms, urethral discharge and meatal swelling or redness are often absent. An exudative infection of the Bartholin's ducts, or Bartholinitis, can also occur in women.<sup>164</sup>

Chlamydia infection of the lower genital tract in women can ascend, causing pelvic inflammatory disease, which is any combination of endometritis, salpingitis, tubo-ovarian abscess, and pelvic peritonitis.<sup>169</sup> Perihepatitis, also called Fitz-Hugh-Curtis syndrome, is a complication now known to be more commonly associated with chlamydia than gonorrhoea, and is usually associated with extensive tubal scarring and adhesions. It may present as right upper quadrant pain, fever, nausea and vomiting but evidence of salpingitis may or may not be present.<sup>164</sup>

Pelvic inflammatory disease (PID) is a syndrome that can be polymicrobial and whose clinical presentation is variable. However in young women (under 25 years), chlamydia is the causative organism in 60 – 80% of PID.<sup>170</sup> PID can be asymptomatic, or symptoms can be mild, and include abnormal vaginal bleeding, lower abdominal or pelvic pain, dyspareunia and fever. The gold standard for diagnosing PID is laparoscopy which is impractical, so diagnosis is nearly always clinical, and treatment is advised ahead of laboratory confirmation of infection to minimise or prevent tubal scarring.<sup>171,172</sup> Guidelines for the clinical diagnosis of PID have been suggested, and include abdominal tenderness, guarding or rebound; adnexal tenderness or mass, cervical excitation, and fever.<sup>170</sup> PID increases the risk of ectopic pregnancy, miscarriage, tubo-ovarian abscess, tubal infertility and chronic pelvic pain.

Neonatal chlamydia can occur via delivery through an infected birth canal. Neonatal conjunctivitis and pneumonia are known complications of genital chlamydia infection.<sup>166</sup>

#### 4.2.2 Chlamydial infection in men

The clinical entity in men known as 'non-gonococcal urethritis' (NGU) had been present for many decades before it became evident that chlamydia was the causative organism in many if not the majority of cases.<sup>164</sup> Further, with improved detection techniques in the 1980s, chlamydia became implicated in a greater range of genital syndromes in men than previously thought.<sup>173</sup>

The penile urethra is the primary site of chlamydia infection in men and can be asymptomatic in 50% of cases,<sup>174</sup> or cause mild symptoms of dysuria and/ or urethral discharge. Urethral inflammation might be present on Gram stain.<sup>164</sup>

Epididymitis has been attributed to chlamydia in the majority of cases affecting younger men (under 35 years) and complications of this are orchitis, obstructive azoospermia and testicular atrophy.<sup>175</sup> In symptomatic men, unilateral scrotal swelling, pain, tenderness and fever may be

present, as well as urethritis. However symptoms of epididymitis can be present without any clinical signs of urethritis.<sup>164</sup>

Despite many studies investigating the association between chlamydia infection and prostatitis, it remains unclear as to the role of the organism in men with prostatitis. This is mainly linked to the difficulties with isolation and detection of the organism from the upper reproductive tract in men; however many researchers believe that chlamydia is implicated in prostatitis and with male infertility secondary to prostatitis.<sup>174</sup> Similarly, the role of chlamydia in sperm parameters, such as motility, is controversial, and thus the importance of chlamydia in male infertility remains unclear.<sup>175</sup>

### 4.2.3 Chlamydial syndromes that occur in men and women

Chlamydia can cause proctitis in men and women: the infection is usually asymptomatic, but can cause rectal pain, bleeding, diarrhoea or rectal discharge. Symptoms tend to be milder however, compared to gonococcal proctitis or proctitis associated with LGV.<sup>164,176</sup> Chlamydia can also cause pharyngitis when transmitted via oral sex, and is typically asymptomatic; the serovars linked with STIs can also cause inclusion conjunctivitis with mucopurulent discharge similar to serovars A-C which cause trachoma.<sup>166</sup>

Sexually acquired reactive arthritis has been described in men and women with genital chlamydia, but it is uncommon, and much less common in women.<sup>177</sup> The organism reaches the joints from the urogenital system via circulating monocytes<sup>178</sup> and some develop Reiters syndrome which manifests beyond joints to include conjunctivitis and mucocutaneous lesions.<sup>164</sup>

## 4.2.4 Natural history of genital chlamydia infection

The natural history of genital chlamydia infection is still largely unclear. There are relatively high rates of recurrent infection in young people but these are likely to be new infections or untreated previous infections.<sup>164</sup> It appears that untreated uncomplicated chlamydia infection clears over time with about half infections resolving spontaneously after one year, and there does appear to be partial protective immunity that leads to lower organism loads in subsequent infections.<sup>179</sup>

#### 4.2.5 Management of genital chlamydia infection

Optimal management of genital chlamydia infection involves antimicrobial therapy and notification and treatment of sexual partners. The antibiotic groups of choice are the tetracyclines and macrolides. Treatment regimens of choice are either a seven-day course of doxycycline or a single dose of azithromycin, the latter regime being superior for adherence. Although these regimens have previously been reported as equally efficacious, a recent metaanalysis found there might be increased efficacy of up to 3% in favour of doxycycline for urogenital chlamydia and a 7% increase in efficacy for symptomatic urethral infection in men.<sup>180</sup> Despite the absence of a cell wall, the chlamydia organism is susceptible to beta-lactam antibiotics, the mechanisms for which are not well understood.<sup>181</sup> Thus, in pregnant women, amoxycillin can be used, as can erythromycin. To date, there appears to be minimal or no resistance to these antibiotics.<sup>167</sup>

Acute, sexually acquired pelvic inflammatory disease (PID) is treated empirically with oral ceftriaxone, metronidazole and azithromycin and continued for 14 days. Severe PID requiring hospital admission involves intravenous administration of these antibiotics with follow-up oral antibiotics dependent on the course of the disease and microbiology.<sup>182</sup> Sexually acquired epididymo-orchitis is treated empirically with ceftriaxone and azithromycin with follow up doxycycline or azithromycin over two weeks. Chlamydial proctitis in males and females is treated in the same way as genital chlamydia infection.<sup>182</sup>

Partner notification is a routine part of STI management for many STIs including chlamydia. Current contact tracing guidelines in Australia recommend tracing male and female sexual partners back for six months.<sup>183</sup> Testing of sexual contacts is recommended and an important part of chlamydia management. More recently, partner-delivered treatment has also been advocated. This involves providing antibiotics to the index case to give to their sexual partner/s and has been found to reduce chlamydia transmission, but is currently not legal in Australia.<sup>184</sup> Retesting after three months to screen for re-infection is currently recommended in Australia.<sup>185</sup>

## 4.3 Chlamydia epidemiology

Estimates of the prevalence of any disease or health condition come from either surveillance systems (such as notification data) or epidemiological studies. Because many STIs are asymptomatic and because of the stigma associated with STIs that may prevent help-seeking and testing, there is usually a gap between true prevalence and notification data.<sup>186</sup> Genital chlamydia infection occurs across the world but calculating prevalence at population or subpopulation levels has been difficult to achieve in many countries, and estimates have been made via systematic reviews of prevalence studies and/ or notification and surveillance data. In 2005 the World Health Organisation (WHO) estimated that there were 101 million new cases of genital

chlamydia infection in people aged 15 - 49 years, with a prevalence estimate of 98 million. The majority of chlamydia cases occurred in developing countries, and prevalence among females was higher than for males.<sup>187</sup> By 2008, this estimate had risen to 105.7 million new cases of chlamydia globally in people aged 15 - 49 years with a prevalence estimate of 100.4 million with a similar distribution and female to male ratio.<sup>188</sup> A large prevalence study in non-pregnant women aged 15 - 44 years across 10 areas in eight countries (Nigeria, Colombia, Argentina, Vietnam (2 areas), China, Thailand (2 areas), Korea, and Spain) found a crude prevalence of 3.0%, with the rate varying from 0.2% in Korea to 5.6% in Nigeria. This study found a significant difference in prevalence for women under 25 years and those older, although this age association was not as strong as what had been found in other studies in developed countries.<sup>189</sup> There is currently a global strategy (2006 – 2015) for the prevention and control of STIs<sup>190</sup> that calls for, among other things, improved surveillance measures so that the epidemiology of STIs can be more reliably understood and monitored.

In recent years, surveillance systems for chlamydia have been implemented in several developed countries including Australia. In the USA, chlamydia is notifiable but chlamydia prevalence is more reliably determined via national prevalence survey data. The National Health and Nutrition Examination Survey (NHANES) is conducted annually in the USA among a representative sample of about 5,000 people and covers a wide range of topics.<sup>191</sup> In the 2007 – 2012 cycle of NHANES, chlamydia prevalence among people 14- 39 years was 1.7%. However among sexually active young women (14 – 24 years), prevalence was 4.7% overall and 13.5% among non-Hispanic black females.<sup>192</sup> British and European prevalence data also suggest rates of chlamydia of 2 – 6%, highest in women under 25 years and men under 30 years.<sup>193</sup>

In Australia, chlamydia has been notifiable in all states and territories since 1999, but widespread population prevalence data has not been available. A systematic review published in 2012 of Australian prevalence studies found a pooled prevalence of 5.0% for women younger than 25 years and 3.9% for men under 30 years. Prevalence was higher for young men and women among clinical populations (such as sexual health, family planning or youth health clinics) and higher again for Indigenous men and women, reaching 22.1% among Indigenous women.<sup>194</sup> An enhanced national surveillance program for chlamydia commenced in Australia in 2007 and despite discontinuation of federal funding in 2010, continues currently. The program collates surveillance data from general practice and family planning services, sexual health clinics, Aboriginal controlled community health services and a laboratory network.<sup>195</sup> Analysis of data

from 2006 – 2010 from the sexual health clinic sector of the ACCESS program found that among sexual health clinic attendees, having chlamydia was independently associated with being young (15-24 years), residing in a regional/rural area, being Aboriginal and/or Torres Strait Islander, being a non-Australian resident and attending in 2010 compared with 2006.<sup>194</sup> National notification rates for chlamydia in Australia rose steadily from 1999 until 2013, which saw the first slight decline since national notifications began. Chlamydia nevertheless remains the most frequently notified STI in Australia and notification rates are highest in the 15 – 24 year age group. In 15 – 19 year olds, notification rates are three time greater for females than males, whereas the ratio for 25 – 29 year olds is 1:1.<sup>196</sup>

### 4.3.1 Risk factors for chlamydia

Chlamydia infection is most strongly correlated with young age, and for this reason, age is considered the sole risk factor for screening in young people; in older people other risk factors might be considered before screening. As well as age, risk factors include having a new sexual partner, multiple sexual partners, inconsistent condom use and history of previous STIs.<sup>197</sup> Racial differences can also be found, for example in the USA, African American and Hispanic people have higher rates that white Americans;<sup>198</sup> in the United Kingdom, non-White ethnicity is a risk factor in women and men<sup>166</sup> and in Australia, being Aboriginal and/ or Torres Strait Islander is a risk factor.<sup>194</sup>

The factors which predispose young people to chlamydia (and STIs generally) are biological, psychological, behavioural and sociocultural. Biological changes associated with puberty and their influences on increasing vulnerability to chlamydia are best understood for females. The prepubertal cervix is lined with columnar epithelium which recedes to be replaced with squamous epithelium as oestrogenisation of the cervix and vagina progress throughout puberty and into adulthood. The presence of columnar epithelium, called cervical ectopy, is a definite risk factor for chlamydia (and a possible one for gonorrhoea and HIV infections). Changes in vaginal pH, and in cervical mucous consistency and IgG levels might also play a part in increasing susceptibility to STIs generally in adolescent females.<sup>199</sup>

Unique psychological and cognitive factors among young people include those which are understood in the context of adolescent brain development. These have been described in Chapter 1, whereby sensation seeking increases at a faster rate during puberty than the maturation of the prefrontal cortex which helps to control risk taking.<sup>28</sup> This could predispose

young people to take risks such as having unprotected sex. In addition, individual psychological characteristics have an influence on decision-making and behaviour; for example, perceived risk, intention, self-esteem, self-efficacy and psychological distress can all play a role in mitigating behaviours (especially condom use) that protect young people from, or put young people at risk for, chlamydia and other STIs.<sup>35,200</sup> Behavioural factors that can put young people at greater risk of STI acquisition or transmission include not only total number of sexual partners but also patterns of sexual relationships. Although young people tend to have serially monogamous sexual relationships they can be of relatively short duration and there is some evidence that concurrency of relationships occurs with some frequency.<sup>199</sup> The increasing gap between age of sexual initiation and marriage (or its equivalent) is one of the pubertal transitions that has marked current and recent generations of young people and is thought to be related to the increase in STI rates in this group in many parts of the world.<sup>201</sup>

At the social and cultural levels, many factors can influence a young person's risk of acquiring STIs. Family factors such as communication between parents and adolescents about reducing STI risk can be important. Social and cultural norms, gender inequality, access to health care and laws that permit young people to receive confidential services and consent to their own treatment all play a part.<sup>199,200</sup>

## 4.4 Summary

*Chlamydia trachomatis* has been an elusive organism whose identification, classification and detection proved difficult for many decades. It remains, globally, one of the 'silent epidemics' that can have serious and lifelong consequences for reproductive health in women and men, yet remains easy to treat and cure. For biological, psychosocial and cultural reasons, it remains an infection that is most prevalent among young people. Importantly, chlamydia infection is an excellent candidate for screening, for reasons described in the next chapter.

# CHAPTER 5 STI SCREENING

The first task of the doctor is ... political: the struggle against disease must begin with a war against bad government. Man will be totally and definitively cured only if he is first liberated...

- Michel Foucault, The Birth of the Clinic, 1963

# Introduction

Sexually transmitted infections, like many communicable diseases, have the capacity to cause human suffering, long term morbidity and death. Like other communicable diseases, some STIs have fallen as much into the public health, as into the clinical, realm of medicine. From their public health mantle, governments in many countries, and across diverse portfolios that might include law reform, health departments, surveillance units and education, have been implementing programs that attempt to control the spread of STIs in populations for the past century. This chapter broadly describes the theory of STI control, and STI screening as one mechanism for STI control. The second part of this chapter will examine chlamydia screening in particular. The concept of medical screening as a social intervention will also be explored.

# 5.1 Theory of STI control

STI control, from a public health perspective, refers to one or more organised and integrated programs whose aim is to reduce the public burden of morbidity or mortality caused by STIs. Like many other diseases, both communicable and non-communicable, control of STIs can include prevention (primary and secondary) as well as diagnosis and treatment. Any medical interventions need to occur within systems and structures that are accessible to those in the population who are likely to be affected. Non-clinical interventions such as education and health promotion not only support the directing of individuals in target groups towards medical activities (eg to seek testing or treatment) but play a crucial role in raising community awareness, shaping societal attitudes, and involving target populations themselves in designing and implementing relevant programs. Adequate surveillance systems, research and evaluation are crucial aspects of STI control.

The three pillars of STI control are surveillance, prevention interventions and program support.<sup>202</sup> The capacity to develop and maintain each of these components varies between resource-rich and resource-poor countries and communities and these are reflected in

epidemiological patterns of disease. Surveillance is the systematic collection of data over time that measures specific, identified health outcomes (eg disease incidence or prevalence). It is a cornerstone of public health as it informs program development, planning and evaluation. Surveillance can be active or passive. Passive surveillance is more common across whole government jurisdictions and involves the notification of diseases to a central agency. Analysis of notified cases identifies emerging trends and also helps to indirectly measure impacts of other programs. Active surveillance involves assessing usually a smaller, well-defined population in more detail and following disease patterns over time. Active surveillance can give a rich picture of the particular needs of a community.<sup>203</sup>

Prevention interventions encompass the vast range of clinical and non-clinical activities that aim to prevent or reduce the impact of STIs. These are activities that require engagement with the target populations, and can occur at multiple levels, such as the individual, partnership (including mother-child due to vertical transmission of some STIs) and population levels. Prevention interventions might require the synthesis of various theoretical frameworks and practical strategies, from biomedicine and technology to theories of behaviour, marketing or learning. Examples include the medical technology involved in developing rapid testing for STIs (known as point-of-care testing), the establishment of organised contact tracing systems, mass media campaigns about condom use and the incorporation into school curricula of information about STIs.

Program support for STI control includes the meta-structures required to deliver and sustain prevention intervention activities. Program support includes leadership and management strategies (eg having government strategies and policies in place), legislative reform, workforce development, network development (such as cross-sectoral, interagency, non-government organisations), and the funding of research and evaluation projects.

STI control, while embedded in the broad field of medicine, has faced and continues to face the challenges brought about by social and cultural attitudes surrounding STIs and the power these have had over the past century to influence government policy or funding in many countries.<sup>204</sup>

## 5.1.1 Considerations specific to the epidemiology of STIs

A critical factor in the epidemiology and prevention of communicable disease when compared with non-communicable disease is what is known as the 'dependent happenings relation'.<sup>205</sup> This

refers to the dependence that communicable diseases *and their prevention* have on relational events, namely intimate person-to-person contact. By contrast, non-communicable diseases in populations relate to individual risk and are independent of the occurrence of relational events.

A further concept in STI control is the transmission dynamics model described by May and Anderson in relation to HIV epidemiology.<sup>206</sup> Their theories using mathematical modelling had been applied to the epidemiology of many communicable diseases in both humans and animals in earlier work.<sup>207-209</sup>. The model asserts that the prevalence of an STI in a population is determined by its *reproductive rate*. When an infected individual transmits an infection to one or more susceptible individuals in the population, the reproductive rate is greater than one, and the prevalence increases. When the reproductive rate is below one, the infection in a population will die out. In relation to STIs, the reproductive rate,  $R_0$  is the product of three factors,  $R_0=\beta cD$  where:

 $R_0$  = number of new infections that an infected individual generates  $\beta$  = average probability of transmission per sexual encounter c = average number of sexual partnerships per unit time D = duration of infectiousness

The values  $\beta$  and c are averages. In a population, sexual encounters might occur once only between two individuals ('casual encounters') but there might be many casual encounters within a population, or encounters might occur many times between the same two individuals ('long term partnership'). The  $\beta$  value is an average of the probability of transmission per encounter that includes all types of encounters. This value is specific not only to a specific infection but also to specific sexual practices – it can be different for vaginal compared with anal intercourse for example.<sup>210</sup> The value c refers to the average number of sexual partnerships over time, or the rate of partner change. Although almost impossible to measure at a population level, the rate of partner change introduces the concept of a 'core group' in STI transmission dynamics theory. The core group refers to those individuals whose rate of partner change is high enough to maintain the reproductive rate above one.<sup>202</sup> A non-core group is generally much larger than a core group and some of its members might come into contact from time to time with those from the core group. The average duration of infectiousness of an STI (D) is a critical factor in STI epidemiology, and a predictor of the infection's endemic prevalence.<sup>210</sup> This factor is dramatically impacted on by treatment, which requires detection. The prevention of viral STIs for which there are no cures tends to focus on  $\beta$  or c. The prevention of bacterial STIs tends to focus on the variable D, since bacterial infections can be treated and cured, which reduces transmission.

## 5.2 Medical screening

The history of medical screening dates back over a century. Its differentiation from diagnosis was and still is relatively simple in concept: it seeks to identify a health condition before it becomes symptomatic or clinically apparent. One of the earliest screening programs was the psychiatric screening of army recruits in the USA army in 1917.<sup>211</sup> The 'periodic health examination' was introduced in 1909 in the USA as a screening method that would prolong life expectancy. The evidence produced a few years later showing reduced mortality was not questioned for many decades despite its limitations;<sup>212</sup> a recent Cochrane systematic review has found that periodic health examinations do not reduce morbidity or mortality.<sup>213</sup> Two important communicable diseases were among the earliest to be screened for – tuberculosis and syphilis. It is thought that the term 'screening' in fact derives in part from the use of the XRay screen to look for latent tuberculosis. The other derivation is from the use of coarse screens in sanitation and public health to keep 'offensive' substances in effluent from polluting rivers.<sup>214</sup> Serology for syphilis screening was developed in the first decade of the 20<sup>th</sup> century, was among the earliest medical screening programs and still exists in much the same form today.

In 1968, Wilson and Jungner, commissioned by the World Health Organisation, published their seminal paper 'Principles and Practice of Screening for Disease'.<sup>215</sup> The paper was a detailed description of principles derived from 'lessons learned' using several screening tests and programmes as case studies, rather than a systematic review of either programmes or evidence. Their emphasis was on non-communicable diseases screening in developed countries since these had long overtaken communicable diseases as dominant causes of morbidity and mortality in resource-rich countries. Wilson and Jungner called for standardisation and uniformity regarding definitions and measurements as well as sound evaluation and the development of evidence for benefits of screening. They cited the Commission on Chronic Illness (CCI) definition of screening as:

...the presumptive identification of unrecognized disease or defect by the application of tests, examinations or other procedures which can be applied rapidly. Screening tests sort out apparently well persons who probably have a disease from those who probably do not. A screening test is not intended to be diagnostic. Persons with positive or suspicious findings must be referred to their physicians for diagnosis and necessary treatment.<sup>216(p.45)</sup>

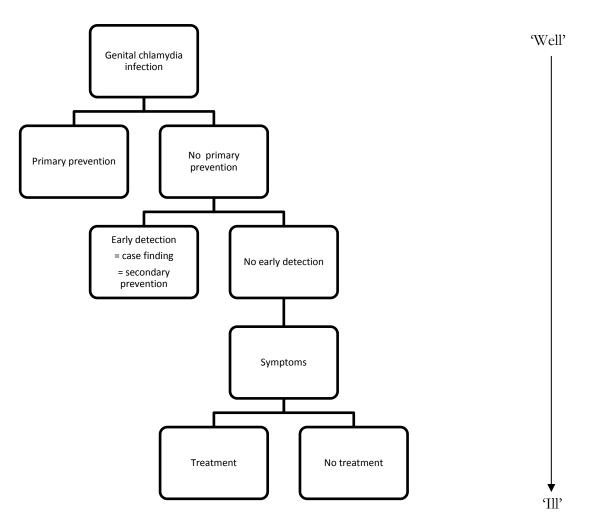
Their 'Principles of Early Disease Detection' were described as the following:<sup>215</sup>

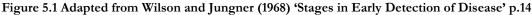
- The condition sought should be an important health problem.
- There should be an accepted treatment for patients with recognised disease.
- Facilities for diagnosis and treatment should be available.
- There should be a recognisable latent or early symptomatic stage.
- There should be a suitable test or examination.
- The test should be acceptable to the population.
- The natural history of the condition, including development from latent to declared disease, should be adequately understood.
- There should be an agreed policy on whom to treat as patients.
- The cost of case finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
- Case finding should be a continuing process and not a 'once and for all' project.

Despite their age, these principles have largely endured in screening policy and programme development and evaluation, with some additions or considerations that reflect new medical technology, ageing populations, the era of evidence-based health care and policy and the need for more accountability to the population in terms of resource management. In more recent years, more emphasis has been given to considering harm, opportunity cost and the type and strength of evidence to support a screening programme.<sup>217</sup> For example, advances in biotechnology in the field of genetics and genomics may allow for inexpensive, mass capacity to identify genetic conditions, but the cost of providing human resources and services to educate, counsel and help individuals make rational and informed choices is potentially vast. Technological developments in biomedical tests also out-pace the evidence of benefit of their application as screening tools. Further, new frontiers in genetic screening pose whole of society questions about ethics and the law.<sup>218</sup> Harris et al<sup>219</sup> synthesise Wilson and Jungner's and Andermann et al's work, adding their own experiences on the US Preventive Services Task Force and review of screening evaluation literature to emphasise the importance of balancing harm

with benefit, and importantly shift the focus from 'disease' and 'risk factors' to 'health outcomes' and 'predictors of poor health'. Rather than completing a checklist of principles, Harris et al suggest that to evaluate screening a 'balance approach' is more realistic, as this includes examining evidence of harm as well as benefit more carefully and looks at health outcomes (such as morbidity measures and mortality) rather than changes in individual test results.<sup>219</sup>

The principles of screening for communicable and non-communicable diseases do not differ. However, because of the relational nature of communicable diseases, issues such as contact tracing, quarantine and ethical and legal obligations surrounding notification and confidentiality become critical at a public health level.<sup>190</sup> In resource-poor communities where morbidity and mortality from communicable diseases remain prevalent, access to technology and structural supports are also important considerations in screening. Wilson and Jungner illustrated the stages of early disease detection (screening) diagrammatically using tuberculosis as a case example.<sup>215</sup> Their original diagram is reproduced in Figure 5.1, using chlamydia as the example.





## 5.2.1 The organisation of screening in Australia

Screening for disease or an asymptomatic condition can be a clinical intervention for an individual at a given point in time and is usually opportunistic. Indeed clinical screening constitutes an important part of preventive health care and often takes place in primary health services. Population screening also has individual health ramifications (ideally, benefits) but differs from clinical screening in that it must be organised and targeted at sufficiently large proportions of a population.<sup>220</sup>

Today, organised screening in Australia takes place within a population screening framework endorsed by the Australian Health Ministers Advisory Council (AHMAC). The Screening Subcommittee of AHMAC developed the framework in 2008, based on the Wilson and Jungner principles with additional qualifications that there be a strong evidence base to support a screening program and that population benefits outweigh harms.<sup>221</sup> The AHMAC framework articulates explicit requirements concerning infrastructure and workforce support and access and equity. Their criteria for a screening program are that the Screening Program must:

- respond to a recognised need.
- have a clear definition of the objectives of the program and the expected health benefits.
- have scientific evidence of screening program effectiveness.
- identify the target population which stands to benefit from screening.
- clearly define the screening pathway and interval.
- ensure availability of the organisation, infrastructure, facilities and workforce needed to deliver the screening program.
- have measures available that have been demonstrated to be cost effective to encourage high coverage.
- have adequate facilities available for having tests and interpreting them.
- have an organised quality control program across the screening pathway to minimise potential risks of screening.
- have a referral system for management of any abnormalities found and for providing information about normal screening tests.
- have adequate facilities for follow-up assessment, diagnosis, management and treatment.
- have evidence based guidelines and policies for assessment, diagnosis and support for people with a positive test result.

- have adequate resources available to set up and maintain a database of health information collected for the program.
- integrate education, testing, clinical services and program management.
- have a database capable of providing a population register for people screened that can issue invitations for initial screening, recall individuals for repeat screening, follow those with identified abnormalities, correlate with morbidity and mortality results and monitor and evaluate the program and its impact.
- plan evaluation from the outset and ensure that program data are maintained so that evaluation and monitoring of the program can be performed regularly.
- be cost-effective.
- ensure informed choice, confidentiality and respect for autonomy.
- promote equity and access to screening for the entire target population.
- ensure the overall benefits of screening outweigh the harm.<sup>221(p.11)</sup>

Australia currently has national screening programs for breast cancer, cervical cancer and bowel cancer as well as newborn screening for a range of congenital and metabolic conditions and hearing. A national screening program for chlamydia is being considered, and awaiting further evidence.

# 5.3 Chlamydia screening : a work in progress

# 5.3.1 The medical rationale for chlamydia screening

Scholes et al <sup>222</sup> were the first to conduct a randomised controlled trial to evaluate the impact of chlamydia screening in women on the incidence of pelvic inflammatory disease (PID). Participants were a community based sample of high risk women aged 18 - 34 years enrolled in a health maintenance organisation in Washington state in the USA. Risk status was determined using known predictors of chlamydia infection (such as sexual history and Black race). They found that women who were screened for chlamydia had a significantly lower incidence of PID at 12 month follow up (relative risk = 0.44). Fast forward to the present time and the first Cochrane protocol for a systematic review has been published, whose objectives are *to assess the effects and safety of chlamydia screening in pregnant and non-pregnant women and in men, compared with standard care, on chlamydia transmission and on complications of infection.*<sup>223(p.3)</sup> This will extend and update previous systematic reviews by Nelson, <sup>224</sup> Honey,<sup>225</sup> Meyers,<sup>197</sup> Low,<sup>226</sup> Gottlieb<sup>227</sup> and Guy.<sup>228</sup>

Randomised controlled trials (RCTs) to evaluate chlamydia screening on the incidence of PID and/ or ectopic pregnancy and/or tubal infertility that have been published include Giertz,<sup>229</sup> Scholes (1990-2),<sup>222</sup> Ostergaard (1997-8),<sup>230</sup> POPI (2004-7),<sup>231</sup> and Andersen.<sup>232</sup> Other non-RCT studies include cohort studies without a control group,<sup>233</sup> historical cohort studies<sup>234-237</sup> and ecologic studies.<sup>238-241</sup> While some of the earlier trials suggested a significant reduction in PID incidence attributable to chlamydia screening of asymptomatic women,<sup>222,229,230</sup> later studies suggest a weaker impact. A latter study<sup>232</sup> also showed a non-significant impact on the incidence of ectopic pregnancy, tubal infertility, in vitro fertilisation, and epididymitis in men. It is thought that the findings of these more recent studies could be related to re-infection and a need for retesting women who have been treated. This has led to two RCTs currently underway in Australia ('ACCEPt') and The Netherlands (Chlamydia Screening Implementation). These are register based screening trials that employ multiple screening rounds.<sup>223</sup>

#### 5.3.2 History of chlamydia screening programs

Chlamydia is the only STI where population based screening programs have been implemented. The goal of these programs is to identify and treat enough cases within the target population/s for the overall prevalence to decrease. In doing so, there will also be individual benefits, such as reduction in infertility and ectopic pregnancy in women.<sup>234</sup> The chlamydia screening programs currently in place across several (developed) countries are not by any means identical or even uniform either in their target populations or in their structure or components. What is described as a 'program' in some countries is more like a collection of different guidelines and policies in some, but not all, jurisdictions, rather than a nationally coordinated, organised and evaluated public health program.

Sweden was the first country acknowledged for introducing a national, opportunistic screening program, in 1983.<sup>242</sup> In fact, it has subsequently been argued that it was not a screening program *per se*, because, although widespread, it was not nationally coordinated.<sup>193</sup> In the USA, opportunistic chlamydia screening was introduced through a nationally funded Infertility Prevention Program in 1995<sup>243</sup> and in the UK a national opportunistic screening program commenced in 2003.<sup>244</sup> The Netherlands became the first country to trial register-based screening in 2008.<sup>193</sup> Several European countries have introduced opportunistic screening widely, with Norway and Denmark now piloting register-based approaches as well.<sup>193</sup>

Two systematic reviews of the impact of chlamydia screening programs on prevalence of either chlamydia or pelvic inflammatory disease have been somewhat inconclusive and inconsistent.<sup>197,226</sup> They each found that there have been two register-based trials<sup>222,230</sup> that suggest an impact on the incidence of PID after 12 months but came to different conclusions about whether this should lead to recommendations about screening men as well as women. The United States Preventive Services Task Force recommended screening for all young sexually active women in 2001, and updated their guidelines in 2006, which did not include screening men (due to insufficient evidence).<sup>197</sup> The Public Health Agency of Canada currently recommends screening of all sexually active women under 25 years and also advises screening of sexually active young men, with the acknowledgement that there is an evidence gap surrounding this recommendation.<sup>245</sup>

Like the USA, Canada and most other countries, Australia currently has clinical guidelines for chlamydia screening rather than an organised screening program. In Australia, chlamydia screening is recommended for all sexually active women and men aged 15 – 29 years by the Royal Australian College of General Practitioners<sup>246</sup> and the Australasian Chapter of Sexual Health Medicine via the Sexual Health Society of Victoria's National Management Guidelines for Sexually Transmissible Infections.<sup>170</sup>

### 5.3.3 Chlamydia control: Australian story

Although notification of communicable diseases, screening and quarantine all contributed to Australian public health efforts in some capacity from the early days of colonisation, the HIV/ AIDS epidemic of the 1980s led to the development of more coordinated efforts to strengthen STI and other communicable diseases control. The Communicable Diseases Network of Australia and New Zealand was formed in 1987, this later became (and still is today) the Communicable Diseases Network of Australia (CDNA). In 1991 the National Notifiable Diseases Surveillance System (NNDSS) was established and is overseen by the CDNA. The NNDSS relies on individual state and territory cooperation through the CDNA.<sup>247</sup> Chlamydia notification data first appeared on the NNDSS in 1994, but New South Wales data was not included until 1999.<sup>248</sup>

Advocacy for chlamydia control in Australia started in the early to mid-1980s, in response to increasing numbers of presentations of pelvic inflammatory disease coupled with advances in diagnostic tests (immunofluorescence) that made systematic testing feasible (Basil Donovan,

Professor and Program Head, The Kirby Institute, University of New South Wales, oral communication in a meeting, 7 March 2014). The National Venereology Council of Australia, an advocacy body formed in 1979 – 1981<sup>249</sup> named chlamydia a priority STI, second only to HIV, in 1981.<sup>165</sup> A National Health and Medical Research Council Working Group to address pelvic inflammatory disease made several recommendations in 1988 – 1989, but HIV/ AIDS became a more urgent priority (Basil Donovan, Professor and Program Head, The Kirby Institute, University of New South Wales, oral communication in a meeting, 7 March 2014).

Once national surveillance data became available, chlamydia became the most frequently notified communicable disease in the country (and remains so today). In Australia's first National STI Strategy, chlamydia control and prevention was one of the three priorities (the other two related to STIs in populations, namely Aboriginal and Torres Strait Islander people and gay and other homosexually active men).<sup>250</sup> Opportunistic screening and an organised screening program were both discussed in the first National Strategy, and a Chlamydia Control Implementation Committee (CPIC) was convened. A competitive grants program for developing and evaluating chlamydia testing strategies was established to inform a potential national screening program. In addition, an enhanced surveillance system for chlamydia was funded, the Australian Collaboration for Chlamydia Enhanced Sentinel Surveillance (ACCESS).

By the end of the term of the first national strategy, evidence for an organised screening program remained lacking. The second national STI strategy<sup>251</sup> identified four priority populations (with young people being one of them) and six priority action areas of which one was research. The Department of Health and Ageing funded a randomised controlled trial to evaluate the impact on chlamydia prevalence of screening in general practice <sup>252</sup> and this study is ongoing at the time of writing.

# 5.4 Sociological considerations

Health screening is by nature a social as well as a medical activity. Its aim historically had been to protect the public rather than, or as much as, the individual. This was particularly true for communicable diseases, the exemplar disease being tuberculosis, where mass population screening was introduced in many countries in the first half of the 20<sup>th</sup> century. STIs, namely syphilis and gonorrhoea, were screened for in returned soldiers in both world wars. Psychiatric screening of army recruits in the first half of the 20<sup>th</sup> century was also undertaken, where men

with 'abnormalities' could pose a threat to their fellow soldiers.<sup>214</sup> Thus the early decades of medical screening focused on public 'threat'.

In the second half of the 20<sup>th</sup> century, chronic, non-communicable diseases became more prevalent in the developed world, and their aetiologies and management were multifactorial. The concept of 'risk factors' came into being, and were entities that could potentially be screened for. One's perception of one's own individual 'threat' from invisible 'disease' led to the 'emergent figure, that of the subjective and wilful patient.<sup>214(p.185)</sup> During the 1980s, more attention was given to the individual 'costs' of screening particularly psychological costs such as anxiety (which could lead to false measurements, such as artefactually raised blood pressure), the harms that could result from false positive or false negative test results and the choice of individuals to participate or take up screening. The sociological evolution of medical screening in the 20<sup>th</sup> century in fact seems to mirror the changing conceptualisation of the patient, from passive to autonomous, and from objective to subjective.<sup>214,253</sup>

By the 1980s, medical screening presented a sociological paradox: as a tool for promoting health equity in society and protecting the citizenry as a whole from disease, it also became a tool for greater surveillance and regulation of the individual.<sup>254</sup> Social science researchers also challenge the notion that participation in screening is morally neutral. Howson's work on cervical screening participation for example found that women not only accepted cervical screening as 'routine' and 'normal' and an activity of 'enlightened self-interest', but also felt a moral duty to other women to participate.<sup>254</sup>

A central tenet of population-based screening, and its uniqueness in the history of medicine, is 'that non-symptomatic individuals should make their bodies available to health professionals for regular inspection, and that this process needs to be routinised if it is to protect the health of citizens.<sup>253(p.165)</sup> This shift in medical thinking is equally a shift in social interaction.

In summary, medical screening was a revolutionary step in both the technology and sociology of medicine. It can on the one hand be seen a 'socialist advancement' that brings health benefits to the whole population, while on the other hand gives medicine different forms of power over populations through surveillance and by creating new subjectivities within the medical discourse of normalcy and abnormalcy, and as willing participants or non-compliers, neither of which may be seen as morally neutral.

# CHAPTER 6 ACCESS TO SEXUAL HEALTH CARE FOR YOUNG PEOPLE IN AUSTRALIA

Sometimes the questions are complicated and the answers are simple.

attributed to Dr Seuss (1904 – 1991)

# Introduction

The Australian health system has been described as complex, hybrid, mixed and fragmented. This is due to an eclectic group of factors such as Australia's history of federation leading to different levels of government and their powers and responsibilities for funding public services, recurrent tensions between political ideologies in relation to health care reforms, and the rising costs and complexities of health care in an ageing population. Shortly after this doctoral research commenced, a newly elected Australian government proposed the introduction of some of the most significant health care reforms in decades, including new hospital funding models and in the organisation and coordination of primary health care services at local levels. As this thesis comes to its conclusion, a new and different federal government plans to revise the restructure of primary health care such as a compulsory general practice co-payment, and the potential privatisation of primary health care networks and general practice training.

This chapter will very briefly describe the Australian primary health care system and access issues facing young Australians. The main emphasis of this chapter is to present a literature review of specific strategies for increasing chlamydia testing among young people, within our Australian health system context. A significant proportion of this literature review has been published as a systematic review and this article will be embedded in this chapter. An updated literature review has been added to highlight any new research that addresses the same research question of 'what strategies, programs, clinical or educational interventions have led to an increase in chlamydia testing among sexually active young people (up to 25 years)?'

# 6.1 The Australian health system

Australia's health system consists of largely taxation-funded primary, secondary and tertiary clinical services, as well as preventive, health promotion and public health services. Public hospitals throughout Australia are managed by state and territory ('State') governments, but funded through combinations of State and Commonwealth structures, and there are also

networks of privately-funded private hospitals some of which are owned by international companies. Private hospitals include for-profit and charitable not-for-profit enterprises, are diverse in scope,<sup>255</sup> and make up about 30% of hospital bed stock.<sup>256</sup> Public health services are governed by State and local governments, with the former managing public and preventive health programs (eg delivery of school-based adolescent immunisations, disease surveillance) and the latter responsible for services such as sanitation, water quality and food hygiene.<sup>256</sup> Health promotion also falls under the remit of State governments, although there are several examples of Commonwealth-State health and intersectoral collaborations addressing issues such as tobacco control and some types of cancer prevention.<sup>256</sup>

The organisation of primary health care in Australia has seen considerable change over the past 20 years. The primary health care sector is dominated by general practice, but this has gradually shifted from being predominantly uni-disciplinary small business enterprises to much bigger multidisciplinary service centres, many owned by large private corporations. To strengthen and support general practice, the Commonwealth introduced funding for a "Divisions of General Practice" network in 1992: these were geographically-based membership infrastructure organisations and by 2004, 94% of general practitioners (GPs) were members of a Division.<sup>257</sup>

The first-ever National Primary Health Strategy released in 2010 introduced new primary care organisations to replace Divisions of General Practice, called Medicare Locals. <sup>258</sup> Medicare Locals have a broader remit than the previous Divisions of General Practice: to coordinate primary health care within local areas through supporting a range of primary care providers including GPs, working with local hospital networks, addressing after hours GP services, identifying service gaps and coordinating service to try to address those gaps, establishing and maintaining service directories in local communities and to be accountable to local communities for the effectiveness and quality of services.<sup>259</sup> The current federal government (2014) plans to abolish Medicare Locals and replace them with fewer Primary Health Networks in mid-2015.

Since the early 2000s, changes in the composition of general practices have also occurred with the development of practice nursing. Australia has lagged behind many other developed-country primary health care systems in introducing nurses as part of a general practice team, and despite the rapid expansion of a practice nurse workforce in Australia, there remain an absence of clear career pathways for practice nurses as well as structural (and to some extent cultural) barriers to enhancing their roles in primary care.<sup>260,261</sup> In 2009, almost 60% of general practices employed

one or more practice nurses,<sup>261</sup> with funding linked to specific procedures or programmes, and which have included some preventive health and screening activities. In 2012 the Commonwealth Government introduced a Practice Nurse Incentive Program Practice nurses to further enhance and expand their role.<sup>262</sup> Practice nurses are either registered nurses or enrolled nurses and their roles within general practices vary from practice to practice.<sup>261</sup>

In the early 1970s, sweeping national health reform also saw the introduction of a national network of 'Community Health' services which have evolved quite separately from general practice. These have become mostly State-run primary care facilities that may be population-based (eg youth health services, women's health services, child and family services, refugee health services) or health-issue specific (eg sexual health services, drug and alcohol services, mental health services).<sup>263</sup> In addition, the primary health sector includes services such as Community Controlled Aboriginal Health Services, Aboriginal Medical Services, family planning clinics, pharmacies and other services. In 2006, the Commonwealth government introduced a national network of '*headspace* centres', which are primary health/ mental health services for young people 12 - 25 years. (www.headspace.org.au) Funding and governance for this web of primary health care services is mixed, most are government organisations but some are non-government organisations while others are consortia or privately owned.

Australia's health expenditure was estimated in 2011- 2012 to be 9.5% of gross domestic product, of which 70% was funded by governments.<sup>264</sup> Underpinning the health system and expenditure are the national insurance scheme, 'Medicare', introduced (as 'Medibank') in 1975 and the Pharmaceutical Benefits Scheme (introduced in the 1950s), both of which subsidise general practice and specialist consultations, a range of other defined health services (eg psychology and allied health) as well as a range of pharmaceuticals.<sup>256</sup> All Australian citizens and permanent residents are eligible for Medicare, as well as certain other groups, such as New Zealand citizens, visitors from countries with reciprocal health care agreement and some others.<sup>265</sup> Medicare subsidises the cost of consultations with doctors, optometrists and in certain circumstances dentists and allied health professionals. These professionals can accept the Medicare rebate as full payment and bill Medicare directly for services (including, for example, the pathology services involved in performing a chlamydia test). This direct billing is called 'bulk billing'. Alternatively, a professional can charge their own fee (which is not capped) which patients/ clients pay upfront, and later claim their rebate from Medicare. To obtain pharmaceutical products that are subsidised by the Pharmaceutical Benefits Scheme, a person

must also be enrolled in Medicare and have a Medicare number. However Australians have significant out of pocket health costs,<sup>266</sup> the third highest among OECD countries, with the greatest expenditure being for pharmaceutical products among older people and private health insurance for young people.<sup>267</sup>

Like many health systems in the developed world, Australia recognises the need for collaborative, integrated care and streamlined and timely communication between different parts of the health system. However the primary health care system in Australia remains fragmented and inequities of access due to cost, rurality and other factors continue to plague sections of the population.<sup>268</sup>

# 6.2 Access to primary health care for young Australians

The changing landscape of primary health care in Australia currently means that services for young people are disparate and fragmented on the one hand, and that young people have choice and a diversity of services on the other. With the current generation of young people growing up in a digital world, the impact of technology on their perceptions of access and their experiences of health care are not fully understood. Australian research into young people's access to primary health care, that still informs policy to some extent in some parts of the country today, is over ten years old and predates social media.

The first large scale study into young people's access to primary health care in Australia took place in the early 1990s in Victoria.<sup>269</sup> Ten years later a state-wide qualitative study was conducted in New South Wales.<sup>61</sup> Barriers to access were grouped into three categories: lack of awareness of the services available, especially in general practice where there were perceptions that only physical health needs would be addressed; personal/ psychological factors including concerns about confidentiality and embarrassment; and structural barriers such as cost and transport. These findings echoed international research particularly with respect to confidentiality concerns being a major barrier to help-seeking, but two unexpected findings were the lack of understanding about the role of general practitioners extending beyond physical health assessments and the consistency of findings across socioeconomic groups – more privileged young people experienced the same barriers as those from more deprived areas. International literature reviews published more recently and that have included these Australian studies' findings have found that across the developed and developing world, barriers to access are generally similar. While in some settings, physical access and availability are more problematic

than in other settings, the less tangible barriers of confidentiality concerns and feeling judged are universal.<sup>270,271</sup>

The concept of 'adolescent-friendly' or 'youth-friendly' health services is now over two decades old in some countries; the World Health Organisation has been very active in the past 15 years to assist developing countries to orient services towards becoming accessible and acceptable to adolescents (10 - 19 years) and has published a range of documents describing adolescent friendly health care.<sup>272</sup> A systematic review published in 2013 to define indicators of youth-friendly care as described by young people (10 - 24 years) themselves, examined quantitative and qualitative research that specifically sought young people's experiences with health care. The review then derived a set of eight core domains of 'adolescent-friendly care' which were: accessibility of health care, staff attitude, communication, medical competency, guideline-driven care (includes policies on confidentiality), age-appropriate environment, involvement in health care and health outcomes.<sup>271</sup>

Australian research into youth-friendly health services from provider perspectives identified seven principles: accessibility (included confidentiality policies), evidence-based practice, youth participation, collaboration, professional development, sustainability and evaluation. This research aimed to assist service and programme providers from diverse settings and sectors to systematically orient their services to improve their youth-friendliness.<sup>273</sup>

Thus at the commencement of this doctoral research (2007) young people 16 – 25 years across Australia had a range of primary health care services they could access for sexual health concerns, including STI and chlamydia testing. Universal health insurance (Medicare) would be able to cover the entire cost of consultations and testing if the young person was eligible and if agreed to by providers of those services. Treatment for STIs including chlamydia was and is available freely in some services (eg sexual health clinics) and as a subsidised pharmaceutical obtainable from retail pharmacies. Although it is legal for young people under 18 years to obtain chlamydia testing and treatment without parental consent in almost all circumstances, concerns about confidentiality and sensitivities around discussing sexual behaviour and sexual health could certainly pose barriers to seeking advice, testing and treatment for STIs. Lack of awareness about chlamydia was also another potential barrier. In this context, the following literature review is presented to describe strategies that increase young people's rates of chlamydia testing in Australia.

# 6.3 Strategies to increase chlamydia testing among young people in Australia: literature review

Opportunistic chlamydia screening of all sexually active young people has been formally recommended in Australia for over a decade, and is incorporated into clinical guidelines for preventive health in general practice.<sup>246</sup> The first national STI strategy 2005-2008<sup>250</sup> brought focused attention on both chlamydia and young people (16 - 25 years) and specifically explored strategies to increase chlamydia testing in this age group. The following published systematic review covers research conducted in Australia and published between 2000 and 2009. The aim of the systematic review was to identify interventions that could reduce the incidence and / or transmission of sexually transmitted infections and HIV in young people (12 - 25 years) in Australia. Following this is an updated literature review (Chapter 6.4, see p.84).

.../pages 63-84: Kang M, Skinner SR, Usherwood T. Interventions for adolescents and young people in Australia to reduce HIV and sexually transmitted infections: a systematic review. *Sexual Health* 2010;7:1-22.

A signed statement from co-authors verifying the contribution I made towards this publication can be found in **Appendix A**.

# Interventions for young people in Australia to reduce HIV and sexually transmissible infections: a systematic review

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**Abstract.** *Background*: Like young people in other developed countries, sexually active young Australians can have an increased risk of acquiring sexually transmissible infections (STIs). This paper reviews intervention programs that aim to reduce the incidence and transmission of HIV and STIs among young people in Australia. *Methods*: Articles were identified from seven databases. Intervention studies conducted in Australia that included young people aged 12–25 years were reviewed. A two-dimensional matrix consisting of 'setting' and 'intervention type' was developed to categorise each study. *Results*: Forty-two studies met the inclusion criteria, and the majority were uncontrolled intervention studies. Of these, 23/42 studies measured participation in chlamydia  $\pm$  other STI testing and found that the highest participation rates took place in non-clinical and non-general practice health care settings. Four studies facilitated access to testing indirectly, through the internet or other media. Ten studies involved the provision of education and measured its impact on factors such as knowledge, attitudes and/or behaviour. Three studies involved novel immunisation strategies for either hepatitis B or human papillomavirus vaccines. Two studies evaluated the impact of enhanced STI surveillance programs on prevalence rates. *Conclusions*: Proactive STI testing in non-clinical and some health settings appears feasible and achieves higher testing rates than in general practice; however, more evaluation of testing strategies in general practice settings is required. New technologies such as the internet and SMS are useful adjuncts for influencing behaviours such as condom use and STI testing. Media campaigns that promote STI testing can have a positive impact on testing rates.

Additional keywords: adolescents, education, internet, screening, testing, vaccination.

#### Introduction

The median age of first vaginal intercourse among Australia's youth population today is 16 years, which is earlier than in previous generations.<sup>1</sup> Like young people in other developed countries, young sexually active Australians are more likely to have multiple partners, unprotected sex and high-risk partners, with poorer access to services compared with adults, all of which puts them at an increased risk of acquiring and transmitting sexually transmissible infections (STIs).<sup>2</sup> Genital chlamydia (Chlamydia trachomatis) infection is the most common notified STI in Australia. Rates are highest in the 15-29 year age groups and have increased annually since national surveillance data collection began in 1999.<sup>3</sup> Among Australia's Indigenous population, STI patterns and rates resemble those in developing countries; several STIs are hyperendemic in certain remote regions of the country and Indigenous adolescents are most at risk.<sup>4</sup> In these communities, gonorrhoea (Neisseria gonorrhoea) and syphilis are more prevalent, and their rates have risen in recent years.<sup>5</sup> Trichomonas vaginalis, genital herpes (herpes simplex virus) and human papillomavirus (HPV) infection are not notifiable but the latter two are common among young people while

trichomonas infection is prevalent among Indigenous women.<sup>6</sup> Rates of newly acquired hepatitis B (HBV) infection have fallen among young people in recent years.<sup>5</sup> Although Australia remains a low prevalence country for HIV infection, the number of new HIV diagnoses has risen over the past decade. In 2008, there were 272 out of 995 new diagnoses of HIV infection in Australia among 13–29 year olds. In Australia overall, 85–90% of new infections over the past 5 years affect males, with a median age of 33–38 years. Higher proportions of new HIV infections in Aboriginal and Torres Strait Islander people are attributed to heterosexual contact and injecting drug use. However, the majority of HIV infections attributable to heterosexual contact in Australia are among those born in high prevalence countries.<sup>5</sup>

Public health responses to HIV and STIs have occurred at national, state and local levels, beginning with the first national HIV/AIDS strategy in 1989. In the 20 years since then, four further national HIV/AIDS strategies have been launched and the country's first national STI strategy was launched in 2005. There are also national hepatitis C (HCV) and national Aboriginal and Torres Strait Islander sexual health and bloodborne virus strategies. Together, these four strategies have 'the common goal of preventing and reducing the transmission of infectious diseases and improving treatment, care and support for those affected'.<sup>7</sup> Young people (variously defined as those from 12 to 16–25 years of age) have featured most notably in the national STI strategy 2005–2008 where those aged 16–25 are identified as one of three target populations for chlamydia prevention and control.<sup>6</sup> The federal government has funded initiatives such as the development of a national sexuality education framework for secondary schools, entered into funding agreements with state governments to deliver relevant sexual and reproductive health services, and funded national HBV and HPV vaccination programs.

The success of Australia's national HIV/AIDS strategies has been well documented, and is attributed to a strong partnership model that involves consultation and collaboration between government, affected communities, service providers and researchers.<sup>7</sup> Harm minimisation approaches, community participation, peer education and health promotion as well as innovative service delivery have resulted in the lowest HIV rates among commercial sex workers in the world, and substantially lower rates among injecting drug users and homosexually active men compared with other developed countries.<sup>7</sup>

Government policies are important and potentially impact on the epidemiology and burden of disease due to HIV and STIs in young people in Australia, but may be insufficient alone. Systemic, structural and attitudinal factors are also important, and include young people's access to comprehensive sexuality education, media and primary health care.

This paper reviews intervention programs that aim to reduce the incidence and transmission of HIV and/or STIs among young people in Australia. This review is limited to articles and abstracts published in peer-reviewed journals since 2000.

#### Methods

Articles for review were identified from the following databases: MEDLINE, PsycINFO, SCOPUS, CINAHL, Cochrane, EMBASE and ISI. The MeSH heading search terms used were: 'sexually transmitted diseases' OR chlamydia infections OR gonorrhoea OR syphilis OR 'papillomavirus infections' OR 'herpes genitalis' OR HIV OR 'trichomonas infection' OR Hepatitis B AND adolescent AND Australia. Abstracts from conference proceedings were included and references from systematic review articles were also searched.

Articles were included if they described *original research studies* conducted in Australia, focussed on young people in the age range 12–25 years either as research subjects or as direct beneficiaries of the intervention, and if these studies delivered a program that aimed to impact on awareness, knowledge, attitudes or behaviour and behavioural intent, or that facilitated access to STI testing or management (including treatment and contact tracing). Studies where the proportion of participants 25 years and under was less than 20% (ascertained by contacting authors if not stated in the paper) were excluded.

One author (MK) read each article and recorded the following: target population, proportion of the final sample that included young people aged 12–25 years, study design,

evaluation method, description of intervention/s, main outcome measures and authors' conclusions. RS and TU read all the abstracts and 10 full articles each so that inter-rater comparisons for each of the above criteria could be made between MK and either RS or TU for a total of 20 articles. It was evident after this process that an objective scoring or weighting system for comparing studies was not applicable, due to the diverse nature of the studies. Rather, the three authors developed a two-dimensional matrix consisting of 'setting' and 'intervention type'. This was considered the most useful way to categorise each study (rather than, for example, by STI type or study design) because it considered the physical context in which to engage young people in sexual health care (setting) and the strategies used to engage them (intervention type).

Settings were classified as:

- general practices
- non-general practice primary health services
- secondary schools
- other non-health community settings
- media
  - cyberspace.

#### Intervention types were:

- Type 1: facilitating immediate access to STI/HIV testing of asymptomatic people *outside routine clinical care*
- Type 2: facilitating indirect access to STI/HIV testing of asymptomatic people
- Type 3: provision of information, education or training to improve knowledge, awareness, influence attitudes, or impact on STI risk-reduction behaviour
- Type 4: enhancing surveillance programs to improve STI control
- Type 5: improving vaccination rates of vaccine-preventable STIs among susceptible populations.

Outcomes linked to directly or indirectly *reducing the impact* of *STIs* among young people in each study were identified and described. For example, although many Type 1 intervention studies reported on STI prevalence, for the purposes of this review, the outcome of interest for reducing STI impact was *participation* in testing. In contrast, where the intervention was an enhanced surveillance program (Type 4), change in prevalence rates was the outcome of interest since it was an indicator of the effectiveness over time of an STI control program.

<sup>6</sup>Routine clinical care' for STI/ HIV testing was determined by relevant clinical guidelines over the period 2000–2009.<sup>8–11</sup> Testing for chlamydia is currently recommended for all sexually active people 25 years and under, but over the review period, this did not include a specification for testing pregnant young women. Guidelines for testing for other STIs and HIV vary according to subpopulations, and include men who have sex with men (MSM), Aboriginal and Torres Strait Islanders, sex workers and injecting drug users.

#### Results

Of 252 articles retrieved using the search methods, 42 met the inclusion criteria (Table 1).<sup>12-53</sup> Of these, 19 targeted only

Bitual (2009) <sup>21</sup> Ic-3t-year old patients of neoropolina general protoces         Total (16-24) years impact + quintarion protoces given would propolic protoces given protoces given protoces protoces given protoces protoces protoces protoces	First author and year of publication	Population targeted for intervention and setting	Total sample size (% of total N aged 25 or less)	Study design and evaluation method	Intervention/s	Outcome measures of interest in this review	Authors' conclusions
Senior (public) secondary school students in the Australian Capital       795 (100%)       Uncontrolled intervention study       Provision of sexual health       Participation rate participation rate proceeding clinics and proceeding clinics proceeding	Bilardi (2009) <sup>12</sup>	16–24-year old patients of metropolitan general practices	871 (100%)	Uncontrolled intervention study Pre- and post-intervention impact + qualitative evaluation		Proportion of 16–24 year olds attending intervention practices who visited website Proportion of 16–24 year olds attending intervention practices tested for CT Acceptability of website to GPs and YP	Offering online risk asst tool did not lead to increase in testing; online tool seen as favourable by GPs but many barriers to referring patients; ineffectiveness of intervention might be due to other considerations rather than the intervention itself
GPs in the Australian     N/A     Randomised controlled     GPs in intervention     CT       Capital Territory     trial     practices given study     packs containing     equipment and       Capital Territory     trial     packs containing     equipment and     packs containing       S     Injecting drug users in     314 (54.5%)     Uncontrolled intervention     Clinic staff 'on foot'     Pr       known injecting     not offer CT testing when     performing Pap screen     to all 16–39-year-old     women       Victoria     314 (54.5%)     Uncontrolled intervention     Clinic staff 'on foot'     Pr       vomen     vomen     performing Pap screen     post-intervention     Pristing when       Victoria     1314 (54.5%)     Uncontrolled intervention     Pristing when       Participation rate     and at injecting centres, and invited them to attros     approached injecting centres, and invited them to attros	Bowden (2005) <sup>13</sup>	Senior (public) secondary school students in the Australian Capital Territory	795 (100%)	Uncontrolled intervention study Post-intervention participation rate	Provision of sexual health information followed by establishment of screening clinics and project help desk within participating schools	Participation rates in STI testing	Screening at school feasible and acceptable to students; link with education and health promotion important
Injecting drug users in       314 (54.5%)       Uncontrolled intervention       Clinic staff 'on foot'       Pr         known injecting       study       approached injecting       approached injecting         locations in Melbourne,       Post-intervention       drug users on the streets         Victoria       participation rate       and at injecting centres,         and invited them to       and invited them to         strend outreach clinic       for STI/BBV screening         Self-collected blood and       swab specimens offered	Bowden (2008) <sup>14</sup>	GPs in the Australian Capital Territory	NA	Randomised controlled trial	GPs in intervention practices given study packs containing equipment and pathology forms for CT testing and asked to offer CT testing when performing Pap screen to all 16–39-year-old women	CT screening rate per practice visit by women aged 16–39 years	Asking GPs to combine CT screening with Pap screening doubled the odds of CT screening per general practice visit for women aged 16–39 years
	Bradshaw (2005) <sup>15</sup>	Injecting drug users in known injecting locations in Melbourne, Victoria	314 (54.5%)	Uncontrolled intervention study Post-intervention participation rate	Clinic staff 'on foot' approached injecting drug users on the streets and at injecting centres, and invited them to attend outreach clinic for STI/BBV screening Self-collected blood and swab specimens offered	Proportion attending clinic who provided specimens for STI testing	Self-collected specimens acceptable; high prevalences of infections and risk behaviours

Table 1. Studies on interventions aimed at young people in Australia included for review (n = 42) BBV, blood-borne viruses; CT, *Chlamydia trachomatis*; GP, general practitioner; HBV, hepatitis B virus; MSM, men who have sex with men; MG, *Mycoplasma genitalium*; NG, *Neisseiria gonorrhoeae*;

Review of STI interventions for Australian young people

First author and year of publication	Population targeted for intervention and setting	Total sample size (% of total <i>N</i> aged 25 or less)	Study design and evaluation method	Intervention/s	Outcome measures of interest in this review	Authors' conclusions
Buhrer-Skinner (2009 <i>a</i> ) <sup>16</sup>	16-25-year-olds, Indigenous people and MSM living in Queensland	96	Uncontrolled intervention study Post-intervention impact and outcome evaluation	Self-collection, mail-in CT collection kits developed; promoted among target groups via posters, flyers, website and service providers; and distributed by several services or by mail following phone/ email request Specimen collection and processing, data management and follow-up services established	Proportion of appropriately returned kits Proportion of people diagnosed with CT appropriately treated	'Kits' easy to implement; excellent follow-up and treatment rates
Buhrer-Skinner (2009 <i>b</i> ) <sup>17</sup>	'High risk' people for CT as determined by sexual health service data in Townsville, Queensland	346 (80%)	Uncontrolled intervention study Post-intervention participation rate	Provision of sexual health information and education followed by establishment of screening facilities at multiple non-clinical venues	Participation rates at different venues Acceptability of testing among target groups Proportion of positive cases treated	Identification of 'high risk' groups and collaboration with community groups to deliver screening programs are viable and efficient complementary strategies for CT management
Chen (2007) <sup>18</sup>	16-29-year-olds in Victoria	N/A Population of 16-29 year olds in Victoria=1M	Uncontrolled intervention study Pre- and post-intervention impact evaluation; post- intervention process evaluation	Narrowcast media campaign in metropolitan and non- metropolitan regions of Victoria	Change in CT testing and notification rates Campaign recall Campaign website visits	Increased testing appeared to be a result of the campaign, and increased notifications a result of increased testing
Chen (2009) <sup>19</sup>	16-25-year-old pregnant women across four antenatal centres in Melboume	1044 (100%)	Uncontrolled intervention study Post-intervention participation rate	16-25-year-old women attending one of four antenatal centres offered CT testing	Participation rates in CT testing	High participation rates achieved in this setting; selective <i>v</i> . universal screening of pregnant women under 25 needs further consideration
Davis (2007) <sup>20</sup>	Tertiary students aged 16–26 years in ACT	445 (92.6%)	Uncontrolled intervention study Post-intervention participation rate	Outreach to university student events with establishment of screening facilities	Participation rates in CT testing	Outreach at student activities and events is acceptable for CT testing

Using drag nurses helped with recruitment and potentially de- stigmatised STIs	Prevalence of CT in this population of adolescents low	To date, there are increased numbers of the target group accessing the service and improved knowledge	Nurse-led recruitment was successful and reached ahard-to-reach population	STI screening in football clubs is feasible	Campaign did not impact on knowledge, condom use, CT testing or CT notifications	Peer support effective but challenging; need for flexibility due to rapidly changing online environments
Participation rates in CT and NG testing	Participation rates in CT testing	Number of target group accessing outreach clinic Observed change in CT knowledge	Participation rate Follow-up rates	Participation rates in CT, NG and MG testing	Change in CT testing and notification rates in Victoria Change in knowledge Change in condom use Campaign recall	Number of interactions Level of engagement of target groups Experience of online health promotion for peer supporters
Volunteers dressed as drag nurses approached patrons of three MSM entertainment venues and one community function, and offered urine and throat swab screening for CT and NG	Education program about infertility prevention delivered, followed by establishment of on-site screening facilities at schools staffed by nurses	Provision of information about sexual health via 'feel good nights' Establishment of screening clinics	Nurse-led recruitment of 18–25-year-olds attending emergency department (non- patients as well as patients)	Information and education session followed 2 weeks later by on-site facilities for screening within football clubs	Media campaign in Victoria	Trained volunteers entered chat rooms to deliver sexual health messages and attempt engagement in private chats about sexual health
Uncontrolled intervention study Post-intervention participation rate	Uncontrolled intervention study Post-intervention participation rate	Uncontrolled intervention study Post-intervention impact evaluation	Uncontrolled intervention study Post-intervention participation rate	Uncontrolled intervention study Post-intervention participation rate	Uncontrolled intervention study Pre- and during intervention impact and process evaluation	Uncontrolled intervention study Process evaluation
202 (estimate 25%)	1174 (100%)	Not stated	100%	108 45.4% <20 54.6% 20–29	N/A 600 young people surveyed to assess changes in knowledge, condom use and recall	1469 exposures and 60 interactions (74.2% $\leq 25$ where age provided)
MSM patrons of entertainment venues and a community function in Brisbane, Queensland	Secondary school students in Queensland	15–30 year old Indigenous youth in remote Western Australian communities	18–25-year-olds attending emergency department in Perth hospital, Western Australia	16–29-year-old men in Australian Rules football clubs in rural/ regional Victoria	18–25-year-olds living in Victoria	Same-sex attracted young people and MSM in Perth, Western Australia
Debattista (2002 <i>a</i> ) <sup>21</sup>	Debattista (2002 <i>b</i> ) <sup>22</sup>	Dunn (2007) <sup>23</sup>	Dykstra (2008) <sup>24</sup>	Gold (2007) <sup>25</sup>	Gold (2008) <sup>26</sup>	Hallett $(2007)^{27}$

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First author and year of publication	Population targeted for intervention and setting	Total sample size (% of total $N$ aged 25 or less)	Study design and evaluation method	Intervention/s	Outcome measures of interest in this review	Authors' conclusions
Hocking (2006) <sup>28</sup>	18–35-year-old women living in Melbourne, Victoria	979 (21.6%)	Uncontrolled intervention study Post-intervention participation rate	Participants given verbal information via telephone, written information via mail and freecall telephone number and website address; provided with equipment to collect urine specimen at home to mail in	Participation rate in CT testing Follow-up rates	Mailed urine specimens feasible but low response rates
Huang (2008) <sup>29</sup>	Resident 14–40-year-old Aboriginal people at beginning of annual screen in remote community	(50–55%)	Annual cross-sectional prevalence surveys	Residents visited 'on foot' to complete annual population census immediately before annual screening	Participation rate in CTn NG and syphilis testing Treatment rate Interval to treatment rate Annual trends in CT, NG and syphilis prevalence	Annual screening has led to decrease in CT and syphilis; nise of NG possibly due to travelling of core transmitters and change in transmission dynamics
Kalsi (2007) <sup>30</sup>	International students at university in Queensland	Not stated	Descriptive study	Range of sexual health information and discussion sessions targeting international students at a university	Feedback from students	International students are at high risk for sexual health problems and report favourably on workshops
Kang (2006) <sup>31</sup>	14–25-year-old homeless and high risk young people urban/rural New South Wales attending both clinical and non- clinical programs within youth health services	333 (100%)	Uncontrolled intervention study Post-intervention participation rate	Dedicated sexual health nurse or doctor approached potential participants individually and in groups to provide information about CT	Participation rate in CT testing Follow-up rates	Raising awareness and providing information about CT, and allowing discrete placement of urine specimen increased participation
Kang (2009) <sup>32</sup>	16–25-year-olds living in Australia accessing a chlamydia website designed for young people	705 (100%)	Randomised controlled trial	Personalised emails from sexual health nurse or doctor inviting confidential and anonymous discussion about CT risk and testing	Self-reported CT testing in previous 6 months Condom use Change in knowledge and attitudes	Engaging in email interaction is associated with higher rates of CT testing; condom use and some attitudes improved; knowledge did not change

 Table 1.
 (continued)

Sporting clubs are feasible, acceptable and innovative venues to educate, screen for and treat CT	Pregnant indigenous women should be screened for CT; women may be able to predict their risk of CT	Receiving regular sexual health-related SMS and email messages can improve knowledge in young people and health seeking behaviour in young women. These media have considerable potential for sexual health promotion	Completion poor overall no difference between standard and accelerated; intravenous drug use lower completion	Specimen drop -off program is not effective for screening for CT	Lack of increase of HIV testing among target group might be due to study design factors rather than campaign inadequacy, or both	(Continued next page)
Participation rate in CT testing Follow-up rates	Participation rate in CT testing	Change in STI knowledge Self-reported discussion with clinician about sexual health Self-reported STI testing in previous 6 months	Completion of accelerated 3 dose vaccine course Comparison between standard 6 month and accelerated (3 week schedule)	Proportion of requested kits returned	Proportion of HIV tests requested by members of target group at two SHCs immediately before and after campaign	
Sports clubs visited 2 weeks before explain testing; testing facilities established and testing offered after training to all eligible participants	CT testing offered to antenatal clinic clients in remote area	SMS and email used to send health messages to young people attending music festival, followed over 12 months	Non-HBV immune clients offered either accelerated or standard HBV vaccination course	Self-collection kits for CT and drop-off points developed and widely promoted at youth oriented events in area of eastern Sydney	Ethnic media campaign (print and radio)	
Uncontrolled intervention study Post-intervention participation rate	Uncontrolled intervention study Post-intervention participation rate	Randomised controlled trial	Uncontrolled intervention study Impact evaluation	Uncontrolled intervention study Impact evaluation	Uncontrolled intervention study Pre- and post-intervention impact evaluation	
709 (95%)	218 (50.5%)	994 (median age 19)	2085 (85% ≤30 yrs, mean age 27 yrs)	195 (67.2%)	1067 (~40%)	
16–25-year-olds attending sporting clubs in rural Victoria	Pregnant women attending antenatal services in remote north-western New South Wales	16–29-year-olds attending music festival in Melboume, Victoria	All non-HBV immune clients of Kirketon Rd Centre, Sydney New South Wales	16–24-year-olds in eastern and south eastern Sydney, NSW	Members of 14 non- English speaking communities across Australia	
Kong (2009) <sup>33</sup>	Lenton (2007) <sup>34</sup>	Lim (2007) <sup>35</sup>	Macdonald (2007) <sup>36</sup>	Martin (2009) <sup>37</sup>	McMahon (2004) <sup>38</sup>	

Outcome measures of Authors' conclusions interest in this review	Number of CT tests on Impact modest and largely 15–24-year-olds transient conducted by practices Opportunistic screening rate	Descriptive data on Participants and trainers participants' and experiences positive with trainers' experiences and reported improvement in perceived change in knowledge; sustainable knowledge about sexual networks and health; employment require Establishment of networks; greater support for enployment of peer disadvantaged young educators people and more capacity building within organizations	Participation rate for Pap An Aboriginal health smear screening worker trained to Participation rate in TV, perform and advocating for Pap smear not resting participation significantly increased smear participation; apparent low participation in TV, NG and CT testing possibly due to time constraints and service structural factors	Participation rate in CT,Bacterial STI screeningNG, TV or syphilisshould be incorporatedtestinginto antenatal protocolsPerinatal outcomesfor indigenous women	Change in attitudes HIV-positive speakers have a unique impact on young people
Intervention/s Out	GPs met, developed Nuu resources, became 1 'champions' within c their practice, and given Opp resources for initiating, r offering, testing, managing, contact tracing for CT	Peer educator training, Des development and p dissemination of sexual to health educational p materials b Estt Estt	Training of Aboriginal Par health worker in Pap s smear collection Par Eligible women attending N service and due Pap smear offered TV, NG and CT testing	STI testing offered to Par antenatal clinic clients N in urban indigenous to community Per	Person living with HIV/ Cha AIDS delivered AIDS education to secondary
Table 1.         (conunuea)           Study design and         evaluation method	Uncontrolled intervention study Before and during intervention impact evaluation	Uncontrolled intervention study Qualitative evaluation of intervention	Uncontrolled intervention study Post-intervention participation rate	Uncontrolled intervention study Post-intervention participation rate	Matched control study
Total sample size (% of total N aged 25 or less)	N/A	22 (100%)	198 (22.7%)	456 (54.20%)	1280 (100%)
Population targeted for intervention and setting	GPs in urban division of general practice, New South Wales	Indigenous young people in the Australian Capital Territory attending a range of community (non-health) services	Female clients aged 20–69 years due for Pap smear attending community-controlled urban Aboriginal medical service, Queensland	Pregnant clients of community-controlled urban Aboriginal medical service, Queensland	Victorian secondary students aged 14-18 years
First author and year of publication	Меггіц (2007) <sup>39</sup>	Mikhailovich (2005) <sup>40</sup>	Panaretto $(2006a)^{41}$	Panaretto $(2006b)^{42}$	Paxton (2002) <sup>43</sup>

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Impact of brief intervention on self-reported risk perception and behaviour at 3 months not demonstrated	Involvement of respected and trusted Aboriginal female health promotion worker was critical to improving recruitment to study and may have implications for Pap screening rates	Consent and completion rates higher than for other recommended vaccines in this age group	High rate of completion in this setting	Increase in knowledge and change in attitude did not impact on vaccination completion	Walk-in triage system led to increase in younger clients who were less likely to use condoms and more HSV and CT diagnoses	Using websites for partner notification does not harm index client or partner but made no difference to proportion of contacts traced using study protocol	(Continued next page)
Change in self reported risk perception Change in self reported condom use Change in knowledge	Number of Indigenous women participating in study on HPV prevalence	Participation rate in HPV vaccine program Vaccination course completion rate	Participation rate in vaccination program Vaccination course completion rate	Mean school HBV vaccine completion rate Median change in knowledge/attitude of students	Change in clinic attendances; demographic and sexual risk factors, and STI diagnoses of clients	Acceptability of web-based partner notification system Proportion of contacts traced	
Safe sex information and resources delivered by GP	Aboriginal female health promotion worker engaged for project, conducted street walks, attended community forums and introduced drop-in clinics and transport	GPs delivered HPV vaccine in schools to consenting students, with GP clinic mop-up doses	All young drug users offered vaccinations via approaches made on the street or in outreach drug treatment services	Teacher-delivered education program about HBV vaccination	Introduction of walk-in triage system at sexual health clinic	Clients diagnosed with NG or CT given standard contact tracing letter plus password- protected URL to give to partner/s	
Randomised controlled trial	Uncontrolled intervention study Pre- and post-intervention participation of indigenous women in study	Uncontrolled intervention study Post-intervention impact evaluation	Uncontrolled intervention study Post-intervention impact evaluation	Randomised controlled trial Impact evaluation	Uncontrolled intervention study Pre- and post-intervention audit	Randomised controlled trial	
312 (100%)	43 (32.60%)	275 (100%)	90 (100%)	925 (100%)	N/A (not stated)	105 (mean age 30)	
18–25-year-old patients of GPs in central Sydney	Indigenous women in Dubbo, New South Wales	Female students in Years 10–12 in two Queensland high schools	Drug users aged 22 or younger using outreach services in Melbourne, Victoria	Secondary school students in metropolitan Victoria	Clients of Melbourne SHC	Clients of Melbourne SHC aged 16 and over diagnosed with CT or NGU	
Proude (2004) <sup>44</sup>	Read (2008) <sup>45</sup>	Reeve (2008) <sup>46</sup>	Rogers (2005) <sup>47</sup>	Skinner (2000) <sup>48</sup>	Tideman (2003) <sup>49</sup>	Tomnay (2006) <sup>50</sup>	

			Table 1.       (continued)			
First author and year of publication	Population targeted for intervention and setting	Total sample size (% of total N aged 25 or less)	Study design and evaluation method	Intervention/s	Outcome measures of interest in this review	Authors' conclusions
Wade (2007) <sup>51</sup>	16–29-year-old men in urban sporting clubs in Victoria	50 (mean age 24)	Uncontrolled intervention study Post-intervention participation rate	Sports clubs in metropolitan Melbourne visited 2 weeks prior and information and education given; testing for CT and NG offered onsite after training; food and non-alcoholic drinks provided	Participation rate in CT and NG testing	High participation rates at individual sporting clubs
Wilkins (2007) <sup>52</sup>	15–24-year-olds in Western Australia	Focus groups 100% ( <i>N</i> = 29); Surveys 73% ( <i>27%</i> were aged 26–29) ( <i>N</i> = 122)	Uncontrolled intervention study Process, impact and outcome evaluation of intervention	Multimedia campaign	Qualitative data on awareness and recall of campaign and acceptability of SMS Qualitative data on use of campaign materials by GPs Quantitative data on website traffic CT testing rates in Western Australia	SMS acceptable to young people for communicating sexual health information; targeted media increased awareness; significant increase in CT testing likely due to media campaign
Young (2006) <sup>53</sup>	Clinicians in south-eastern Queensland who notified CT or NG during study period	Mean age of young people with STIs being notified = 22	Uncontrolled intervention study Pre- and post-intervention impact evaluation	Clinicians who notified NG or CT during the study period faxed information package with clinical and contact tracing guidelines and resources, with follow up phone calls	Response rate; descriptive data on clinician testing and management practices for notified CT; demographic data on notified cases	Enhanced surveillance could be useful at the local level for CT control

young people within the age range 12–25 and a further four extended the age range for 'young people' up to 29 or 30 years. The remaining 19 studies included young people up to 25 but not exclusively.

There were six randomised controlled trials and one nonrandomised controlled intervention study. There were 32 uncontrolled intervention studies, most of which aimed to determine the feasibility of testing for asymptomatic STIs outside of a clinical setting or routine clinical practice, as well as to measure the prevalence of various STIs. Others were uncontrolled pre- and post-intervention studies that measured impact and/or outcome. Some had a qualitative or process evaluation component. There was one retrospective qualitative evaluation of an intervention,<sup>40</sup> one series of annual prevalence measurements<sup>29</sup> and one qualitative evaluation of a series of educational strategies.<sup>30</sup>

Table 2 enumerates the studies within each dimension of the matrix (Intervention Type by Setting). The majority of interventions (23/42) were categorised as Type 1 (facilitating direct access to STI/HIV testing for asymptomatic people). Most Type 1 interventions (Table 3) were implemented in non-health community settings, such as football clubs, entertainment venues or communities defined by geographical boundaries. Health services other than general practices were also popular for delivering this type of intervention and included settings such as youth health services, antenatal clinics and outreach clinics established by sexual health services. Participation rates in STI testing ranged from less than 10% to over 90%, and the majority of studies reported very high follow-up and treatment rates of those testing positive. Some studies could not report on participation rates due to the nature of the intervention. For example, Bradshaw et al.<sup>15</sup> approached injecting drug users on the streets and invited them to participate in STI testing, but could not measure participation rates due to the informal nature of recruitment (such as approaching groups of people rather than individuals); Buhrer-Skinner et al.<sup>16</sup> facilitated screening using self-collected, mailed-in urine specimens that could be requested through a variety of channels, with denominator unknown.

There were four Type 2 interventions. These all aimed to facilitate STI testing but did so indirectly by encouraging referrals to relevant services. Three of these studies evaluated the impact of internet-based interventions (one also included mobile phone short messaging service, or SMS) on testing rates. Two were randomised controlled trials (RCTs).<sup>32-35</sup> Kang et al.<sup>32</sup> recruited young people through a dedicated website that was promoted through advertising and other media to engage in email interaction with a sexual health nurse or doctor (compared with no interaction) and found those in the intervention group were more likely to have reported chlamydia testing at 6 month follow-up. Lim et al.<sup>35</sup> recruited young people at a music festival to receive SMS and email messages about STIs, and reported increased STI knowledge in males and females, and increased self-reported STI testing in females in the intervention group. In an uncontrolled study, Bilardi et al.<sup>12</sup> recruited young people through general practices, where general practitioners (GPs) referred these patients to a website to complete a risk assessment tool online that would encourage them to seek chlamydia testing

from the GP. They did not find an increase in testing rates before and after the intervention, which could have been due to low referrals to the website by the GPs. An uncontrolled study by Hallett *et al.*<sup>27</sup> used trained volunteers to enter chat rooms that were popular among same-sex attracted young people in Perth, Western Australia. They measured the number of interactions with chat room visitors and the level of engagement with them. They measured intention to seek STI testing and found that all but one participant stated they were likely, very likely or definitely intending to access the service(s) recommended. However, despite reporting 1469 exposures in chat rooms and 60 interactions, only eight participants completed the evaluation questionnaire.

Of the 27 studies categorised as Type 1 or Type 2, only one measured change in condom use following the intervention and two measured change in knowledge, these were both RCTs. Kang *et al.*<sup>32</sup> found an increase in condom use among young people in the intervention group but no change in knowledge, while Lim *et al.*<sup>35</sup> found an increase in knowledge among young women.

There were 10 Type 3 interventions that examined the effect of information, education or training provision on young people's knowledge, attitudes and/or behaviour, and these were implemented across a variety of settings and used a range of study designs (Table 4). Four of these were uncontrolled pre-and post-impact evaluations of media campaigns, three of which specifically targeted young people and chlamydia. Two of these three chlamydia campaign evaluations found significant increases in testing rates before and after<sup>18,52</sup> while one did not.<sup>26</sup> However, the ineffective campaign promoted condom use only (which did not increase) and not chlamydia testing. The six other studies in the 'Type 3' group were highly varied. Proude et al.<sup>44</sup> used an RCT to evaluate the impact of providing training to GPs on condom use of their young patients (18-25 years). No effect was found after 3 months. Tomnay et al.<sup>50</sup> also used an RCT to evaluate the impact on partner notification of a passwordprotected URL (uniform resource locator) for infected clients of a clinic to give to their sexual partners. They found that this intervention had no impact on the proportion of contacts traced. Paxton<sup>43</sup> and Skinner et al.<sup>48</sup> delivered educational interventions in secondary schools. Paxton conducted a matched control study comparing the effect on students' attitudes towards people living with HIV/AIDS when schools utilised HIV-positive speakers and when they did not. They found a significant improvement in attitudes sustained over 3 months in the intervention group. In a RCT. Skinner et al. measured the impact on HBV vaccine completion rates among school students when they were given a comprehensive teacher-delivered educational program about HBV. Although knowledge improved significantly in the intervention group, uptake rates were similarly high in both groups.

Type 4 interventions involved enhanced surveillance programs to control STIs. Young *et al.*<sup>53</sup> implemented an uncontrolled intervention whereby doctors who ordered chlamydia tests from local pathology laboratories were contacted, given an information package about chlamydia and asked to complete a one page de-identified questionnaire for each patient tested. They found a high response rate (93%), and

.9	Table 2. Matrix - interve           Non-GP health service         Secon	interve	ntervention type by a	Matrix - intervention type by setting - number of studies per cell           e         Secondary schools         Other non-health community         N	cell Media	Cyberspace	Total
Facilitating immediate access to screening	Bowden <i>et al.</i> (2008) <sup>14</sup>	Chen <i>et al.</i> (2009) <sup>19</sup> Dvkstra <i>et al.</i> (2008) <sup>24</sup>	Bowden <i>et al.</i> (2005) <sup>13</sup>	setting Bradshaw <i>et al.</i> (2005) <sup>15</sup> Buhrer-Skinner (2009 <i>a</i> ) <sup>16</sup>			
asymptomatic people for sexually transmissible infections	Merrite $a_1$ . (2007) <sup>39</sup>	Kang <i>et al.</i> $(2006)^{31}$ Lenton <i>et al.</i> $(2007)^{34}$ Panaretto <i>et al.</i> $(2006a)^{41}$ Panaretto <i>et al.</i> $(2006b)^{42}$	Debattista <i>et al.</i> $(2002b)^{22}$	Buhrer-Skinner <i>et al.</i> (2009 <i>b</i> ) <sup>17</sup> Davis <i>et al.</i> (2007) <sup>20</sup> Debattista <i>et al.</i> (2002 $a$ ) <sup>21</sup> Dunn <i>et al.</i> (2007) <sup>23</sup>			
		Read <i>et al.</i> (2008) <sup>45</sup> Tideman (2003) <sup>49</sup>		Gold <i>et al.</i> (2007) <sup>25</sup> Hocking <i>et al.</i> (2006) <sup>28</sup> Kong <i>et al.</i> (2009) <sup>33</sup> Martin <i>et al.</i> (2009) <sup>37</sup> Wade <i>et al.</i> (2007) <sup>51</sup>			
	2	8	2	11	0	0	23
Facilitating access to screening asymptomatic people for sexually transmissible infection	c	c	c	c	c	Bilardi <i>et al.</i> (2009) <sup>12</sup> Hallett <i>et al.</i> (2007) <sup>27</sup> Kang <i>et al.</i> (2009) <sup>32</sup> Lim <i>et al.</i> (2009) <sup>32</sup> 4	4
indirectly	>	>	>	>	>	r	r
Provision of information, education or training	Proude <i>et al.</i> (2004) <sup>44</sup>	Tomnay <i>et al.</i> (2006) <sup>50</sup>	Paxton (2002) <sup>43</sup> Skinner <i>et al.</i> (2000) <sup>48</sup>	Kalsi <i>et al.</i> (2007) <sup>30</sup> Mikhailovich and Arabena (2005) <sup>40</sup>	Chen <i>et al.</i> (2007) <sup>18</sup> Gold <i>et al.</i> (2008) <sup>26</sup> McMahon <i>et al.</i> (2004) <sup>38</sup> Wilkins and Mak (2007) <sup>52</sup>		
	1	1	2	2	4	0	10
Vaccination	c	Macdonald <i>et al.</i> (2007) <sup>36</sup> Rogers and Lubman (2005) <sup>47</sup>	Reeve <i>et al.</i> (2008) <sup>46</sup>	c	c	c	"
Surveillance/control program	0	z Huang <i>et al.</i> (2008) <sup>29</sup> Young <i>et al.</i> (2006) <sup>53</sup>	4	2	5	5	n an
	0	2	0	0	0	0	2
Total	Э	13	5	13	4	4	42

Sexual Health

Settino/study	Intervention + control	Particination + treatment rate	Comments
(by name of first author)			
<i>General practice, n = 2</i> Bowden (2008) <sup>14</sup> General practices in the Australian Capital Territory	Unit of randomisation was the practice Intervention group: GPs asked to offer CT testing when performing Pap; given study packs containing path forms and equipment needed to contain specimens. Control group: GPs provided with laminated copies of guidelines for CT screening derived from various sources and asked to implement these during usual clinical practice	36.4% of eligible practices Intervention practices – 6.9% eligible women screened; screening rate per Pap smear 54.1% <i>Control practices</i> – 4.5% eligible women screened, screening rate 34.8% per Pap smear	The feasibility of CT screening at the time of undertaking a Pap smear was demonstrated. Participating general practitioners offered this in the context of an RCT to which they had been recruited by a local university department of general practice
Merritt (2007) <sup>39</sup> General practitioners from the Hunter, New England region in New South Wales	Self-selected GPs attended meetings to develop local strategies to improve opportunistic chlamydia testing in general practice, became 'chlamydia champions' in their practice, and developed resources for GPs and patients to be shared with colleagues in their practices	Median percentage of target group who attended a project practice and were tested increased from baseline to late intervention from 6.7–10.2% for females and 4.5–6.3% for males, which were higher than average for all practices in region; however, these were not adjusted for sexual activity or previous testing. Testing increases not sustained in most practices	Information and encouragement alone are unlikely to result in sustained behaviour change by general practitioners
Non-GP health service, $n = 8$ Chen (2009) <sup>19</sup> Four large metropolitan antenatal clinics	16-25-year-old women attending one of four antenatal centres offered CT testing	88% participation rate: 31/32 infected women treated but 1 was not contactable	Context and setting amenable to offering CT screening, which also included use of interpreters and translated information, resulting in high participation and treatment rates
Dykstra (2008) <sup>24</sup> Emergency department of large metropolitan hospital	Intervention: Nurse-led recruitment of 18–25- year-olds attending emergency department (non-patients as well as patients) <i>Comparison</i> : self-initiated strategy	Not stated	Mechanisms and participation insufficiently described for comment
Kang (2006) <sup>31</sup> Two urban and one rural youth health service (target: high risk and homeless young people)	Nurse or doctor approached youth health service clients at drop-in, arts/music/ education activities, as well as clinics to offer CT testing; 2/3 participants were non- clinical. Identifying barriers to participation in first centre improved participation in subsequent two centres	Participation rate not measurable due to multiple approaches, but estimated to be over 80% All CT positive participants contacted	'Engagement' with researcher (time spent explaining study, informal approaches, developing trust) was an important mechanism within the context of youth health centres being 'safe' places for marginalised young people to 'hang out' or attend formal services, and was critical for participation

Table 3. Intervention Type 1 studies: facilitating direct access to STI/HIV testing for asymptomatic people

(Continued next page)

	Table 3.	(continued)	
Setting/study (by name of first author)	Intervention $\pm$ control	Participation $\pm$ treatment rate	Comments
Lenton (2007) <sup>34</sup> Antenatal services in remote north- western New South Wales	CT testing offered to antenatal clinic clients in remote area	52% overall 34.6% Indigenous participation 59.4% non-Indigenous participation	Difference between participation rates for Indigenous and non-Indigenous women warrants further exploration and understanding
Panaretto (2006 <i>a</i> ) <sup>41</sup> Community-controlled urban Aboriginal Medical Service (AMS), Queensland	Training of Aboriginal health worker in Pap smear collection; all women attending AMS and due a Pap smear encouraged by Aboriginal health worker to have Pap smear and STI screen	35.6% of eligible population participated in Pap smear; of these, 31% participated in TV testing	The Aboriginal health worker was employed to coordinate a Well Women's Program at the AMS
Panaretto (2006b) <sup>42</sup> Community-controlled urban AMS, Queensland	STI testing offered to antenatal clinic clients in urban indigenous community	88–94%	Women were offered screening as part of the AMS antenatal care protocol
Read (2008) <sup>45</sup> Family Planning service in regional New South Wales	Consultation and collaboration with health promotion officer (HPO) from community; street walks with HPO and nurse; attendance at community forums; provision of drop in clinics and transport assistance	Not measured; increase in recruitment from 1–42 in study; increase in Pap attendances from 29–81 in 12 months	Principle of consultation and collaboration with members of target population community might be applicable more generally for engagement of target group in health promotion activities
Tideman (2003) <sup>49</sup> Sexual health clinic in Melboume	Introduction of walk-in triage system	N/A New client numbers increased by 20% with significantly increased proportion of younger clients	Increasing service flexibility through structural and operational changes is likely to improve accessibility of service
<i>Secondary schools, n = 2</i> Bowden (2005) <sup>13</sup> Two public secondary schools in Australian Capital Territory	Project team provided sexual health information; clinical rooms set up in schools near toilets, venepuncturist set up, clinics set up (either appointment or drop- in) and project help desk set up. Follow-up by mobile phone; offered treatment at school, sexual health clinic or GP	31% of students in the schools	Participation rate referred to all students including those not sexually active, which may reduce apparent effectiveness of this approach
Debattista (2002 <i>b</i> ) <sup>22</sup> Fourteen secondary schools in Queensland	Infertility prevention education program, then screening offered on site at schools by nurses, individual positive students contacted and treated	30–50% participation by students aged 15–18 years and up to 80% in rural schools	Requirement for parental consent in opt-in schools is a significant barrier
<i>Other non-health community setting, n = 11</i> Bradshaw (2005) <sup>15</sup> Known injecting locations in Melbourne, Victoria	Clinic staff on foot recruited IDUs in injecting centres and on the streets; self-collected urine, tampons ± blood samples	Participation rate not measurable due to informal approaches needed	Location and atmosphere of outreach clinic, and strategies for facilitating testing via 'on foot' approaches were mechanisms adopted in the context of the day-to-day lives of this population and appear to be effective. Their success would also require a skilled and trusted workforce. Low HBV vaccination coverage is of concern

(Continued next page)

	Table 3	Table 3.         (continued)	
Setting/study (by name of first author)	Intervention $\pm$ control	Participation $\pm$ treatment rate	Comments
Hocking (2006) <sup>28</sup> Victoria	Eligible participants telephoned, and mailed information and specimen collection	64% of eligible participated; however, final sample size represented only 9% of all households contacted; 43% of eligible participants returned urine specimens. Free treatment provided to all CT positive participants	Large number of households contacted to achieve desired sample size; however, participation rates among eligible women were good. Thus household screening may not be a realistic option on its own for promoting screening, but may fit within a broader intervention using this approach
Kong (2009) <sup>33</sup> Sporting clubs in rural Victoria	Sports clubs visited 2 weeks before to explain testing; testing offered after training to all eligible participants	95% of players; 24% of clubs 100% CT positive participants treated	Excellent fit between mechanism and context with excellent participation and treatment rates. Utilising nurses from existing community organisations considered essential
Martin (2009) <sup>37</sup> Eastern and south-eastern Sydney	Outreach with information and self-collection kits at multiple youth events + capacity to order kits via phone or email	413 kits requested out of possible 5000; 47.2% of ordered kits returned; 6/7 CT positive participants treated	Multiple strategies explored and contrasted mechanisms within same geographic context, with direct engagement in person at outreach events found to be the most effective for achieving better outcome (rate for returning of urine samples)
Wade (2007) <sup>51</sup> Sports clubs in metropolitan Melbourne	Clubs visited 2 weeks prior, and information and education given; testing for CT and NG offered on-site after training; food and non- alcoholic drinks provided	3/6 clubs; 87% participation Follow-up rate not stated	Excellent fit between mechanism and context with good participation rates

Setting/study (by name of first author)	Intervention or control	Main findings	Comments
General practice, $n = I$ Proude (2004) <sup>44</sup> General practitioners from central Sydney	Participating general practitioners trained to provide brief advice to reduce STI risk. Unit of randomisation was the patient. <i>Intervention group (INT)</i> : Young person asked about STI risk and given a resource pack. <i>Control group (CONT)</i> : Young person asked about smoking risk	Significant change in risk perception for hepatitis in both INT and CONT groups from baseline to follow-up, but not for HIV, STIs or pregnancy. No difference between INT and CONT for changes in risk behaviour at follow-up. Majority of young people in each group at baseline indicated no objection to sexual history taking, or to being given information on safe sex or illicit drug use	Intervention included both advice from GP and 'resource pack'. Few details of advice from GP and no quality assurance to ensure that it was given as planned
<i>Non-GP health service, n = I</i> Tomnay (2006) <sup>50</sup> Sexual health centre in Melbourne	<sup>e</sup> 1 Participants were patients of sexual health centre who tested positive for an STI. Unit of randomisation was the patient <i>Intervention group</i> : Standard partner letter and password-protected URLs with information and resources about NG and CT for partners. <i>Control group</i> : Standard partner letter	Overall low use of website by partners of participants in INT group. No significant difference between INT and CONT groups in contacting all partners, contacting any partners or number of partners traced per person	Contact tracing was not enhanced by providing sexual partners of 'index cases' with a dedicated website URL, suggesting that a standard letter is as effective
<i>Secondary schools, n = 2</i> Paxton (2002) <sup>45</sup>	Unit of randomisation was the school. Schools were self-selected, as 'intervention' if they invited a speaker who was a person living with HIV/AIDS (PWHA) to deliver HIV/AIDS education <i>Intervention group</i> : Students in schools where PWHA delivered talks at schools on safe sex. <i>Control group</i> : Students from matched schools that did not utilise PWHA speakers	Significant changes in attitudes to HIV positive persons and safe sex were sustained at 3 months after intervention for female students only. Male students had little change even immediately after intervention	Effective method for education and attitudinal change for females only, however most of PWHA speakers were female or gay males
Skinner (2000) <sup>48</sup>	Unit of randomisation was the school. Schools were randomly selected and allocated to intervention (teachers deliver an educational package to students) or control (standard information brochures given out)	Greater changes in attitude and knowledge about HBV and vaccination in intervention than control students. No difference in already high level of vaccination completion between intervention and control schools	Comprehensive education delivered by teachers can improve knowledge and attitudes but does not impact on vaccination uptake and completion in a school setting
Other non-health community setting, $n = 2$ Kalsi (2007) <sup>30</sup> Print materia University, arrival, inf Queensland intermitten student lea with interm	<i>ty setting,</i> $n = 2$ Print material given to international students on arrival, information stalls at Orientation week; intermittent workshops for international students, student leaders and professionals working directly with international students	Positive feedback from students	This is an important group of young people. Further evaluation of effective strategies to increase knowledge and change behaviour are important

(Continued next page)

		Table 4.         (continued)	
Setting/study (by name of first author)	Intervention or control	Main findings	Comments
Mikhailovich (2005) <sup>40</sup> Services supporting Indigenous youth, Australian Capital Territory	Young indigenous people aged 13–21 recruited and given extensive peer education training involving three components – residential, organisational and follow-up. Development and dissemination of sexual health educational materials including comic books, stickers, posters and peer education training manual	Self-reported improved confidence, knowledge, skills, use of health services and re-entry to school or work by peer educators. Only partially met secondary objective of developing partnerships to support a network of peer educators and improve access to services for indigenous young people	Innovative program, with apparent benefits limited by evaluation methods and lack of sustainability
Media, $n = 4$ Chen (2007) <sup>18</sup> Victoria media campaign Nov 2002–Jan 2004 (expansion of campaign June 2003)	Narrowcast media – posters and takeaway cards in entertainment venues and tertiary institutions in metropolitan venues. Expansion in June 2003 to non-metropolitan regions, internet, bus and tram routes. Messages were gender specific, and pointed to asymptomatic nature of chlamydia and availability of testing	Significant increases in testing rates for women and men aged 16–30 years between Jan 2002 and March 2004. Strong correlation between testing rates and chlamydia notification rates. Significant increase in frequency of visits to website. Campaign recall moderately high	Supports the role of well targeted media campaigns in changing behaviour
Gold (2008) <sup>26</sup> Victorian STI awareness media campaign July–Sept 2007	State-wide media campaign; details not described	No significant changes in either median number of chlamydia tests per month at sentinel sites in Victoria, or in Medicare claims for chlamydia tests in Victoria for 15–24-year-olds. Campaign recall 37%; no difference in history of STI testing, STI knowledge or condom use between those who recalled campaign and those who did not	Negative findings compared with similar other studies, reasons not clear but possibly because CT testing was not a dominant campaign message
McMahon (2004) <sup>38</sup> National ethnic media campaign run in conjunction with World AIDS day Nov-Dec 2000	Ethnic media campaign involving print and radio media in 14 target languages	Non-significant increase in number of HIV tests performed on patients from target group in two SHCs (Sydney and Melbourne)	Sexual health clinics promoted by campaign rather than general practice, but access issues and preferences for target population for sexual health care were not identified before campaign
Wilkins (2007) <sup>52</sup> Western Australia Chlamydia campaign June-Sept 2005	Multimedia strategy including radio advertisements, posters in pubs, clubs, hotels, universities and TAFEs, print advertisements in metropolitan and university press, email advertisements sent via radio email list, SMSs sent to subscribers aged 18 and over of Blue Sky Frog or Smarter than Smoking databases, and an interactive website	Increase in chlamydia testing from baseline to during campaign: 21% for females, 29% for males; increase in chlamydia notifications in Western Australia during campaign period of 12% for females and 4% for males. Campaign recall 63% overall. SMS seen as good marketing strategy by 58%; email interaction seen as positive. Poor uptake of poster displays in GP surgeries visited	Email appears popular when young people asked but only 56 emails sent among several thousand website visits; SMS also rated as bad or very bad by 32%. However, popularity of internet for seeking sexual health information suggests this is an important tool to continue to develop for facilitating behaviour change. Increase in notifications mirrored increase in testing (age groups not identified)

significant increases in the number of chlamydia tests performed and the rate of positive tests before and after the intervention. Huang *et al.*<sup>29</sup> evaluated a comprehensive control program in a remote region of the Northern Territory that provided community education and training of staff, but with a major focus on annual population-wide screening. Between 1996 and 2003, the age-adjusted prevalence rates of gonorrhoea, syphilis and chlamydia all decreased; from 2003 to 2006, gonorrhoea rates rose, chlamydia rates plateaued and syphilis rates continued to decline.

Type 5 interventions were novel vaccination programs: two were for HBV and one was for the HPV vaccine, with the main outcome measure being vaccination course completion. Both HBV vaccine interventions utilised an accelerated schedule of 0, 7 and 21 days, and targeted high risk groups including injecting drug users. McDonald et al.<sup>36</sup> found low completion rates (21%) while Rogers and Lubman 47 achieved a 71% completion rate. Both programs offered free vaccines. The main difference between the two interventions appears to be the degree of outreach, with Rogers and Lubman's study involving recruitment 'on the streets' and administration of the vaccines in participants' preferred venues (which included homes and drop-in centres), whereas McDonald et al.'s study administered the vaccines only within a health service and in other clinical outreach settings. The other vaccination study utilised local general practitioners within secondary schools for the administration of HPV vaccines to adolescent girls.<sup>46</sup> The three-dose completion rate was 79%, higher than that for other adolescent vaccines delivered at school in a comparable region in Queensland. This was attributed to the integration of general practice into the school immunisation program, providing opportunity for catch-up vaccination to take place in general practices and providing continuity of care by general practitioners.

#### Discussion

This review identified a diverse range of intervention studies that aimed to reduce the impact of STIs in Australia among populations that included young people aged 25 years and under. Interventions studied varied from those directed at primary prevention (such as vaccination) and secondary prevention (such as testing asymptomatic people and contact tracing), to interventions that aimed to impact on factors affecting behaviour such as awareness, knowledge and attitudes.

Chlamydia screening has been found to be cost-effective in different settings and different countries,<sup>54</sup> including Australia.<sup>55</sup> An international review of chlamydia screening programs has called for more RCTs to examine the effectiveness of opportunistic and proactive chlamydia screening.<sup>56</sup> The large number of studies in this review (23/ 42) reporting on participation in testing for asymptomatic chlamydia infection reflects both the epidemiology of this infection, and a national, funded strategy to inform the development and implementation of a national chlamydia screening program. One used an RCT design,<sup>14</sup> all the others were uncontrolled intervention studies measuring postintervention participation rates and all but one<sup>49</sup> used proactive screening approaches. Thus these studies are comparable and provide important evidence for the feasibility of screening in this age group.

The highest reported rates of participation in testing by far was in sports clubs among young men, with three separate studies reporting rates of between 87 and over 95%. Studies in schools, entertainment venues and other non-health care settings achieved participation rates of between 20 and 40%. Many young people do not participate in organised sport or other non-clinical contexts that lend themselves to screening. In contrast, nearly 90% of women and 70% of men aged 15–24 years visit a general practitioner at least once a year.<sup>57</sup> Increasing chlamydia testing in general practice is thus a candidate for increasing population coverage. It is disappointing, therefore, that both studies conducted in general practice achieved very low rates of testing (between 6 and 10%). Clearly, despite the appropriateness of this setting for chlamydia screening, there remain significant barriers that will need to be addressed if general practice is to be part of a chlamydia screening program for young people. Several Australian studies<sup>58,59</sup> have reported that young people are willing to be tested for chlamydia by their general practitioner and feel that this would be appropriate and acceptable. In the Australian context, a financial incentive such as a specific Medicare item might promote this. Providing education to general practitioners may also contribute to effectiveness.<sup>60</sup> The Australian Government is currently conducting a pilot chlamydia screening program in general practice to explore the strategy further.

There are other components of the primary health care system in Australia that could be utilised to target young people for chlamydia (and other STI) screening and some studies in this review have explored these (e.g. youth health services that target homeless young people, Family Planning clinics, sexual health clinics, Aboriginal Medical Services and emergency departments). Participation rates for screening achieved in these studies (~50% to >90%) were also much higher than screening rates in general practice. Nevertheless, these services are much fewer in number compared with general practices, are generally not well known to young people, <sup>61</sup> and/or they target specific populations of young people and would not have the capacity to screen all sexually active young people.

Four studies utilised the internet to facilitate screening indirectly, by providing information and encouragement to visit a health service. The two studies of higher methodological quality (both RCTs) demonstrated an effect on health-seeking behaviour and suggest that new technologies are a promising and viable adjunct to other strategies promoting testing and sexual health.

Educating young people about STIs is a prerequisite to reducing their impact; 10 of 42 studies evaluated educational interventions. The contexts in which education took place in this review included formal classroom teaching in secondary schools, health education in clinical facilities, peer education, informal and opportunistic education, and a range of media campaigns. Overall, there were only a small number of studies, some of which were of inadequate methodological quality to draw firm conclusions about effectiveness.

Curriculum-based HIV and STI education in schools can impact on sexual behaviour and risk reduction when well designed.<sup>62</sup> Sexuality education is a component of secondary school curricula across the country and there has been a national framework for sexuality education since 2000, although this has not been uniformly implemented.<sup>63</sup> Between 2002 and 2008 in national surveys of secondary students and sexual health. knowledge about all STIs increased slightly but, apart from knowledge about HIV, was generally poor.<sup>64</sup> The two education intervention studies in this review that took place in secondary schools were of moderate to high methodological quality; however, they are limited in their generalisability by the specific outcomes they measured: attitudes towards people with HIV,43 and attitudes towards, knowledge about and vaccination completion rates for HBV.<sup>48</sup> Further research into educational interventions in Australian secondary schools to measure not only knowledge and attitudes, but behavioural change in relation to STIs and HIV (including condom use and accessing health care) would be valuable.

Media campaigns are another vehicle for mass education about STIs and HIV. A recent systematic review of HIV/AIDS mass media campaigns in 23 countries<sup>65</sup> found that such campaigns have a positive impact on behaviour change or behavioural intentions. In our review, three studies evaluating chlamydia campaigns used a similar methodology and suggest that promoting chlamydia testing, in addition to condom use does appear to have an impact on chlamydia testing at least in the short term. We found no evidence of benefit from opportunistic health promotion or education by general practitioners to reduce STI risk in young people, although further research is required.

The two vaccine-preventable STIs, HPV and HBV, have received government support through universal infant and adolescent catch-up vaccination programs (HBV, since 2000) and a school-based vaccination program for young adolescent females (HPV, since 2007). Immigrants from high prevalence countries constitute the majority of people living with chronic HBV in Australia, while Indigenous Australians, injecting drug users and MSM are also disproportionately affected.<sup>66</sup> The two studies in this review that addressed HBV vaccination suggest that novel approaches are a useful adjunct to universal immunisation and support the call for a comprehensive national strategy for HBV.<sup>66,A</sup>

Only 5 out of 43 studies took place in secondary schools. This may reflect the challenges in accessing the education sector for participation in research, in particular sexual health research. Secondary schools were separated from other non-health community settings because over 90% of young people remain in school past year  $10^{67}$  and therefore schools provide nearly complete access to this age group. Furthermore, the education sectors across state and territory jurisdictions have specific mandates in terms of health promotion, provision of health education, and policies regarding student health and welfare, and so present a potentially sustainable setting for sexual health intervention. Research in schools most often requires parental consent, which is recognised as a significant

barrier to participation,<sup>68</sup> and may erroneously lower participation rates and reported success. Interventions to improve direct access to screening in this context reported moderate success as did educational interventions in changing knowledge and attitudes. There are many aspects to the school environment that make it ideal for sexual health education and screening, and this context should not be overlooked.

Rates of STIs are but one of many potential indicators of adolescent sexual health, and any interventions or policies that attempt to reduce STI rates or their burden of disease need to take into account the impact of psychosocial, socioeconomic and cultural factors on sexuality and sexual behaviour more broadly. There remain gaps in knowledge about the needs of some groups of young people, such as those from culturally and linguistically diverse or refugee backgrounds, and we found several studies that specifically excluded young people who could not speak English. None of the studies identified in this review specifically targeted same-sex attracted young people, those with disabilities or very young sexually active adolescents. Many innovative programs lack rigorous evaluation. Given the centrality of general practice to the primary health care system and the acceptability of STI testing in general practice to young people, there appears to be a need to build its capacity to better serve young people's sexual health. Australia led the way globally in the late 1980s by the introduction of policies and approaches that actively engaged with the communities most affected by HIV and contained its spread. Some two decades later, Australia has not implemented a national sexuality education curriculum, and lacks either a national youth health policy or youth sexual health policy. Australia's young people are a diverse population with differing sexualities and varied sexual health needs. Whether beginning sexually active lives or simply becoming curious about sexual futures, our young people's sexual health deserves a more prominent position in policy, research, education and health services agendas.

#### Conflicts of interest

None declared.

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up period	<u>1 able 9.2</u> <i>Getchteaup visitors</i> , number of up period	I quesuonnaires commenced and	quesuonnaires commenced and promotional activities over the enrolment and follow
Month/Year	No. of unique visitors	No. of questionnaires begun (% of visitors)	Getcluedup promotional activity
March 2007	Not available	212	<i>Dolly</i> magazine and website advertisements Triple] TV interview and weblink 2/3/07
April 2007	Not available	112	<i>Dolly</i> magazine and website advertisements
May 2007	Not available	182	<i>Dolly</i> magazine and website advertisements Sexperts media interview and weblink 15/5/07 Youthpas email 29/5/07 re- study
June 2007	2030	75 (3.7%)	Weber Shandwick Australia PR campaign
July 2007	2196	105 (4.8%)	Weber Shandwick Australia PR campaign Sexbo end Iulv
Aug 2007	3374	102 (3.0%)	Weber Shandwick Australia PR campaign
Sep 2007	3584	70 (2.0%)	
Oct 2007	3,422	81(2.4%)	
Nov 2007	3,276	74 (2.3%)	
Dec 2007	2,380	48 (2.0%)	
Jan 2008	2,744	6 (until 4 January)	
		(Total 1067)	

# 6.4 Updated literature review on strategies to increase chlamydia testing among young people

To update the previous, published systematic review and expand it beyond Australia to other developed countries, but to narrow it to chlamydia (+/- other STIs) testing only, a literature search was conducted in Medline, for studies and systematic reviews from any developed country published in English between 2010 and 2015, that specifically evaluated interventions to increase chlamydia testing in young people. A systematic review published in 2007 with the same criteria was also included, as this added to our systematic review by including studies conducted outside Australia.

Strategies to increase chlamydia testing in sexually active young people have been evaluated within and outside primary health care settings. Although our systematic review in Australia found that the highest participation rates in testing occurred in non-health settings, we also felt it important to turn to interventions within primary health care, especially general practice, since most young people access general practice each year and Medicare funding structures make this a feasible setting in the absence of dedicated, sustained chlamydia screening funding. Two systematic reviews have examined chlamydia testing specifically in primary health care settings and these cover publications within the periods 2002 - 2005 (Ginige 2007, four studies) <sup>274</sup> and 2002 - 2010, (Guy 2011, 11 additional studies, 15 in total)<sup>275</sup>. This latter systematic review included the three studies conducted in general practice that we had identified in our review, as well as two new studies. The current Medline search has identified a further six studies or reviews conducted in primary care settings, published between 2010 and 2014.<sup>276-281</sup> A large cluster randomised controlled trial is underway in Australian general practices and is the first to utilise practice nurses to screen for chlamydia in 16 - 29 year olds.<sup>282</sup>

# 6.4.1 Chlamydia testing interventions in primary care

### 6.4.1.1 General practice and primary care clinical settings

The types of intervention employed in primary care to increase chlamydia testing that have been evaluated can be grouped into four main categories: (1) systemic, multifaceted change within practices (2) clinician prompts, education or upskilling (3) clinician or practice financial incentives and (4) linking testing with Pap screening.

Interventions involving systemic change within practices included combinations of strategies within categories (2), (3) or (4) as well as the introduction of practice policies, training of other

practice staff, introducing promotional materials for patients in the waiting rooms, and providing practice support via visits or other contact from dedicated personnel. These studies have taken place in general practices in Australia <sup>283</sup> and the UK, <sup>278,280</sup> and in a variety of primary health facilities in the US (eg women's health and paediatric clinics) <sup>279,281,284-286</sup>. All but one<sup>285</sup> of these studies showed significant increases in chlamydia testing, some of which were sustained for over 12 months. The Australian study took place in six general practices in the Greater Newcastle area in New South Wales and involved GPs participating in the development of a suite of interventions and being able to tailor them to suit their practices. The range of strategies included education, upskilling, linkage to Pap testing and other relevant consultations such as contraception counselling and travel advice, and resource development for clinicians and patients, as well as the designation of a 'champion' within a practice to advocate for increased testing. Increases in testing rates were modest and not sustained, and there was no comparison control group. GPs involved in the study suggested that financial incentives for GPs and increased community education to drive patient demand for testing could be useful.<sup>283</sup>

Among interventions involving clinician prompts, education and/ or upskilling, only two showed significant improvements in chlamydia testing rates,<sup>287,288</sup> while others showed no effect. The two effective interventions were quite different from one another. One was a randomised controlled trial based in the USA and involved internet based continuing medical education learning modules about chlamydia delivered every three months over a year to family physicians, the control group received different educational modules.<sup>287</sup> The other was a cluster randomised controlled trial among general practices in the UK involving workshops and modified laboratory forms over six months.<sup>288</sup> In both, the main outcome measure was chlamydia testing rates. None of the studies in this group of intervention types involved clinician education or upskilling in Australia; one involved patient education that was facilitated by contact with a GP and found no increase in chlamydia testing.<sup>280</sup> One Australian study used computer reminders for GPs and found a small but significant increase in testing.<sup>290</sup>

The use of financial incentives for clinicians and/ or practices has been studied in Australian and UK general practices. The Australian study reported no increase in testing but the incentive was small (\$5 per test) and was not paid until the trial had finished.<sup>289</sup> The UK study involved a combination of incentives and education and was considered in the type (1) multifaceted interventions that showed large increases in chlamydia testing.<sup>278</sup>

Finally, one Australian study evaluated the impact of linking chlamydia testing with Pap screening in general practices and found a significant increase in testing.<sup>291</sup> Although increases in testing were significant, a major limitation is that Australian guidelines recommend that Pap smear screening does not need to commence until age 18, one quarter of the women screened were over 30 years, and the frequency of Pap screening is only every two years.<sup>275</sup>

#### 6.4.1.2 Community pharmacies

A systematic review of chlamydia testing interventions in community pharmacies was published in 2013.<sup>277</sup> It found nine studies conducted in pharmacies in the USA, England, Scotland, Australia and The Netherlands and described two broad approaches. The first was a populationbased approach where campaigns targeting young people encouraged them to attend local pharmacies to request a testing kit. The second approach was directed at pharmacists offering and facilitating a test opportunistically when a young person attended for other reasons (eg to obtain contraception). 'Rates of return' of chlamydia tests were the outcome measure, and these varied from 38% to 64% in the population based strategies and from 12% to 28% in the opportunistic screening strategies.<sup>277</sup> Acceptability to young people of having chlamydia tests offered by pharmacies was high and the providers (pharmacists) mostly found the work rewarding. However this review found that many pharmacists made decisions about offering testing based on their perceptions of risk rather than age or gender alone. Barriers such as feeling uncomfortable, lack of privacy or increased workload were reported but were not major.<sup>277</sup>

#### 6.4.2 Chlamydia testing interventions in non-health settings

In the five years since our systematic review, several new studies have been published that evaluate the use of the internet / e-technology to increase chlamydia testing. Of seven new published studies (up to November 2014) retrieved from a Medline search (excluding our own), five have explored or evaluated internet-based strategies, one reports on home-based testing and one reports on the register-based chlamydia program in The Netherlands. In addition, school-based screening programmes in different parts of the USA have been evaluated.

In the United Kingdom, a randomised controlled trial was conducted by recruiting through a Facebook page, where the intervention was an interactive website and the control group was directed to a non-interactive website. Sexual health questionnaires were administered at baseline and at three month follow up. Chlamydia testing kits were posted, at the time of the three month questionnaire, to participants' addresses that were allocated randomly. Monetary incentives of

two different values were also randomly assigned. The trial has found that return rates of testing kits was 41.65%, but that being sent a kit significantly reduced the likelihood of the young person completing the follow up questionnaire. Being offered a higher value monetary incentive also increased the follow up rate.<sup>292</sup> This trial was followed by a qualitative study among trial participants and found that the young people found the study interventions, including receiving chlamydia testing kits, acceptable.<sup>293</sup>

A website-based intervention involving sending out a chlamydia testing kit was piloted in Baltimore Maryland in 2004<sup>294</sup> and has since expanded to, or been adopted or replicated by, other states. The kit, test and treatment for chlamydia were all free to participants in this programme. An evaluation of this program in some counties of Illinois, USA found a kit return rate of just under 40%, with significantly more females than males requesting kits. The researchers found that advertising of the website was essential for driving demand for testing kits, and that males, blacks and those from rural counties were less likely to request kits.<sup>295</sup> A Facebook page intervention pilot study was conducted in a county in Illinois to evaluate the impact of the information contained in the Facebook page on condom use, intentions to use condoms, number of sexual partners in past 12 months, diagnoses of some STIs and intentions to seek testing. The study also measured testing rates within local health districts before and after the intervention, the proportion of the target group that received testing according to health district data, decreased over the same time.<sup>296</sup>

A public health initiative in Ottawa, Canada, involved development of a website targeting young people 15 - 29 years and was launched in 2011. The website provided information about chlamydia and gonorrhoea but also a downloadable request form which, together with a urine sample, could be taken to a number of participating laboratories across the city. In the first twelve months, the website had over 11,000 unique visitors, and 104 requisitions were made for chlamydia testing, just under 58% of which were from people in the target age range. The authors state that budget constraints made it difficult to promote the website, but feel that the use of technology in this way has great promise.<sup>297</sup>

A randomised controlled trial in one county in Norway used the national population register to allocate residents aged 18 - 25 years with a postal address into an intervention or a control group. Those in the intervention group received a letter and a home based mail-back testing kit

whereas those in the control group received nothing, and would have been subject to usual care (opportunistic screening in the health system). Sixteen and a half percent of those in the intervention group were tested over the study period compared with 3.4% in the control group. The implications of these findings on overall chlamydia prevalence and on pelvic inflammatory disease and infertility however could not be established.<sup>298</sup>

Researchers in The Netherlands have piloted, trialled and evaluated a register based chlamydia screening programme using mailed home-based testing kits over several years. Individuals within the target group (females and males aged 16 - 29 years from three counties) selected from municipal registers were sent letters by mail to their home addresses inviting them to request a home based kit via a website. They were sent repeat invitations annually over three years, participation rate at the first round was 16.1% and, contrary to expectations, participation rates fell over time. There was no difference in chlamydia positivity between the intervention group and the control group (who did not receive letters, simply usual care at their general practitioner). Although chlamydia positivity declined among those who completed all three cycles of screening, the researchers concluded that given participation rates, there is not sufficient evidence to justify a national roll out of a register based screening programme, nor that register based screening is superior to opportunistic screening.<sup>299</sup>

The USA has an established school-based clinic system, with school settings being ideal for delivering preventive health care including chlamydia/ STI screening. A recent summary of effective programmes delivered and evaluated in school based clinics was published by the Centers for Disease Control and Prevention.<sup>300</sup> Five studies described in this report found that annual chlamydia screening was feasible in most settings, reduced chlamydia prevalence in most cases and was cost effective.

#### 6.5 Conclusion

A great variety of strategies aiming to increase chlamydia testing among sexually active young people has been evaluated in many countries. To date, published studies give us some indication of the effectiveness of methods upon testing rates, while results of studies that measure impact on chlamydia prevalence and incidence of PID and infertility are still pending. While some programmes have shown excellent participation rates when implemented outside of health settings, the health system currently remains the essential structure to support and sustain chlamydia screening in an asymptomatic population, such that efforts continue to be directed towards improving the capacity of the health workforce to manage chlamydia screening and the experiences of young people who access them.

# CHAPTER 7 AIMS OF THIS RESEARCH

The focus of this research is chlamydia screening among sexually active young people as a strategy for chlamydia control in this population. Reducing the spread of genital chlamydia infection in young people has the ultimate goal of reducing morbidity, particularly tubal infertility.

This research consists of two separate but linked studies. The primary study is a randomised controlled trial (RCT) and the secondary study is qualitative, using in-depth interviews among a subsample of volunteers from the RCT.

The first study took place within a national policy context that addressed the epidemiology of chlamydia in the Australian population. Like many other developed countries, chlamydia control in Australia received increasing attention in the mid-1990s and early 2000s, culminating in the first national STI strategy that prioritized both chlamydia and young people. This study was one of several public health intervention 'pilot' studies to be evaluated as part of this strategy and its planning and development are fully described in the following chapter.

However I wanted to attempt to gain insight into how young people perceive not only chlamydia testing but also how they understand sexually transmitted infections broadly. Given the changing ways in which adolescent sexuality has been understood over the past century or so, and global efforts to prioritise adolescent sexual and reproductive health in recent decades, it seemed important to gather information from young people about chlamydia and STIs that looks beyond the concepts of 'risk' and 'stigma' which have been described. I wanted to be able to speak to young people about their experiences of the RCT in order to add meaning to quantitative findings. I also wanted to explore with them the ways in which they develop understandings about STIs, in order to think more deeply about strategies for chlamydia control.

The primary study involved the development and evaluation of an intervention to increase chlamydia testing among asymptomatic, sexually active young Australians aged 16 - 25 years. The secondary study was designed to immediately follow the primary study and participants in the secondary study were recruited from among those who completed the primary study.

This doctoral research has two broad aims:

- *i*. To evaluate the impact of an internet-based interactive relationship between health professionals and young people on testing rates for chlamydia
- ii. To explore the meanings attributed by young people to chlamydia and chlamydia testing and other sexually transmitted infections

The following chapters describe the objectives, methods and results of two separate and linked studies. Chapters Eight to Fourteen describe the randomised controlled trial and Chapters Fifteen and Sixteen describe the qualitative study.

## **CHAPTER 8**

## METHOD (RANDOMISED CONTROLLED TRIAL)

## Introduction

A randomised controlled trial (RCT) was designed to evaluate an intervention aimed at increasing chlamydia testing among young Australians. It is worth noting that the proposal initially submitted to the Department of Health and Ageing's Chlamydia Targeted Grants Program<sup>301,302</sup> did not incorporate an RCT but rather a pre- and post- intervention study with no control group. After we received notification of the success of the grant application and we began to plan the study in more detail, it became obvious that a more robust design could be applied without any change in the original concept or loss of innovation.

The RCT was conducted in cyberspace, with a new, project-specific website [www.getcluedup.com.au (getcluedup)] as the vehicle for recruitment and baseline and follow up measurements. The intervention was delivered via email communication that occurred outside getcluedup. The intervention sought to engage study participants in email interaction about chlamydia testing, by offering personalised, confidential and anonymous clinical advice about how to access testing services and procedures involved in testing. Participants in the Control group also received emails, which were not personalised and did not offer clinical advice. Follow up occurred six months after enrolment.

The primary outcome was self-reported chlamydia testing at six months follow up, while secondary outcomes were condom use and changes in knowledge and attitudes.

#### 8.1 The research team

The grant application was led and written by me in January 2006. The research team was multidisciplinary and cross-sectoral, consisting of myself (with expertise in youth sexual health and access to health care), an adolescent physician with sexual health expertise (affiliated at the time with the University of Western Australia), a sexual health physician with clinical and epidemiological expertise (affiliated with the University of Sydney) and two colleagues from the Inspire Foundation. These five individuals were named on the grant application as "The Cyberspace Consortium", with the University of Sydney as the lead organisation.

Once the grant had been secured, I sought to put forth the proposal for this Doctorate of Philosophy, incorporating the evaluation of the intervention and adding a qualitative research arm that would explore participants' experiences of the RCT and their understandings of sexually transmitted infections more broadly. The Department of Health and Ageing gave approval for the funded project to be used for study towards the degree.

The research team for the RCT then expanded, to include a Research Nurse, and my supervisor, a professor of general practice who also had expertise in access to health care for young people and other marginalised populations.

#### 8.1.1 The Inspire Foundation

The Inspire Foundation (www.inspire.org.au) was formed in 1998 with a mission to reduce youth suicide in Australia using e-technology. Its flagship service is *ReachOut*, a website aimed to promote youth mental health (www.reachout.com.au). I had already worked with the Inspire Foundation in a number of ways, mainly providing content expertise to some material on *ReachOut*. By 2006, *ReachOut* had achieved significant reach (30% of young Australians were aware of the website) and had developed a five-core-component platform that included presenting evidence based health information via factsheets, online health forums, online gaming that was being evaluated for improvement in mental health outcomes, social networking and portable digital media.<sup>303</sup> *ReachOut* was also on the cusp of expanding into the US market. A founding principle of *ReachOut* was youth participation and this was executed in many ways.

As well as *ReachOut*, the Inspire Foundation ran another web-based program called *ActNow* (www.actnow.com.au). *ActNow* was a youth development and youth advocacy program that focused on involving and training young people in promoting awareness, and becoming advocates for mental health and other issues. The research partnership with the Inspire Foundation for this study also meant that there was scope to utilise *ActNow* youth networks and web-based program expertise to help promote *getcluedup* and the RCT. *ActNow* ceased operating as a separate program in 2009 and its functions were integrated into *ReachOut*.

A partnership with the Inspire Foundation was mutually beneficial. The e-technology and youth participation expertise brought to the research team by the Inspire Foundation was invaluable for implementing the study due to existing youth networks, advice about website development, social networking and promoting the website. The research team members from the Inspire Foundation were the *ReachOut* Manager and Content Coordinator at that time. The research and sexual health expertise that belonged to the other three team members helped to expand *ReachOut* content expertise beyond mental health, and provided an opportunity for participation in a robust research study.

## 8.2 The Youth Consultants

Embedded in the grant proposal and the study design was the explicit desire to ensure a level of youth participation. Using Roger Hart's model of youth participation<sup>304</sup> the research team determined that the most practical and meaningful level of participation would be "Rung 5" on the 8-rung "Ladder of Participation", illustrated below.

8. Child-initiated, shared decisions with	
adults	
7. Child-initiated and directed	
	D
6. Adult-initiated, shared decisions with	egre
children	es of
5. Consulted and informed	part
	Degrees of participatior
4. Assigned but informed	ation
3. Tokenism	
	Non- participatior
2. Decoration	- pĩ
	artici
1. Manipulation	patic
	nc

Hart described this level of participation as 'young people ...work[ing] as consultants for adults in a manner which has great integrity. The project is designed and run by adults, but children understand the process and their opinions are treated seriously.' <sup>304(p.12)</sup> The grant proposal contained budget item lines that specifically provided for payment of a committee of young people who would be consulted

about the development of the website, as well as about the study design, particularly strategies for recruitment, the intervention, measurement instruments and data analysis.

There were two phases of youth consultation. The first specifically related to the development of *getcluedup*. The youth consultants were asked to provide comment on the content, language and style and also offer feedback on the graphics and layout of the website once it had been designed in draft by a commercial web developer. For this phase, twenty young people were recruited via the *ReachOut* youth ambassador network, by approaching a secondary school close to the office of the Inspire Foundation in Sydney, and through colleagiate networks. Colleagues from the Inspire Foundation assisted with recruitment via their youth ambassador network, and I recruited the remaining youth consultants by approaching the school's careers advisor and welfare teacher, and colleagues. Consultation during this phase took place remotely: youth consultants were sent draft *getcluedup* content either electronically or mailed hardcopy to read and comment on, and their feedback was provided by email or return mail. These youth consultants also provided structured feedback on the preliminary *getcluedup* design provided by the web developer prior to going live; this included feedback on graphics, colours, layout and navigation.

Once *getcluedup* was ready to launch, a more formal Youth Advisory Committee was established to provide consultation on the study from commencement to conclusion. This was the second phase of youth participation. This committee included two of the *ReachOut* youth ambassadors who were recruited during phase 1, and an additional two youth ambassadors. All four of these young people lived in regional towns or cities in New South Wales. Further recruitment took place via a national e-list known as *youthgas*, to which I subscribed. This process recruited seven young people, one an indigenous young man from the Northern Territory, two young women from Melbourne, and two young men and two young women from Sydney. Six other Sydney-based youth consultants were recruited through phase 1 youth consultants. Two young people who participated in phase 1 remained for phase 2, and they invited friends or peers, which recruited a further four. Thus the total number of youth consultants for phase 2 was 17.

The Inspire Foundation provided office space for Youth Advisory Committee meetings, which were all facilitated by me. Three face-to-face meetings were held over the course of the study, in April and June 2007 and May 2008. Youth consultants provided input between meetings as well. At the initial meeting, the youth consultants provided feedback about and suggestions for promoting *getcluedup*, and each consultant completed the online questionnaire as a 'dummy run'.

At the second meeting, the consultants offered suggestions for wording and frequency of emails and subject headings for the Intervention group that might enhance engagement (the Control group received identical, non-personalised emails and wording could not change). Further comment about *getcluedup* was also provided. Between the first and second meetings, one of the youth consultants developed a *MySpace* (www.myspace.com) page for the project. *MySpace* was one of the early social networking sites, having commenced in 2003. In 2007 *MySpace* was the most popular social networking site globally; *Facebook* did not surpass this until 2008.<sup>305</sup> At the third face-to-face meeting in May 2008, suggestions for improving the follow up rate were offered, and some preliminary data was examined for the youth consultants' information.

#### 8.3 Creating the study setting - website development

Three commercial web development companies were consulted and provided quotations for developing the study website. The one chosen was *David Trewern Design* (now *DT*, <u>www.dtdigital.com.au</u>) as they offered the required technology with appealing graphic design within the budgetary allowance. The technical requirements included:

- Multiple, hyperlinked webpages containing information about chlamydia, chlamydia testing and access to health services
- Downloadable factsheets that could be edited, updated, added or removed
- Links to other web based resources that could be updated, added or removed
- Clickable tiles on the homepage and all other webpages inviting participation in the RCT, which linked to the Participant Information Statement and subsequently to the baseline questionnaire
- A subsequent link to the follow-up questionnaire that could be emailed to participants
- Baseline and follow up questionnaires that could be completed online, with secure, downloadable data
- A novel 'quick quiz' clickable on the homepage, with the capacity to change the quiz question with downloadable data
- A Comment and Feedback page that website visitors could complete; on submission an email would automatically be sent to a University of Sydney mailbox
- Website traffic data collection
- Website hosting

Technical options that were not taken up due to cost and resource management issues included a real time forum facility and a blog facility. *David Trewern Design* developed the graphics, layout,

and data collection and storage, and I provided all written content, including research documents associated with the RCT (Participant Information Statement, questionnaires). Website content was also sent to the Department of Health and Ageing for approval before publication (there were no changes required). A young person was commissioned to provide some illustrations for the website as well. These were diagrams of a chlamydia bacterium, and of the female and male genital and reproductive systems.

The Youth Consultants provided feedback on content (text) and website design prior to launch. Their feedback influenced the logo (facial expressions, cultural diversity), design (especially colour), and content (revision of some text to minimise jargon, simplify the text or additional information about how to access health care). Feedback overall was positive, and minimal changes were needed.

The website content was divided into three main sections: *About Chlamydia*; *Answers and Advice*; and *Getting Help*. The site map, downloadable factsheets, and drawings commissioned from the young graphic artist are all included in **Appendix B**.

All content, including the research questionnaires (baseline and follow-up) were presented in HTML (Hypertext Markup Language) format, the main document format of the world wide web. This format allowed maximum accessibility for study participants wishing to complete the questionnaires.

*David Trewern Design* hosted the website on their server. They applied for the domain name and organised the SSL (Secure Sockets Layer) Certificate to encrypt research data when transferred between the server and user-browsers.

*Getcluedup* remained live until December 2011. *David Trewern Design* had hosted it at no cost until this time. No further funds were available to continue to host or update it.

The getcluedup homepage as it appeared during the study period is shown in Figure 8.1.





## 8.4 Website promotion

Several strategies were used to promote *getcluedup*. The website was advertised in *Dolly* magazine and on the *Dolly* website from March to June 2007. *Dolly* magazine is an Australian teenage girls magazine published at the time by Australian Consolidated Press Magazines (now Bauer Media) and had a readership of 550,000 per month in 2007, with over 50% being over 16 years.<sup>306</sup> The magazine advertisements are included in **Appendix C.** Although *Dolly* advertising was the most costly strategy and targeted only females, it was chosen because of its large reach and because of my longstanding professional relationship with the magazine. This allowed me to negotiate cost as well as inclusion of specific questions about chlamydia in the *Dolly* annual 'sex survey'.

*ReachOut* also promoted *getcluedup* via its homepage intermittently over the study period and a *youthgas* email (<u>www.youthgas.com.au</u>) was sent when *getcluedup* was launched. A MySpace page (see https://myspace.com) developed by one of the youth consultants contained a link to the website.

A Google Ad Grant was applied for and granted in March 2007. Google Ad Grants is part of Google's advertising program known as AdWords. A Google Ad Grant is a non-profit edition of the advertising program.(www.google.com.au/grants) This equated to free 'sponsorship' in Google, such that search terms nominated by me (eg 'chlamydia' 'STIs') entered in Google from Australian computers would bring up *getcluedup* first.

In addition, miscellaneous opportunities for website promotion were found via media interviews, links on other websites, via business card placement at university orientation days and during SexPo in Sydney in 2007.(www.sexpo.com.au) In June 2007, a Public Relations company, Weber Shandwick Australia (www.webershandwick.com.au), was recruited to boost promotion of *getcluedup*. I had had some experience with this company due to their involvement in another sexual health promotion campaign for which I was a spokesperson. Thus a discounted rate was negotiated and the company promoted *getcluedup* using a variety of strategies including media interviews, targeting youth websites and creating weblinks, and targeting university students in New South Wales, Queensland and Victoria.

#### 8.5 Recruitment

Separate from, but dependent upon, website promotion was study promotion and recruitment. Visitors to *getchuedup* were invited to participate in the study if eligible via a large banner on the homepage and several other links on other webpages. However the *Dolly* magazine and website advertisements and links to other websites did not promote the study, only the website. The *youthgas* e-list was used to promote the study, as were some of the media interviews. The *MySpace* page also published a paragraph about the study (but mainly provided information about chlamydia with a link to *getcluedup*).

#### 8.6 Scope of the getcluedup data

#### 8.6.1 Study questionnaires – baseline and follow-up

The baseline questionnaire was directly accessible by any visitors via *getcluedup*, but information and consent procedures were developed to recruit only those eligible to enter the study (see 8.10 below). By contrast, the follow-up questionnaire could only be accessed via a link sent (by email) to study participants. Once either questionnaire was accessed however, the server managed the data in the same way. As soon as visitors or study participants exited the questionnaire page, any data entered (even if only one response) were stored on the server and downloaded as CSV (Comma Separated Values) files. These .csv files were exported as Excel data files, containing one line of data per database record. Information in the Excel files formed the raw data for analysis.

#### 8.6.2 Quizzes

*Getcluedup* also had a quiz facility. This was a series of rotating short questions, accessible to all visitors, appearing on the homepage, and requiring yes/ no answers. The quiz questions were about chlamydia, and answers could easily be found on *getcluedup*. The quiz questions could be changed, written de novo, uploaded and rotated by me. Visitor responses were stored as .csv files and exportable as Excel data files. This data gave a snapshot of visitors' knowledge about chlamydia, but was mainly intended to provide a simple means of interacting with the website.

#### 8.6.3 Website contact form

The website had a Contact Form facility. When the contact form was completed by a website visitor, an email was generated and sent to an email address set up by the University of Sydney ('cluedup@usyd.edu.au') which was accessible only by me and the research nurse. The Contact Form invited visitors to ask questions about chlamydia or chlamydia testing. To receive a reply, they had to provide an email address.

#### 8.6.4 Website feedback form

This webpage allowed visitors to provide comments and feedback about the website. Completing this form generated an email to the 'cluedup@usyd.edu.au' address.

#### 8.7 Participants

Young people aged 16 to 25 years were named as one of three priority target groups in the First National Sexually Transmissible Infections Strategy<sup>250</sup> (the other two groups were men who have sex with men and Aboriginal and Torres Strait Islander people). The Chlamydia Targeted Grants Program specified that most of the projects funded needed to undertake testing for chlamydia and suggested a range of settings in which projects could take place, such as clinical, educational, accommodation and occupational settings. The decision to make cyberspace the setting for this study was an exciting innovation in that, for the grant providers, it was unique and unprecedented, and for the research team it provided scope to reach the target population nationally, unrestricted by service or geographical boundaries.

To be eligible for enrolment in the RCT, participants had to be aged 16 to 25 years, to be residing in Australia (although not necessarily an Australian permanent resident or citizen), to have engaged in penetrative sexual intercourse (vaginal or anal) and to be able to provide a valid email address.

The study also had to be conducted in English. Census data from 2006 showed that among people aged 15 to 24 years, 93% spoke English only OR were proficient or very proficient in English. Of the remainder, only 1% were not proficient in English (for 6%, proficiency was not reported). English proficiency among people who speak languages other than English was highest in the 15 - 24 year age group in the 1996 and 2001 Census; in 2006 it was second highest in this age group (and highest in the 25 - 34 year age group). However of those not proficient in English, the lowest percentage was consistently in the 15 - 24 year age group across all three Censuses.<sup>307</sup> See Table 8.1.

	NESB* but	NOT proficient	NESB but	NOT proficient
	proficient	young people	proficient ALL	ALL
	young people	(15 – 24 years)		
	(15 – 24 years)			
1996	14.9%	1.2%	11.9%	3.0%
2001	15.6%	0.9%	12.6%	2.9%
2006	15.8%	1.0%	13.1%	2.8%

Table 8.1 English proficiency among young people: 2006 Census data

\*NESB = non-English speaking background

English language acquisition among immigrants to Australia is also relatively high. Further, foreign language acquisition is more rapid among adolescents than adults, or even younger children.<sup>308</sup> With a very small proportion of the target population lacking English proficiency, and the overall aim of increasing testing rates across the mainstream sexually active youth population, the decision to conduct the study only in English was thought to be pragmatic and reasonable.

#### 8.8 Study power

The study aimed to detect at least an 8% difference in chlamydia testing rates between the intervention and control groups. With statistical significance taken at 0.05 and to achieve power of 90%, a minimum of 320 participants in each group was required. Because a dropout rate of up to 50% was anticipated in the control group, and a much lower dropout rate of 10% anticipated in the intervention group, the target sample size was calculated based on these projections, and randomisation was unequal. Target sample size was 320 in the intervention group and 640 in the control group, giving a total sample of 1000.

#### 8.9 The intervention

The study was designed in mid-2006. At this time, email communication was thought to be a feasible intervention using e-technology. Although instant messaging and social networking sites were available and young people spent more time engaging in these online activities,<sup>309</sup> email was, and remains, a more formal method for communication, appropriate for a relationship between a young person and health professional. Email also offered privacy and anonymity.

The Australian Census has collected information about computer and internet use since 2001.<sup>310</sup> Over the past decade, internet usage in Australian households has steadily increased, and broadband has steadily replaced dial-up internet connections. This study took place between March 2007 and January 2008. In 2007, 91% of Australian families had the internet at home, with 76% having broadband and over the study period internet usage increased in households from about 5.8 million to over 6 million.<sup>311</sup> In early 2008 in Australia, young people (14 – 24 years) were online more than older people, with 97.5% being online more than once a week. Indeed 52% and 62% of 14-17 year olds and 18 – 24 year olds respectively were defined as heavy internet users (8+ times per week).<sup>311</sup> Modes of online communication among 8 – 17 year old Australians in 2007 found that, of 34 minutes per day spent in online communication, 18 minutes was spent using instant messaging, 11 minutes spent using social networking sites and 5 minutes spent emailing. Girls spent more time than boys communicating online, while boys spent more time than girls playing online games.<sup>312</sup>

Participants' email addresses were obtained securely from baseline questionnaires. All email addresses that contained the correct syntax (xxx(@xxx.xxx)) were assumed to be valid, however those that bounced back immediately with an error message stating 'unknown address' were deemed invalid email addresses and those participants were then excluded from the study.

All participants in the study received emails. Those allocated to the Intervention group received **personalised** emails. These were defined as emails coming from the personal email address of either the research nurse or myself, addressed the young person by their first name (if supplied), contained a link to the staff profile on the University of Sydney website, and offered email interaction about chlamydia and chlamydia testing. The emails contained prompts with questions about chlamydia testing knowledge, such as "do you know where you can get tested in your local area?" or "did you know you can get tested confidentially?" Further email content depended on the responses and questions from study participants. Engagement in email interaction was defined as a minimum of one response from the participant. Examples of email interaction among engaged study participants in the Intervention group are included in **Appendix D (i)**.

Emails sent to participants in the Control group followed a standard format and were sent once a month from baseline to follow up (six emails in total). They did not contain our names or links to our staff profile and were sent from the study mailbox (<u>cluedup@med.usyd.edu.au</u>). None of the young people in the Control group responded to any emails during this time. Text of the initial email sent to Control group participants is included in **Appendix D** (ii).

The initial email to the young person, whether allocated to the Intervention or Control group, was sent within one business day after baseline data was downloaded.

## 8.10 Consent procedures - participant flow through the website

The study was promoted on *getchiedup* via clickable panels and tiles on every webpage. One click took the visitor to the consent page, which outlined two of the three inclusion criteria (age 16 – 25 years and residing in Australia). To proceed from this page to the baseline questionnaire, website visitors had to click on a link to the Participant Information Statement and check that they had read it, then they had to enter an email address in a space provided (third inclusion criterion). Once this was entered, the visitor was taken directly to the baseline questionnaire.

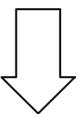
Data was downloaded once an email address was entered on the consent page. This process is illustrated in Figure 8.2.

## Figure 8.2: Flowchart illustrating consent procedure on getcluedup

Website visitor clicks on

## invitation to participate link

on homepage or other webpage



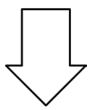
**Consent page** contains:

- inclusion criteria (age, residing in Australia and

space to type email address)

- link to Participant Information Statement that must

be opened and checked as "read"



**Baseline questionnaire** 

#### 8.11 Assessment measures

#### 8.11.1 Website traffic

Website traffic data were to have been collected using a built-in program called LiveStats applied by the web developer. However there were problems with this program and data were unavailable. After three months, Google Analytics, a free program downloadable on the world wide web, (www.google.com.au/analytics) were applied to the website by creating a Google account. Data collected included number of unique visitors, keywords used in Google searches, and referring websites.

#### 8.11.2 Baseline questionnaire

Participant data were collected by questionnaire at baseline and at six-month follow up. The baseline questionnaire collected data on demographics, education/ occupation, substance use, sexual history, previous STIs, knowledge about chlamydia and attitudes to chlamydia testing. The questions about chlamydia knowledge and sexual history were taken from the National Survey of Secondary Students and Sexual Health.<sup>313</sup> Questions about smoking, alcohol and drug use were taken from the National Survey of Secondary Students and Sexual Health<sup>314</sup> I developed questions about attitudes and barriers and piloted these among a group of young people (youth ambassadors and interns from the Inspire Foundation).

#### 8.11.3 Follow-up questionnaire

The follow-up questionnaire contained questions about sexual history, chlamydia testing, knowledge and attitudes. The questions were worded identically to baseline questions, but the follow up questionnaire omitted questions on previous diagnoses of other STIs, and smoking, alcohol and substance use. Additional questions in the follow up questionnaire enquired into management of a positive chlamydia test (antibiotics, partner notification and retesting). The baseline and follow-up questionnaires are included in **Appendix E**.

#### 8.12 Randomisation and allocation

For allocation of participants, a computer-generated random number was used. Allocation to intervention or control groups was done on a 1:2 ratio based on the anticipated loss to follow up described above, so that there would be twice as many enrolled in the Control group as the Intervention group. Random numbers were obtained from the generator by the same clinicians who sent emails to all study participants. Allocation took place as soon as a young person was

deemed eligible (downloaded data showed email address, eligible age, an Australian postcode and ticked "Yes" to having had intercourse) without any other information about the participant being known. A random number (1, 2 or 3) was generated. The number "1" allocated the young person to the Intervention group, and "2" or "3" to the Control group.

## 8.13 Ethical Approval

The Human Research Ethics Committee (HREC) of the University of Sydney was applied to for ethical approval of this study in September 2006. The HREC requested clarification about confidentiality and anonymity of email correspondence, provided suggestions for website advertising and requested minor amendments to the Participant Information Statement. The HREC accepted the research team's responses to its concerns and gave ethical approval at its next meeting in October 2006.

#### 8.14 Statistical analysis

Statistical analysis was performed with SPSS version19 [IBM Corp., USA] with the individual as the unit of analysis. Proportions are presented with 95% confidence intervals (95% CI). The specific statistical tests used for each analysis are described in more detail in the following chapters. In summary, chi-square analysis was used to assess differences in proportions, independent samples and paired samples t-tests were used to compare continuous variables and the Mann-Whitney U test to compare scoring ranks. To adjust follow-up values for baseline values, analysis of covariance was used for knowledge questions and logistic regression for binary outcome measures.

#### 8.15 Registration with Australian and New Zealand Clinical Trials Registry

This study was registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12607000582459).

## **CHAPTER 9**

#### GETCLUEDUP WEBSITE TRAFFIC

The faces are great, they're happy because they know something you don't.

I think that this slogan is really good!

The layout and design is appealing. It looks easy to navigate and sets up an idea of how the content will be presented.

[The information is] ... relevant, also answers a lot of questions young people tend to ask on this subject ...very easy to understand - no confusing language or long words.

Thanks for asking young people for our opinions - it's projects like this that make young people feel valued.

 sample of comments from Youth Consultants, males and females 17 – 20 years, during website development

#### Introduction

The website, *getcluedup*, (www.getcluedup.com.au) was the setting of the randomised controlled trial (RCT) (See Chapter 8.3). *Getcluedup* was launched on 7 March 2007. Recruitment into the RCT commenced simultaneously, and the study was promoted on *getcluedup*'s homepage and all webpages for the duration of the recruitment period. Recruitment stopped on 4 January 2008, with the study promotional banners removed and links to the study disabled. *Getcluedup* remained live until December 2011. This chapter will report on website traffic, information about website promotion, and volume of downloaded study data during the recruitment period. Website traffic data from January 2008 until September 2008, the extent of the follow up period, will also be presented.

#### 9.1 Measuring website traffic – methodological issues

Technology for measuring website traffic evolved rapidly during the 2000s. The web developer for *getcluedup* used a program called LiveSTATS which was developed by a Canadian software company called DeepMetrix Corporation in 1996. LiveSTATS was an installable software program and an early 'live website statistics solution'.<sup>315</sup> Version 8 of this program was released in 2005<sup>316</sup> and was the version used by our web developer to apply to *getcluedup*. DeepMetrix

Corporation sold LiveSTATS to Microsoft in January 2008, and Microsoft now runs a program called Microsoft Business Analytics.

Google Analytics was released by Google in November 2005, having acquired the software, Urchin, from the company (Web Depot) that developed the technology, in March 2005.<sup>317</sup> Google Analytics is a tracking application that inserts hypertext markup language (HTML) code in each page of a website which enables traffic to be recorded.<sup>318</sup> Google Analytics is free and is currently the most utilised analytic program on the internet.<sup>319</sup>

*David Trewern Design*, now called *DT*, the web developer, was able to provide web traffic data generated by LiveSTATS for *getcluedup* from June to September 2007. They had already advised me to install Google Analytics to *getcluedup* in June 2007. This gave a few months of comparison data, which highlighted what were presumably technological differences between the two analytic programs and which led to significant data disparities, shown in Table 9.1.

	LiveSTATS	Google Analytics
	<b>Distinct visitors</b>	Absolutely unique visitors
June 2007	5475	2030
July 2007	5482	2196
August 2007	7099	3374
September 2007	6736	3584

Table 9.1 LiveSTATS vs Google Analytics web traffic data June to September 2007

The technical staff at *DT* advised that Google Analytics data were likely to be more reliable, which was partly related to Google Analytics being able to detect 'real' visitors an exclude 'spiders' (automated internet trawlers that visit a website). Only Google Analytics data for *getcluedup* will be presented in the remainder of this chapter. It should be noted that other website traffic data reported in this chapter cannot be directly compared with *getcluedup* traffic data, because the web analytic programs used were unknown.

## 9.2 Getcluedup promotion

The two main promotional strategies at the time of the launch of *getcluedup* were paid advertising in *Dolly* magazine and its website, for three months, and regular homepage promotion on *ReachOut*. To ascertain the extent of the reach of the promotions, unique visitors to each of these

websites was recorded over the first three months of the study period. A unique visitor was defined as someone coming from a unique Internet Protocol (IP) address, to give an approximation of the total number of individual people who viewed *getcluedup*. The following data were provided in June 2007 by those organisations.

#### Dolly website - unique visitors

Mar 2007	426,598
Apr 2007	299,605
May 2007	298,154

#### ReachOut website - unique visitors

March, April, May 2007	456,708
------------------------	---------

In June 2007 the Public Relations company Weber Shandwick Australia was engaged to run a three-month promotional campaign to try to boost website traffic, in order to improve study recruitment rates. In their Program Evaluation Report, they report that their campaign resulted in 10,780,349 impressions on a range of youth-oriented websites. An impression is a measurement used in online advertising that indicates that an advertisement was displayed; technically it refers to a webpage appearing on the user's screen.<sup>320</sup>

#### 9.3 Getcluedup traffic

Website traffic through *getcluedup* allowed a direct estimation of the number of unique visitors to the website over time. Because the web developer had agreed as part of their contract to provide traffic data via LiveSTATS, no other traffic data was collected for the first three months. Unfortunately this program did not work and no traffic data was available. Google Analytics was then applied to *getcluedup* in June 2007.

Between 1 June 2007 and 4 January 2008 (the recruitment period during which traffic data were available), website traffic rose and fell, with the highest traffic in September 2007 (3584 unique visitors) and the lowest in December 2007 (2380 unique visitors). Beyond the recruitment period, website traffic increased slowly and steadily until September 2008. Figure 9.1 shows the website traffic for *getcluedup* from June 2007 until September 2008.



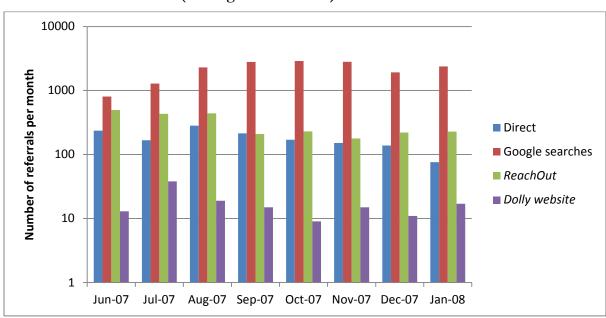
Figure 9.1 Website traffic for getcluedup using Google Analytics

Because any data submitted on the baseline questionnaire were automatically stored and exported into an Excel file, the number of questionnaires commenced could also be recorded. Table 9.2 shows the number of unique visitors and number of baseline questionnaires that were begun each month over the recruitment period. Additional information about specific promotional activities is also included.

As Table 9.2 shows, 1067 people began the baseline questionnaire over the recruitment period. Of these, 1013 completed the questionnaire, although a further 145 were excluded due to insufficient data (see Chapter 11).

## 9.4 Referral sources to getcluedup

Google Analytics reports on referral sources and this data provided useful information about the potential impact of the advertising and other promotional strategies. The overwhelming majority of visitors arrived via a Google search. Direct referrals were those whereby the *getcluedup* uniform resource locator (URL) was entered directly into the visitor's web browser. Referrals from the *Dolly* website continued even after advertising ceased (without significant decline in number). Referrals from *ReachOut* were steady throughout the recruitment period. See Figure 9.2.



<u>Figure 9.2</u> Number of referrals to *getcluedup* from Google searches, *ReachOut* and *Dolly* websites and direct traffic (NB logarithmic scale)

Over the same period (June 2007 – January 2008) there were consistent referrals also from the Australian Broadcasting Commission (ABC) website (average 137 referrals/ month), presumably from the Triple JTV website (www.abc.net.au/triplej/tv). Other more prominent referral sources (over 20 referrals/ month) included the University of Sydney student health service, and various state and national family planning services.

## 9.5 Discussion

Website reach was modest throughout the study period, with a few thousand unique visitors per month. It is difficult to compare *getcluedup* traffic with either *Dolly* or *ReachOut* traffic data from the same time period, due to those websites' longevity and marketing capacity. The three websites might also have used different web analytic programs.

Evaluations of media campaigns in Australia about STIs targeting young people also provide a rough comparison. For example, in Western Australia from 2007 - 2008, a state-wide media campaign targeting young people was launched, which included a website about STI prevention (www.safesexnogrets.com.au). This campaign occurred at about the same time as the getcluedup study and website traffic data for January to July 2008 show 330 to 1055 unique visitors per month (average = 623/month).<sup>321</sup> In late 2008, the Northern Territory health department replicated the Safe Sex No Regrets campaign, targeting young people and promoting chlamydia testing, reporting between 604 and 1028 unique visitors per month (average = 722) to the campaign website (http://safesexnoregrets.nt.gov.au/) which ran from September 2008 to August 2009.<sup>322</sup> In New South Wales, a state health department media campaign targeting young heterosexuals aged 16 - 24 was rolled out from August to October 2009 and re-launched in 2011. A campaign website (www.gettested.com.au) was active throughout these campaign periods and was live until mid-2014. Traffic data for this website is available from January to June 2011 and shows spikes in visitor traffic during February and May 2011 (reaching a maximum of approximately 2000 'visits' in those months), which coincided with digital and television advertising.<sup>323</sup> However it is not clear from any of these reports how website traffic was measured.

Referral sources data strongly suggests that having a Google AdWord grant had a significant impact in driving traffic to *getcluedup*, since most referrals came via a Google search. The AdWord grant bypassed any immediate need for 'Search Engine Optimisation', a process of using keywords and creating hyperlinks that helps to improve a website's ranking in a Google Search (google.about.com). Without the AdWord grant, it is likely to have taken months or longer for *getcluedup* to appear within the first few pages of a Google search. The direct traffic is likely to have come from the *Dolly* magazine advertisements, since there were very few other ways that visitors would have known the *getcluedup* URL. However, even if all direct traffic came via *Dolly* magazine advertisements, based on this and *Dolly* website referral data, the paid *Dolly* advertisements only resulted in modest referrals.

The number of *getcluedup* visitors who commenced the baseline questionnaire was only a very small fraction of all visitors. However it is impossible to know whether the visitors would have been eligible but not interested in participation, or whether they were ineligible, or both. Having promotion of the study solely dependent on website promotion and traffic might explain the very low proportion of visitors who commenced the baseline questionnaire.

## CHAPTER 10

## BASELINE DATA

## Introduction

Between March 2007 and January 2008 over one thousand sets of data were downloaded from <u>www.getcluedup.com.au</u>. These were all examined manually for validity, completeness and eligibility.

Data sets deemed invalid were those which:

- Were known to be done as tests by youth consultants or researchers (who used identifiable email addresses with their name or the term 'youth consultant')
- Had spurious email addresses (eg one@two.three.edu.au; test@test.com)
- Provided spurious data (such as fictitious Australian postcodes or country of birth)
- Had already entered the study and whose email address was recognisable as a duplicate

These data were discarded and no emails sent.

Data sets deemed incomplete were those which:

- Provided only an email address or demographic information but no sexual history or beyond

An email was sent to the email address provided acknowledging their visit to the website and the initiation of questionnaire completion. They were invited to provide feedback. There were no responses received from these people.

Data sets that were deemed valid and complete were assessed manually for eligibility for enrolment in the randomised controlled trial (RCT). The three relevant columns in the downloaded data files were scanned initially:

- Age
- Residing in Australia (as determined by postcode or an email address indicative of Australian residence)
- Answering 'yes' or 'no' to the question 'have you ever had penetrative sex?'

Anyone who stated their age as under 16 years or over 25 years, or who listed a postcode of residence as one outside of Australia was excluded, and their data discarded.

However there were many data sets that were otherwise valid and complete where the answer to the question about penetrative sex was 'no'. These data were kept, and the participants treated as though Controls. However they were not assigned a Study Number.

Data were analysed using SPSS Statistics v 19.0 [IBM Corp., USA]. Categorical variables were compared between groups using Yate's continuity corrected chi-square tests for 2x2 tables or Pearson's chi-square tests for larger tables. Continuous variables were compared using independent samples t-tests. Statistical significance was taken at p < 0.05. In the Tables throughout this chapter, p values of less than 0.05 are shown in bold.

#### 10.1 Demographic characteristics of the baseline sample

The total number of complete data sets of people aged 16 to 25 years and residing in Australia was 856. Of these, 704 were sexually active and therefore eligible for enrolment in the RCT, and 152 were not sexually active and excluded from the RCT.

Of the 856 young people who provided baseline data, 677 (79.1%) were female, 175 (20.4%) were male and 4 (0.5%) did not state their sex. The mean age of the whole group was 19.8 years (SD=3.0). All states and territories of Australia were represented, as were all geographic locations (Major City, Inner Regional, Outer Regional, Remote and Very Remote). Twenty-seven young people (3.2%) were either Aboriginal or Torres Strait Islander or both. Seven hundred and fifty-five (88.2%) young people were born in Australia while 812 (94.9%) spoke English as their main language at home.

Table 10.1 summarises the main demographic characteristics of the sample of completed datasets. Australian Bureau of Statistics data from the 2006 Census<sup>324</sup> are listed in the adjacent column.

	Sample at baseline 2007 16 – 25 years Valid percent	Australian population 15 – 24 years in 2006 Percent
Sex = female	79.1	48.7
Born in Australia	88.4	84.1
Born overseas in English speaking country	6.7	5.3
Born overseas in non-English speaking country	5.1	10.1
Aboriginal and/ or	3.2	3.4
Torres Strait Islander	5.4	5.1
Speak English at home	95.3	84
State of residence		
New South Wales	33.0	32.2
Victoria	25.7	24.9
Queensland	17.8	19.9
Western Australia	9.2	10.2
South Australia	5.7	7.4
Tasmania	4.0	2.3
Australian Capital Territory	3.4	1.9
Northern Territory	1.2	1.1
Geographic location		
Major cities	71.5	68.4
Inner regional	18.5	19.6
Outer regional	9.1	9.1
Remote	0.7	1.4
Very remote	0.1	0.9

# <u>Table 10.1</u>: Sociodemographic characteristics of the sample (n = 856) compared to the population aged 15-24 years from the 2006 Census<sup>324</sup>

## 10.1.1 Countries of birth for those not born in Australia, and language spoken at home

Ninety-nine of the 856 young people (11.6%) were not born in Australia while 40 (4.7%) spoke a language other than English at home. The list below shows country of birth and language spoken at home for those not born in Australia.

Non-English speaking country (language spoken at home) n=42

China (Chinese) Croatia (Bosnian) Egypt (Arabic) Finland (Finnish) France (English) Germany (Italian) Guyana (English) Hong Kong x 2 (Chinese, Vietnamese) Indonesia x3 (Chinese x 1, Indonesian x 2) Italy x2(English x 1, German x1) Japan x 2(Chinese, English) Kenya (Swahili) Liberia (English) Macau (Vietnamese) Malaysia x 7 (English x 7) Nepal (Nepalese) Netherlands x 2 (Dutch, English) Peru (Spanish) Philippines (Tagalog) Russia (Russian) South Korea (English) Spain (English) Sri Lanka x2 (English x2) Ukraine (English) Vietnam x 3 (Vietnamese x 3) Zimbabwe x2 (English x2)

English-speaking country + all speak English at home n = 57 Canada Fiji Ireland x3 New Zealand x 19 South Africa x5 United Kingdom x 24 United States of America x 4

## 10.1.2 Occupation and living situation

Over 55% of the young people in the baseline sample were studying at school, university or other tertiary setting and over one quarter were in full time work. The great majority had completed a Year 10, Year 12 or tertiary qualification.

Just under 60% of the young people were living at home with family, with just over 40% living away from home, most of these being in private rental, own home or with friends. Only six young people (0.7%) were living in a refuge or supported accommodation. Of those who listed "other" for living situation, almost all were living in boarding school or campus based accommodation at university.

Table 10.2 shows the occupation and living situation for the baseline sample.

	Frequency	%
Occupation	(n=856)	
Occupation	226	27 (
School	236	27.6
University or Other Tertiary	237	27.7
Full time work	230	26.9
Part time work	42	4.9
Casual work	29	3.4
Looking for work	43	5.0
Work and Study	9	1.1
Parenting or Domestic	15	1.8
Other	12	1.4
Not stated	3	0.4
Education Level		
Did not complete Yr 10	35	4.1
Completed Yr 10	265	30.1
Completed Yr 12	342	40.0
Completed University	205	23.9
Not stated	9	1.1
Living situation		
At home with parents/ guardian	495	57.8
Away from home	357	41.7
Not stated	4	0.5
If living away from home:		
Private rental or own home	302	35.3
With friends	18	2.1
Refuge or supported accommodation	6	0.7
Other	31	3.6

## <u>Table 10.2</u> Occupation and living situation of the baseline sample (n=856)

## 10.2 Young people with invalid email addresses

Email addresses that always bounced (after weekly attempts for three months) were deemed to be invalid, and thus these young people were excluded from the RCT (since having a valid email address was one inclusion criterion for enrolment into the study). There were forty invalid emails in the sexually active group and eighteen in the non-sexually-active group (5.7% cf 11.8%; p = 0.006). The group of young people with invalid email addresses were compared to the group whose email addresses did not bounce. They were found to be significantly younger, more likely to be Aboriginal or Torres Strait Islander, more likely to live outside a major city and less likely to have completed school or university. Table 10.3 shows demographic characteristics for young people with, and without, valid email addresses.

Substance use histories were also compared between the groups with valid and invalid email addresses. Although young people with invalid email addresses were more likely to have never drunk alcohol, they were also more likely to have had more than five drinks in a row in the past two weeks. Those with invalid email addresses were also more likely to have used marijuana or other illicit substances in the past 30 days. Table 10.4 shows substance use histories for young people with, and without, valid email addresses.

Differences between those with valid and invalid emails were also compared with respect to sexual histories for those in the sexually active group (n=704). These data are reported later (see 10.4).

	Valid emails valid percent	Invalid emails valid percent	P value
Ν	798	58	
Mean age	19.9 years	18.7 years	0.002
Sex = female	79.2	77.6	0.84
Born in Australia	88.2	91.4	0.61
Aboriginal and/ or Torres Strait Islander	2.5	12.1	<0.0001
Speak English at home	95.3	94.8	1.0
State of residence			
New South Wales	33.4	26.4	0.23
Victoria	25.5	28.3	
Queensland	17.9	17.0	
Western Australia	9.1	11.3	
South Australia	5.2	13.2	
Tasmania	4.0	3.8	
Australian Capital Territory	3.6	0	
Northern Territory	1.3	$\overset{\circ}{0}$	
Geographic location		¥	
Major cities	73.2	47.2	<0.0001
Inner regional	17.5	34.0	
Outer regional	8.5	17.0	
Remote	0.8	0	
Very remote	0.0	1.9	
Occupation			
School	26.4	43.1	0.13
University or Other Tertiary	28.6	15.5	
Full time work	27.3	20.7	
Part time work	4.8	6.9	
Casual work	3.3	5.2	
Looking for work	5.1	3.4	
Work and Study	1.1	0	
Parenting or Domestic	1.8	1.7	
Other	1.3	3.4	
Education Level		•	
Did not complete Yr 10	3.4	14.0	< 0.0001
Completed Yr 10	30.8	38.6	
Completed Yr 12	41.0	31.6	
Completed University	24.8	15.8	
Living situation			
At home with parents/ guardian	57.7	63.8	0.36
Away from home	42.3	36.2	0.00

# Table 10.3:Baseline demographic information comparing young people with valid<br/>(n=798) and invalid (n=58) email addresses

	Valid email addresses n = 798 valid percent	Invalid email addresses n = 58 valid percent	Statistical test	Statistic (degrees of freedom)	p value
Tobacco					
Regular smoking (includes 'regularly but not daily' and 'daily' smokers)	23.7	31.0	Chi square	1.593 (1)	0.21
Alcohol					
Frequency of alcohol consumption			Chi square	13.49 (2)	0.001
Never	10.7	25.0			
Once/week-once/ month	47.5	28.6			
Weekly or more	41.8	46.4			
Five drinks in a row in past 2 weeks			Chi square	9.964 (3)	0.02
Never	50.0	42.9			
Once	25.4	14.3			
Twice	13.0	21.4			
Three or more times	11.6	21.4			
Marijuana use at all in past 30 days	14.2	27.8	Chi square	7.206 (1)	0.007
Illicit drugs at all in past 30 days	9.4	21.8	Chi square	8.587 (1)	0.003

<u>Table 10.4</u>	Substance use history comparing young people with valid (n=798) and
	invalid (n=58) email addresses

# 10.3 Differences between young people who reported ever and never having had sex at baseline

#### 10.3.1 Demographic factors

The mean age of the young people reporting that they had ever had sex at baseline (sexually active group, n=704) was significantly higher than the mean age of those reporting never having had sex (non-sexually active group, n=152) although modal age and age range were the same (16 years, 16 - 25 years respectively). Figures 10.1 and 10.2 show age histograms for the sexually active and non-sexually-active groups.

Young people in the sexually active group were also more likely to be male, to have changed schools and home more frequently and to speak English at home. Table 10.3 shows demographic differences between the sexually active and non-sexually-active groups.

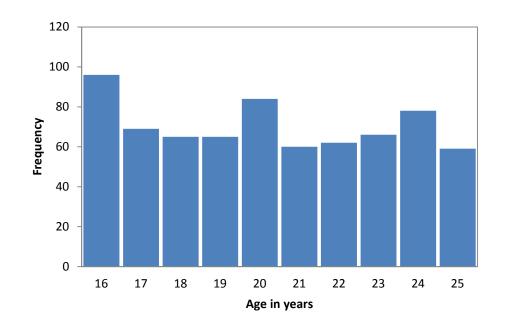
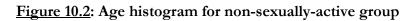
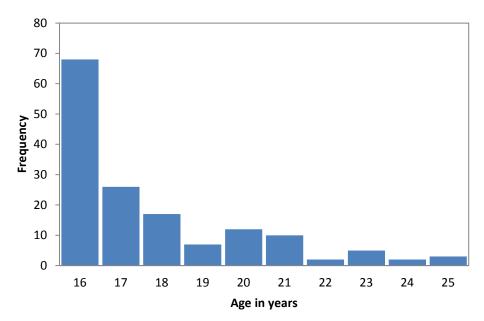


Figure 10.1: Age histogram for sexually active group





	Sexually active N = 704	Not sexually active N = 152	Statistical test	Statistic (degrees of freedom)	P value
Age in years (SD)	20.3 (2.9)	17.8 (2.3)	Independent samples t- test	-9.936 (854)	<0.0001
Mean number of times changed school since kindergarten (SD)	1.6 (1.0)	1.4 (0.9)	Independent samples t- test	-2.295 (843)	0.02
Mean number of time times changed homes since kindergarten (SD)	2.0 (1.3)	1.4 (1.1)	Independent samples t- test	-4.624 (846)	<0.0001
Gender (female)	78.0%	86.1%	Chi square	4.465 (1)	0.04
Born in Australia	88.4%	88.8%	Chi square	0.982 (1)	0.89
English as main language	96.3%	90.7%	Chi square	7.393 (1)	0.01
Aboriginal and/or Torres Strait Islander	3.2%	2.6%	Chi square	0.023 (1)	0.88
Geographic location			Chi square	3.972 (4)	0.41
City Inner Outer Remote	70.9% 19.6% 8.8% 0.7%	74.7% 13.7% 10.3% 1.4%			
<b>Education</b> Did not complete Yr 10 Completed Yr 10 Completed Yr 12 Completed university	4.6% 26.5% 41.6% 27.3%	2.0% 53.3% 34.7% 10.0%	Chi square	46.988 (3)	<0.0001

<u>Table 10.5:</u> Comparing demographic factors between sexually active and non-sexually active young people

#### 10.3.2 Smoking, alcohol and other substance use

Young people who reported having had sex at baseline were significantly more likely than those who reported not having had sex at baseline to smoke regularly, drink alcohol, binge drink (defined as 5 or more drinks in a row), have used marijuana or any illicit substances at all in the past 30 days.

Table 10.6 shows the differences in substance use at baseline between the two groups.

	Sexually active n = 704	Not sexually active n = 152	Statistical test	Statistic (degrees of freedom)	p value
Tobacco					
Regular smoking (includes 'regularly but not daily' and 'daily' smokers)	29.0%	2.7%	Chi square	30.189 (1)	<0.0001
Alcohol					
Frequency of alcohol consumption			Chi square	140.2 (2)	<0.0001
Never	6.3%	36.7%	Ĩ		
Once a week to once a month	45.0%	51.9%			
Weekly or more	48.8%	11.3%			
Five drinks in a row in past 2 weeks			Chi square	92.1 (3)	<0.0001
Never	42.0%	84.6%	-		
Once	27.4%	12.1%			
Twice	16.0%	2.0%			
Three or more times	14.6%	1.3%			
Marijuana use at all in past 30 days	18.0%	1.4%	Chi square	299.5 (1)	<0.0001
Illicit drugs at all in past 30 days	12.4%	0.0%	Chi square	19.44 (1)	<0.0001

## <u>Table 10.6</u> Comparing substance use rates between sexually active and non-sexually active young people

#### 10.3.3 Substance use among those 18 years and younger

To control for age, smoking, alcohol and other substance use between groups was analysed for those aged 18 years and younger. The different rates of substance use remained significant between young people reporting ever or never having had sex at baseline.

Table 10.7 shows the baseline characteristics of the groups who were sexually active or not sexually active in the group who were  $\leq 18$  years of age.

	Sexually active ≤ 18 yrs n=230	Not sexually active ≤ 18 yrs n=111	Statistical test	Statistic (degrees of freedom)	P value
Tobacco					
Regular smoking (includes 'regularly but not daily' and 'daily' smokers)	29.4%	2.8%	Chi square	31.787 (1)	<0.0001
Alcohol					
Drinking five or more drinks in a row – frequency in past 2 weeks			Chi square	39.776 (3)	
Never	48.2%	83.5%			<0.0001
Once	25.7%	11.9%			
Twice	12.4%	2.8%			
3 or more times	13.8%	1.8%			
Marijuana use at all in past 30 days	21.0%	0.9%	Chi square	23.244 (1)	<0.0001
Illicit drugs at all in past 30 days	12.3%	0.0%	Chi square	14.729 (1)	<0.0001

## <u>Table 10.7</u> Comparing substance use rates between sexually active and non-sexually active young people for those 18 years and younger

#### 10.3.4 Knowledge about chlamydia

There were three response options for the seven chlamydia knowledge questions: 'Yes', 'No' and 'Don't Know'. Knowledge was then calculated using a dichotomous variable (correct/ not correct), with 'Don't Know' and the incorrect responses combined as a 'not correct' group. Young people who were sexually active at baseline were more likely to know the correct answers to six out of seven knowledge questions about chlamydia, and had significantly higher composite scores. The only question for which there was no difference in knowledge was whether chlamydia can lead to sterility among women. The question for which knowledge difference was greatest was for the question about whether condoms can prevent chlamydia. Overall though, knowledge was high. The question for which knowledge was lowest was whether chlamydia could be tested for with a urine sample, where 77% of the sexually active group and 70.0% of the non-sexually active group knew the correct answer. When knowledge between the sexually active and non-sexually active groups was compared for young people aged 18 years and under, these knowledge differences disappeared completely. In fact, in the non-sexually active group, those aged 18 years and under had slightly higher knowledge scores for some questions, and a slightly higher composite score. However these differences were not statistically significant.

Table 10.8 shows differences in knowledge between sexually active and non-sexually active young people in the whole sample and for those aged 18 years and under. The statistical test used was chi square, using Yates' continuity correction. The chi square statistic and degrees of freedom are not shown in the table.

Table 10.8 Comparing chlamydia knowledge between sexually active and non-sexually active young people for whole sample

	and for those aged to years and under						
		M	Whole sample n = 856		Sample ag	Sample aged 18 years and under n = 341	ınder
Question No.	Question	Sexually active n = 704 % correct	Not sexually active n = 152 % correct	P value	Sexually active ≤18yts n = 230 % correct	Not sexually active ≤18 yrs n = 111 % correct	P value
1	Chlamydia is a [STI] that affects only women	89.4	84.7	0.05	86.5	83.8	0.50
5	Chlamydia can lead to sterility among women	84.7	80.5	0.11	80.4	77.3	0.50
3	A woman can have chlamydia without any obvious symptoms	91.3	86.0	0.03	90.4	88.3	0.55
4	A man can have chlamydia without any obvious symptoms	83.4	76.5	0.02	82.6	78.4	0.35
IJ	Chlamydia is curable	84.6	77.3	0.03	82.1	78.4	0.41
9	Chlamydia can be prevented by using condoms when you have sex	91.2	82.0	0.0003	87.8	80.2	0.06
7	Chlamydia can be tested for with a urine sample	77.1	70.0	0.05	77.3	72.1	0.29
	Mean composite score / 7	5.3	4.9	0.001	5.2	5.0	0.19

#### Chapter 10

#### 10.3.5 Attitudes to chlamydia testing

There were eighteen attitude questions requiring a fixed-choice response on a 5-point Likert-type scale (Strongly Agree, Agree, Maybe, Disagree, Strongly Disagree). Responses were combined into a dichotomous variable for analysis: [tending to] agree (Strongly Agree, Agree and Maybe and disagree (Disagree and Strongly Disagree).

There were significant differences between the sexually active and non-sexually active young people with respect to twelve out of eighteen attitudes. Sexually active young people were *more likely* to think that they were at risk of chlamydia, to feel comfortable seeing a doctor or nurse for a chlamydia test, to not want a chlamydia test because of what it might show, to have a test if their doctor or nurse recommended it, to want a chlamydia test to prevent long term health problems and to want a chlamydia test so that their partner would not get it. Sexually active young people were *less likely* to not know how to get a chlamydia test, to feel embarrassed about getting a test, to worry about confidentiality, to prefer a doctor or nurse the same sex, to be concerned about having a sexual history taken or to worry about having a Medicare card.

When responses of those aged 18 years and under were analysed separately, all but three of the attitude differences disappeared. Sexually active young people were still more likely to think they were at risk of chlamydia. However there were *more* likely to feel embarrassed about having a chlamydia test than non-sexually active people aged 18 and under, and *more* likely to be scared of what a chlamydia test might show. This was a reversal of the differences between sexually active and non-sexually active young people, for these two attitudes.

Table 10.9 compares attitude differences between sexually active and non-sexually active young people for the whole sample and those aged 18 years and under. The chi square statistic and degree of freedom are not shown in the table, and numbers in the columns represent the percentage of young people who strongly agreed, agreed or answered maybe.

Table 10.9 Comparing attitudes towards chlamydia testing between sexually active and non-sexually active young people for the whole sample and those aged 18 years and under NB: numbers in columns are percentage (%) who strongly agreed, agreed or answered maybe

			Whole sample n = 856		Sample a	Sample aged 18 years and under $n = 341$	under
No.	. Attitude question	Sexually active n = 704	Not sexually active n = 152	P value	Sexually active ≤18yts n = 230	Not sexually active ≤18yrs n = 111	P value
1	I think I am at risk for chlamydia	61.1	23.5	<0.0001	63.3	27.6	<0.001
7	I don't think I have chlamydia	79.1	83.7	0.28	77.0	82.5	0.28
S	I don't care whether I have chlamydia or not	6.3	7.5	0.75	9.4	11.0	0.68
4	I don't know how to get a chlamydia test	33.4	47.4	0.002	51.5	47.4	0.50
S	I would be too embarrassed to see a doctor or nurse to talk about chlamydia*	43.2	66.4	<0.0001	68.8	55.9	0.03
6	I would not see a doctor or nurse about chlamydia <u>because I</u> am worried about confidentiality	19.8	34.8	<0.0001	39.2	30.6	0.14
2	It is difficult for me to see a doctor or nurse about chlamydia because of transport	17.3	24.1	0.09	28.1	29.7	0.78
<i>∞</i>	I would prefer to see a doctor or nurse who is the same sex as me for a chlamydia test	79.4	91.0	0.002	88.7	85.2	0.41
6	It is difficult for me to see a doctor or nurse about chlamydia because of cost	36.5	38.8	0.69	42.3	48.8	0.29
10	I would feel comfortable visiting a doctor or nurse to get a chlamydia test	76.0	63.9	0.005	60.0	66.5	0.27
						0/	/Continued

**Table 10.9 continued** 

			Whole sample $n = 856$	mple 56	Sam	ple aged 18 n =	Sample aged 18 years and under $n = 341$
IJ	<b>11</b> I do not want to talk to a doctor or nurse about my sexual history	46.2	60.2	0.004	61.1	61.1 56.0	0.41
12	<b>12</b> I can't get a chlamydia test because I don't have a Medicare card	11.2	24.4	<0.001	30.9	23.2	0.16
13	$m{13}$ I don't want a chlamydia test because I'm scared of what it might show $st$	40.0	27.1	0.007	30.2	45.9	0.01
14	14 I don't want a chlamydia test because my partner/s might find out	25.1	30.8	0.21	36.1	31.7	0.45
15	15 I would have a chlamydia test if my partner/s wanted me to	88.5	86.8	0.70	86.2	90.4	0.27
16	16 I would have a chlamydia test if my doctor recommended it	97.4	91.7	0.003	91.7	96.7	0.06
17	<b>17</b> I want to have a chlamydia tes <u>t</u> because I would want to prevent any long term health problems from chlamvdia	94.5	89.4	0.05	90.5	93.3	0.40
18	<b>18</b> I want to have a chlamydia tes <u>t</u> because I don't want to give chlamydia to my partner/s if I have it	95.4	88.1	0.002	89.7	95.2	0.07

\*difference between sexually and non-sexually active young people's attitudes remained significant for those aged 18 years and under but the direction of the difference <u>reversed</u>

#### 10.4 Sexually active young people

The sexually active group (n = 704) was analysed separately to explore sexual history including number of sexual partners, condoms use and history of chlamydia or any other sexually transmitted infections (STIs).

The mean age of the sexually active group was 20.3 years (SD 2.9) and 78.0% were female. The mean age of penetrative intercourse was 16.2 years and mean number of years since first intercourse was 4.1 years. The median range of sexual partners ever was 3 - 5. The median number of sexual partners in the past 12 months was two. Fifty-two percent of the sample reported using condoms during intercourse always or mostly.

One hundred and eighteen young people (16.9%) reported a history of ever being diagnosed with chlamydia at baseline. The next most frequently reported STI was human papillomavirus (HPV, 8.3%) followed by genital herpes (3.9%), gonorrhoea (2.1%) and HIV (1.0%).

One hundred and eighty-eight young people (26.7%) reported having had a chlamydia test in the past six months, of these 70 reported that the test was positive. This gives a prevalence of 37.2% among those young people who reported having had a test six months prior to the study. Sixty-nine of the 70 (98.6%) who reported a positive chlamydia test in the past six months stated that they had received antibiotic treatment and 65 had informed their partner of the result. Forty-seven (67.1%) of those who had tested positive reported that they had returned for a second test. Sixteen of those who had not returned for a second test stated that insufficient time had passed before the test (of reinfection) should be done, while other reasons included transport problems, going overseas or "I like having it [chlamydia]". Four did not give a reason.

#### 10.4.1 Sexually active young people with invalid email addresses

In the sexually active group, forty young people had provided invalid emails and so were excluded from the trial and follow up (see 10.2). The sexual histories they provided at baseline were compared with baseline data from the group (n=664) whose email addresses were valid. Those with invalid email addresses were younger when they first had penetrative intercourse, had had more sexual partners ever, and in the past twelve months, and more likely to have a history of gonorrhoea or genital herpes. Table 10.10 shows the sexual histories for those with valid compared with invalid email addresses in the sexually active group.

Variable	Valid emails n=664	Invalid emails n=40	Statistical test	Statistic (degrees of freedom)	p value
Mean age (SD)	20.3 years (2.9)	19.6 years (3.2)	Independent samples t-test	1.474 (702)	0.14
Mean age of first intercourse (SD)	16.3 years (2.1)	15.1 years (3.8)	Independent samples t-test	3.176 (702)	0.002
Mean no. of years since first intercourse (SD)	4.0 years (2.9)	4.5 years (3.7)	Independent samples t-test	-0.942 (701)	0.35
Number of sexual partners ever One Two Three to five Six to ten Eleven or more	20.8% 12.5% 25.8% 18.5% 22.3%	22.5% 7.5% 5.0% 27.5% 37.5%	Chi square	12.825 (4)	0.01
Number of sexual partners in last 12 months One Two Three to five Six to ten Eleven or more	48.0% 19.8% 21.5% 6.7% 4.0%	40.0% 7.5% 20.0% 10.0% 22.5%	Chi square	29.639 (4)	<0.0001
Use condoms always or mostly	53.5%	40.0%	Chi square	2.244 (1)	0.13
History of chlamydia	16.8%	17.5%	Chi square	0.012 (1)	1.0
History of HPV	8.0%	13.2%	Chi square	0.658 (1)	0.42
History of gonorrhoea	1.7%	10.3%	Fisher Exact		0.006
History of genital herpes	3.2%	15.0%	Chi square	11.25 (1)	0.0008
History of HIV	0.9%	2.6%	Fisher Exact		0.28

## Table 10.10Sexual histories of sexually active young people (n=704) comparing those<br/>with valid and invalid email addresses

#### 10.4.2 Sex differences among sexually active young people

Mean age of first penetrative intercourse for females was significantly younger than males. Males had higher numbers of sexual partners ever and in the past 12 months. Among the STIs, sex was only significant for gonorrhoea, where men were more likely to have had a diagnosis than females. Table 10.11 shows sexual history variables by sex.

Variable	Females n=547	Males n=154	Statistical test	Statistic (degrees of freedom)	p value
Mean age (SD)	20.0 years (3.0)	21.4 years (2.6)	Independent samples t-test	-5.377 (699)	p <0.0001
Mean age of first intercourse (SD)	16.1 years (2.3)	16.7 years (2.3)	Independent samples t-test	-2.900	0.004
Mean no. of years since first intercourse (SD)	3.9 years (3.0)	4.7 years (3.0)	Independent samples t-test	-3.076 (698)	0.002
Number of sexual partners ever One Two Three to five Six to ten Eleven or more	22.9% 12.3% 25.8% 17.8% 21.2%	14.4% 11.8% 20.9% 22.9% 30.0%	Chi square	10.920 (4)	0.03
Number of sexual partners in last 12 months One Two Three to five Six to ten Eleven or more	49.9% 19.3% 20.6% 5.4% 4.8%	40.4% 17.2% 23.8% 12.6% 6.0%	Chi square	12.088 (4)	0.02
Use condoms always or mostly	51.6%	56.5%	Chi square	0.973 (1)	0.32
History of Chlamydia	17.6%	13.9%	Chi square	0.912 (1)	0.34
History of HPV	8.1%	9.2%	Chi square	0.059 (1)	0.81
History of gonorrhoea	1.3%	5.2%	Chi square	6.913 (1)	0.009
History of genital herpes	3.7%	4.5%	Chi square	0.068 (1)	0.79
History of HIV	1.1%	0.6%	Fisher Exact		0.35

<u>Table 10.11</u> Sex differences among sexual history variables in sexually active young people

Knowledge about chlamydia (Table 10.12) and attitudes to chlamydia and chlamydia testing (Table 10.13) were similar for females and males in the sexually active group. Females were more likely than males to want to see a doctor or nurse of the same sex.

	Question	Females % correct	Males % correct	Statistical test	Statistic (degrees of freedom)	P value
1	Chlamydia is a [STI] that affects only women	88.7	91.6	Chi square	0.772 (1)	0.38
2	Chlamydia can lead to sterility among women	85.9	80.5	Chi square	2.311 (1)	0.13
3	A woman can have chlamydia without any obvious symptoms	91.9	89.5	Chi square	0.634 (1)	0.43
4	A man can have chlamydia without any obvious symptoms	83.9	81.8	Chi square	0.245 (1)	0.62
5	Chlamydia is curable	84.2	86.2	Chi square	0.226 (1)	0.64
6	Chlamydia can be prevented by using condoms when you have sex	91.4	90.3	Chi square	0.076 (1)	0.78
7	Chlamydia can be tested for with a urine sample	77.8	74.7	Chi square	0.498 (1)	0.48
	Mean composite score / 7	5.3	5.2	Independent samples t-test	1.139 (699)	0.26

Table 10.12	Chlamydia knowledge by sex among sexually active young people	e
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<u>Table 10.13</u> Attitudes by sex among sexually active young people

1       1 think 1 am at risk for chlamydia       61.2         2       1 don't think 1 am at risk for chlamydia       78.6         3       1 don't are whether 1 have chlamydia or not       6.3         4       1 don't are whether 1 have chlamydia test       6.3         5       1 would be too embarrasced to see a doctor or nurse to talk about chlamydia       6.3         6       1 would not see a doctor or nurse about chlamydia because 1 am worried about confidentiality       20.2         7       1 is difficult for me to see a doctor or nurse about chlamydia because 1 am worried about confidentiality       20.2         8       1 would prefer to see a doctor or nurse about chlamydia because of transport       83.2         9       1 is difficult for me to see a doctor or nurse about chlamydia test       74.6         10       1 would feel comfortable visiting a doctor or nurse about my sexual history       11.4         11       1 do nut want to talk to a doctor or nurse about my sexual history       25.0         12       1 can't get a chlamydia test because 1 for the same act       11.4         13       1 don't want a chlamydia test because 1 worted by but it might show       25.0         14       1 don't want a chlamydia test because 1 would wont to give chlamydia test       25.0         15       1 would here a chlamydia test because 1 would wont any long term beak it might	No.	No. Attitude question	Female	Male	Chi square statistic (df =1)	P value
<ul> <li>I don't think I have chlamydia</li> <li>I don't care whether I have chlamydia or not</li> <li>I don't know how to get a chlamydia test</li> <li>I would be too embarrassed to see a doctor or nurse to talk about chlamydia</li> <li>I would not see a doctor or nurse about chlamydia because of mansport</li> <li>I would prefer to see a doctor or nurse about chlamydia because of mansport</li> <li>I would prefer to see a doctor or nurse about chlamydia because of mansport</li> <li>I would prefer to see a doctor or nurse about chlamydia because of mansport</li> <li>I would prefer to see a doctor or nurse about chlamydia because of mansport</li> <li>I would prefer to see a doctor or nurse about chlamydia test</li> <li>I would feel comfortable wisiting a doctor or nurse to get a chlamydia test</li> <li>I don't want to talk to a doctor or nurse about my sexaal history</li> <li>I don't want a chlamydia test because I and't have a Mediare card</li> <li>I don't want a chlamydia test because I would want to might show</li> <li>I don't want a chlamydia test if my doctor recommended it</li> <li>I would have a chlamydia test if my doctor recommended it</li> <li>I would have a chlamydia test if my doctor recommended it</li> <li>I would have a chlamydia test for y doctor recommended it</li> <li>I would have a chlamydia test for y doctor recommended it</li> </ul>	1	I think I am at risk for chlamydia	61.2	60.7	0.000	0.99
I don't care whether I have chlamydia or not I don't know how to get a chlamydia text I would be too embarrassed to see a doctor or nurse to talk about chlamydia I would be too embarrassed to see a doctor or nurse about chlamydia because of transport It is difficult for me to see a doctor or nurse about chlamydia because of transport It is difficult for me to see a doctor or nurse about chlamydia because of transport It is difficult for me to see a doctor or nurse about chlamydia because of cost It is difficult for me to see a doctor or nurse about chlamydia because of cost I would prefer to see a doctor or nurse about my sexual history I to i difficult for me to see a doctor or nurse about my sexual history I would feel comfortable visiting a doctor or nurse to get a chlamydia test I don't want a chlamydia test because I don't have a Mediare card I don't want a chlamydia test because I on't have a Mediare card I don't want a chlamydia test because I my partner/s might find out I would have a chlamydia test i my doctor recommended ti I would have a chlamydia test for doctor recommended ti I would have a chlamydia test for would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I would want to give chlamydia to my partner/s if I have it	7	I don't think I have chlamydia	78.6	80.6	0.149	0.70
I don't know how to get a chlamydia test I would be too embarrassed to see a doctor or nurse to talk about chlamydia I would be too embarrassed to see a doctor or nurse about chlamydia because of transport It is difficult for me to see a doctor or nurse about chlamydia because of transport I would prefer to see a doctor or nurse about chlamydia because of transport I would prefer to see a doctor or nurse about chlamydia because of cost I would prefer to see a doctor or nurse about chlamydia because of cost I would feel comfortable visiting a doctor or nurse to get a chlamydia test I would feel comfortable visiting a doctor or nurse about ty sexual history I do not want to talk to a doctor or nurse about my sexual history I can't get a chlamydia test because I don't have a Medicare card I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I would have a chlamydia test fray doctor recommended it I would have a chlamydia test fecause I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I would want to give chlamydia to my hore it	ŝ	I don't care whether I have chlamydia or not	6.3	6.2	0.000	1.00
I would be too embarrassed to see a doctor or nurse to talk about chlamydia I would not see a doctor or nurse about chlamydia because of transport It is difficult for me to see a doctor or nurse about chlamydia because of transport It is difficult for me to see a doctor or nurse about chlamydia because of transport It is difficult for me to see a doctor or nurse about chlamydia because of cost I would feel comfortable visiting a doctor or nurse to get a chlamydia test I would feel comfortable visiting a doctor or nurse to get a chlamydia test I do not want to talk to a doctor or nurse about my sexual history I can't get a chlamydia test because I don't have a Medicare card I don't want a chlamydia test because I m scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I would have a chlamydia test f my doctor recommended it I would have a chlamydia test f my doctor recommended it I want to have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I would want to prevent any long term health problems from chlamydia	4	I don't know how to get a chlamydia test	32.8	35.0	0.146	0.70
I would not see a doctor or nurse about chlamydia <u>because I</u> am worried about confidentiality It is difficult for me to see a doctor or nurse about chlamydia because of transport I would prefer to see a doctor or nurse about chlamydia because of cost It is difficult for me to see a doctor or nurse about chlamydia because of cost I would feel comfortable visiting a doctor or nurse to get a chlamydia test I would feel comfortable visiting a doctor or nurse to get a chlamydia test I do not want to talk to a doctor or nurse about my sexual history I can't get a chlamydia test because I don't have a Medicare card I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I nould have a chlamydia test fray partner/s wanted me to I would have a chlamydia test if my doctor recommended it I would have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I would want to give chlamydia to my partner/s if I have it	S	I would be too embarrassed to see a doctor or nurse to talk about chlamydia	42.9	44.1	0.026	0.87
It is difficult for me to see a doctor or nurse about chlamydia because of transport I would prefer to see a doctor or nurse who is the same sex as me for a chlamydia test It is difficult for me to see a doctor or nurse about chlamydia because of cost I would feel comfortable visiting a doctor or nurse to get a chlamydia test I do not want to talk to a doctor or nurse about my sexual history I can't get a chlamydia test because I don't have a Medicare card I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because I'm scared of what it might show I would have a chlamydia test because I'm scared of what it might show I would have a chlamydia test for my partner/s wanted me to I would have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I would want to give chlamydia to my partner/s ifI have it	6	I would not see a doctor or nurse about chlamydia <u>because I</u> am worried about confidentiality	20.2	18.6	0.097	0.76
I would prefer to see a doctor or nurse who is the same sex as me for a chlamydia test It is difficult for me to see a doctor or nurse about chlamydia because of cost I would feel comfortable visiting a doctor or nurse to get a chlamydia test I do not want to talk to a doctor or nurse about my sexual history I can't get a chlamydia test because I don't have a Medicare card I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because my partner/s might find out I would have a chlamydia test if my partner/s wanted me to I would have a chlamydia test if my doctor recommended it I would have a chlamydia test if my doctor recommended it I would have a chlamydia test fecause I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I don't want to give chlamydia to my bartner/s if I have it	~	It is difficult for me to see a doctor or nurse about chlamydia because of transport	18.9	11.7	3.604	0.06
It is difficult for me to see a doctor or nurse about chlamydia because of cost I would feel comfortable visiting a doctor or nurse to get a chlamydia test I do not want to talk to a doctor or nurse about my sexual history I can't get a chlamydia test because I don't have a Medicare card I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because my partner/s might find out I would have a chlamydia test if my doctor recommended it I would have a chlamydia test if my doctor recommended it I want to have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	8	I would prefer to see a doctor or nurse who is the same sex as me for a chlamydia test	83.2	66.0	19.012	<0.0001
<ol> <li>would feel comfortable visiting a doctor or nurse to get a chlamydia test</li> <li>do not want to talk to a doctor or nurse about my sexual history</li> <li>can't get a chlamydia test because I don't have a Medicare card</li> <li>don't want a chlamydia test because I'm scared of what it might show</li> <li>don't want a chlamydia test because I'm scared of what it might show</li> <li>don't want a chlamydia test because I'm scared of what it might show</li> <li>don't want a chlamydia test because my partner/s might find out</li> <li>would have a chlamydia test if my doctor recommended it</li> <li>would have a chlamydia test if my doctor recommended it</li> <li>would have a chlamydia test because I would want to prevent any long term health problems from chlamydia</li> <li>want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I would</li> </ol>	6	It is difficult for me to see a doctor or nurse about chlamydia because of cost	37.7	32.9	0.943	0.33
I do not want to talk to a doctor or nurse about my sexual history I can't get a chlamydia test because I don't have a Medicare card I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because my partner/s might find out I would have a chlamydia test if my partner/s wanted me to I would have a chlamydia test if my doctor recommended it I would have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	10	I would feel comfortable visiting a doctor or nurse to get a chlamydia test	74.6	81.3	2.403	0.12
I can't get a chlamydia test because I don't have a Medicare card I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because my partner/s might find out I would have a chlamydia test if my partner/s wanted me to I would have a chlamydia test if my doctor recommended it I want to have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	11	I do not want to talk to a doctor or nurse about my sexual history	46.5	45.8	0.004	0.95
I don't want a chlamydia test because I'm scared of what it might show I don't want a chlamydia test because my partner/s might find out I would have a chlamydia test if my partner/s wanted me to I would have a chlamydia test if my doctor recommended it I want to have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	12	I can't get a chlamydia test because I don't have a Medicare card	11.4	10.7	0.008	0.93
I don't want a chlamydia test because my partner/s might find out I would have a chlamydia test if my partner/s wanted me to I would have a chlamydia test if my doctor recommended it I want to have a chlamydia tes <u>t</u> because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia tes <u>t</u> because I don't want to give chlamydia to my partner/s if I have it	13	I don't want a chlamydia test because I'm scared of what it might show	41.1	36.8	0.693	0.41
I would have a chlamydia test if my partner/s wanted me to I would have a chlamydia test if my doctor recommended it I want to have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	14	I don't want a chlamydia test because my partner/s might find out	25.0	25.9	0.008	0.93
I would have a chlamydia test if my doctor recommended it I want to have a chlamydia test because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	15	I would have a chlamydia test if my partner/s wanted me to	88.9	87.5	0.098	0.75
I want to have a chlamydia tes <u>t</u> because I would want to prevent any long term health problems from chlamydia I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	16	I would have a chlamydia test if my doctor recommended it	97.4	97.2	0.000	1.00
I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	17	I want to have a chlamydia tes <u>t</u> because I would want to prevent any long term health problems from chlamydia	94.5	94.4	0.000	1.00
	18	I want to have a chlamydia tes <u>t</u> because I don't want to give chlamydia to my partner/s if I have it	95.1	96.5	0.227	0.63

#### 10.4.3 Risk factors for STI

A logistic regression analysis was conducted to predict risk factors for ever having had an STI using age, sex, being Aboriginal and/ or Torres Strait Islander, speaking English at home, number of sexual partners in the past 12 months, number of sexual partners ever, and condom use as the independent variables.

A test of the full model against a constant only model was statistically significant, indicating that the predictors as a set reliably distinguished between those who had ever had an STI and those who had never had an STI.

Nagelkerke's R2 of 0.186 indicated that 18.6% of the variability in ever having an STI was explained by the significant predictors in the model.

As shown in Table 10.14 four of the independent variables made a unique statistically significant contribution to the model (number of sexual partners in the past 12 months, number of sexual partners ever, condom use and being 20 years or older). The strongest predictor in the model was the number of sexual partners ever.

A collinearity output investigated which factors were related to one another. Gender was not a significant univariate predictor of STI but was almost significant as a multivariate predictor. Given that half the youth population is female, an odds ratio of 1.54 for being female is clinically important and a p value of 0.075 is probably on the borderline of significance.

Risk factor	Percent (%) in exposed group	Percent (%) in unexposed group	Unadjusted odds ratio (95% CI)	P value	Wald (degrees of freedom)	Adjusted odds ratio (95% CI)	P value
Gender (female)	24.5%	23.4%	1.06 (0.70, 1.61)	0.86	3.176 (1)	1.54 (0.96, 2.44)	0.075
Aboriginal and/ or Torres Strait Islander	34.8%	23.9%	1.70 (0.71, 4.07)	0.34	-	-	-
English at home	24.6%	11.5%	2.50 (0.74, 8.43)	0.20	-	-	-
Age 20 years and older	30.6%	15.6%	2.39 (1.64, 3.49)	< 0.0001	7.766 (1)	1.83 (1.20, 2.79)	0.005
Condom use never or sometimes	29.5%	19.6%	1.72 (1.20, 2.44)	0.002	3.829 (1)	1.45 (1.00, 2.13)	0.05
Three or more sexual partners last 12 months	47.0%	21.2%	3.30 (2.06, 5.29)	< 0.0001	13.120 (1)	1.27 (1.11, 1.44)	<0.0001
Three or more sexual partners ever	33.2%	7.0%	6.64 (3.96, 11.44)	< 0.0001	27.985 (1)	4.83 ( 2.70, 8.65)	< 0.0001

### Table 10.14 Risk factors for history of any STI

#### 10.4.4 Age as a risk factor for STIs

A chi-square linear by linear association was performed for age in one-year age groups to look for trends. The risk of chlamydia, HPV and any STI increased with age for females but not males (Tables 10.15, 10.16 and 10.20). There was no trend for history of HSV (Table 10.17). Although younger age appeared to be significant among females for a history of gonorrhoea, the total number of young women reporting gonorrhoea was small (Table 10.18). There was a similar pattern for females and males for history of HIV but total numbers were very small (Table 10.19).

	Female			Male	Total	
	n	% within	n	% within	n	% within
		age group		age group		age group
Age						
16 years	7	7.7%	2	40.0%	9	9.4%
17 years	7	11.5%	1	12.5%	8	11.6%
18 years	8	15.4%	0	0.0%	8	12.7%
19 years	9	17.0%	2	18.2%	11	17.2%
20 years	13	24.5%	4	14.8%	17	21.3%
21 years	9	19.1%	2	15.4%	11	18.3%
22 years	9	18.8%	2	15.4%	11	18.0%
23 years	12	25.5%	1	5.3%	13	19.7%
24 years	15	27.3%	4	18.2%	19	24.7%
25 years	7	18.4%	3	14.3%	10	16.9%
Total	96	17.6%	21	14.0%	117	16.8%
p value						
Chi-square linear by linear association	(	0.001		0.810	(	).008

#### Table 10.15History of chlamydia by age and sex

	$\overline{\mathbf{F}}$	emale	]	Male	-	Γotal
	n	% within	n	% within	n	% within
		age group		age group		age group
Age						
16 years	5	5.6%	1	20.0%	6	6.3%
17 years	5	3.3%	1	12.5%	3	4.3%
18 years	0	0.0%	0	0.0%	0	0.0%
19 years	1	1.9%	0	0.0%	1	1.6%
20 years	5	9.3%	1	3.6%	6	7.3%
21 years	5	10.6%	1	7.7%	6	10.0%
22 years	4	8.5%	2	14.3%	6	9.8%
23 years	7	14.9%	2	10.5%	9	13.6%
24 years	10	18.5%	2	9.1%	12	15.6%
25 years	5	13.5%	4	19.0%	9	15.5%
Total	44	8.1%	14	9.2%	58	8.4%
p value						
Chi-square linear by linear association	<	0.0001		0.185	<	0.0001

### Table 10.16 History of HPV by age and sex

	Female		Male		Total	
	n	% within age group	n	% within age group	n	% within age group
Age						
16 years	5	5.5%	1	20.0%	6	6.3%
17 years	4	6.6%	1	12.5%	5	7.2%
18 years	0	0.0%	0	0.0%	0	0.0%
19 years	0	0.0%	0	0.0%	0	0.0%
20 years	2	3.7%	1	3.4%	3	3.6%
21 years	2	4.3%	1	7.7%	3	5.0%
22 years	0	0.0%	0	0.0%	0	0.0%
23 years	2	4.3%	1	5.3%	3	4.5%
24 years	2	3.8%	1	4.5%	3	4.0%
25 years	3	7.9%	1	4.8%	4	6.8%
Total	20	3.7%	7	4.6%	27	3.9%
p value						
Chi-square linear by linear association		0.984		0.572		0.867

### Table 10.17 History of HSV by age and sex

	F	emale		Male	r	Total
	n	% within	n	% within	n	% within
		age group		age group		age group
Age						
16 years	4	4.4%	1	20.0%	5	5.2%
17 years	2	3.4%	1	12.5%	3	4.5%
18 years	0	0.0%	0	0.0%	0	0.0%
19 years	0	0.0%	0	0.0%	0	0.0%
20 years	0	0.0%	0	0.0%	0	0.0%
21 years	0	0.0%	2	15.4%	2	3.3%
22 years	0	0.0%	1	7.1%	1	1.6%
23 years	1	2.1%	1	5.3%	2	3.0%
24 years	0	0.0%	2	9.1%	2	2.6%
25 years	0	0.0%	0	0.0%	0	0.0%
Total	7	1.3%	8	5.2%	15	2.2%
p value						
Chi-square linear by linear association		0.015		0.655	(	0.172

### <u>Table 10.18</u> History of gonorrhoea by age and sex

	Female		Male		Total	
	n	% within age group	n	% within age group	n	% within age group
Age						
16 years	3	3.3%	1	20.0%	4	4.2%
17 years	2	3.3%	0	0.0%	2	2.9%
18 years	0	0.0%	0	0.0%	0	0.0%
19 years	0	0.0%	0	0.0%	0	0.0%
20 years	0	0.0%	0	0.0%	0	0.0%
21 years	0	0.0%	0	0.0%	0	0.0%
22 years	0	0.0%	0	0.0%	0	0.0%
23 years	1	2.2%	0	0.0%	1	1.5%
24 years	0	0.0%	0	0.0%	0	0.0%
25 years	0	0.0%	0	0.0%	0	0.0%
Total	6	1.1%	1	0.7%	7	1.0%
p value						
Chi-square linear by linear association		0.039		0.037	I	0.007

Table 10.19 History of HIV by age and sex

	Female		Male		Total	
	n	% within age group	n	% within age group	n	% within age group
Age						
16 years	11	12.1%	2	40.0%	13	13.5%
17 years	12	19.7%	1	12.5%	13	18.8%
18 years	8	15.1%	0	0.0%	8	12.5%
19 years	10	18.9%	2	18.2%	12	18.8%
20 years	17	31.5%	6	20.7%	23	27.7%
21 years	14	29.8%	4	30.8%	18	30.0%
22 years	13	27.1%	3	21.4%	16	25.8%
23 years	18	38.3%	4	21.1%	22	33.3%
24 years*	20	36.4%	7	31.8%	27	35.1%
25 years	11	28.9%	7	33.3%	18	30.5%
Total	134	24.5%	36	23.5%	170	24.3%
p value						
Chi-square linear by linear association	<(	0.0001		0.112	<(	0.0001

Table 10.20 History of any STI by age and sex

#### **10.5 Discussion**

This chapter presents unique cross-sectional data on 856 Australian young people. It represents a national sample of 16 to 25 year-olds, recruited entirely in cyberspace, and the findings add to knowledge about sexual behaviours of young Australians and their socio-demographic and substance use correlates.

While the sample is not representative of Australian young people, a number of important, representative national samples are available for comparison. This study was conducted the year after the 2006 Census<sup>324</sup> and this data was used for comparing sociodemographic variables. Compared to 2006 Census data young people living in major cities, born in Australia and speaking English at home were over-represented.

This study was conducted the year immediately preceding the national survey of secondary students and sexual health,<sup>325</sup> which takes place every five years, and at the mid-point between the first and second national household surveys of sexual health and relationships, which have taken place twice, a decade apart, in 2002 and 2012.<sup>326</sup> The 2008 national survey of secondary students and sexual health included 2926 young people in Years 10 and  $12.^{325}$  The first study of Australian Sexual Health and Relationships included 2686 people aged 16 - 24 years.<sup>327</sup> For those who had had sexual intercourse, the mean age of sexual debut was 16.2 years, which is entirely consistent with findings from these two major national surveys on sexual behaviour.<sup>325,328</sup>

Sexually active young people were more likely than their non-sexually active counterparts to speak English at home, to smoke regularly, drink alcohol, binge drink and use marijuana or other illicit substances. They also had greater knowledge about chlamydia infection and testing. Sexually active young people reported that they would be willing to have a chlamydia test if their doctor recommended it, or to protect their own or their sexual partner/s' health. Barriers to testing included embarrassment, concerns about confidentiality, cost, transport and not having a Medicare card. Most preferred to see a general practitioner (GP) for chlamydia testing.

We found that being Aboriginal and/ or Torres Strait Islander was a predictor of sexual debut younger than 16 years. This is entirely consistent with sexual experience reported by the first systematic survey of child health among Aboriginal children and young people in Western Australia in 2005.<sup>329</sup> Reasons for earlier sexual activity are thought to reflect earlier social maturity and the cultural acceptability of earlier child bearing.<sup>329</sup>

The other important comparison data come from the National Drug Strategy Household Survey, which was also conducted in 2007 and included 1588 people aged 14 - 19 years, and 2896 people aged 20 - 29 years.<sup>330</sup> Rates of substance use in this sample are difficult to compare with either the 2007 national drug strategy household survey<sup>331</sup> or the 2008 national survey of secondary students and sexual health<sup>325</sup> because of different age groupings, definitions, and wording of questions. In the national drug strategy household survey, 32.4% of 14 - 29 year olds smoked daily or weekly, compared to 24.2% of our sample of 16 - 25 year olds. Patterns of alcohol use were very similar between our sample for those aged 16 and 17 and the 2008 National Secondary Schools and Sexual Health survey.<sup>325</sup> Rates of marijuana and other illicit substance use were reasonably congruent between our sample and the national household survey.<sup>331</sup> The correlation between being sexually active and substance use and the clustering of health risk behaviours are consistent with international studies.<sup>332</sup>

The high proportion who had had a recent positive chlamydia test suggests that those who had reason to be concerned to be searching for relevant information and come across our website. Knowledge about chlamydia was considerably higher for comparable questions than in the national survey of secondary students in 2008 but this may reflect the older age of study participants as well as the bias towards young people interested in chlamydia.

Most young people indicated that they would have a chlamydia test to protect their, or their partner/s' health. This, combined with the fact that one-third of the sample did not know how to get a chlamydia test, while a smaller proportion expressed concerns about confidentiality suggests that education about access to testing is also warranted. Over 60% of sexually active young people in this study preferred to see a GP for chlamydia testing and almost all (males as well as females) would be willing to have a test if their doctor recommended it. National general practice surveillance data has shown that the "opportunity to test" for chlamydia is the strongest predictor for being tested.<sup>333</sup> Yet over the same study period as ours (2007 – 2008), Medicare data showed that only 12.5% of sexually active young women and 3.7% of sexually active young men were tested for chlamydia.<sup>334</sup> This lower testing rate among young men is consistent with sex differences found in the United

Kingdom.<sup>335</sup> Australian GPs identify lack of time and knowledge as barriers to testing, but they also report concern about 'patient embarrassment' as a factor.<sup>336,337</sup> Recent evidence suggests that this concern is misplaced and that most patients are willing to discuss STIs with their GPs.<sup>338</sup>

While forty percent of our sample also nominated embarrassment as a barrier, the majority stated that they would be comfortable visiting their doctor or nurse for a chlamydia test. Our finding that less than 50% of young people did not want a sexual history taken contrasts with earlier research among young Australian women which found that having a sexual history taken was a dominant concern.<sup>339</sup> These apparent contradictions might reflect differences in our sample's experience with chlamydia testing compared with those of the general population. They also highlight nuances associated with, and need for sensitivity when discussing, sexuality and suggest that doctors or nurses should raise the issue, explore sexual histories sensitively, explain confidentiality, normalise testing as part of routine health care and recommend testing when appropriate. Promoting messages about taking care of one's health and one's partner/s' health might also be effective.

In summary, Australian young people begin partnered sexual activity in their mid-teen years, and many are at risk of chlamydia and other STIs. Young people's willingness to consult with doctors and nurses in general practice and other primary care settings and take up testing, should make it a routine part of all consultations with young people.

These baseline findings were published in the following paper:

**Kang** M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Sexual behaviour, sexually transmitted infections and attitudes to chlamydia testing among a unique national sample of young Australians: baseline data from a randomised controlled trial. *BMC Public Health* 2014, 14:12.

Preliminary baseline data were also published as an abstract in conference proceedings in the following publication:

Kang M, Rochford A, Mindel A, Skinner SR, Webb M, Hillier L, Usherwood T.

Young people Get Clued Up about chlamydia: an internet based randomised controlled trial [abstract]. *Sexual Health* 2007;4, 285–312.

A copy of these publications and statements from all authors verifying my contribution to them can be found in **Appendix F.** 

#### Chapter 11

#### **RESULTS OF THE RANDOMISED CONTROLLED TRIAL**

#### Introduction

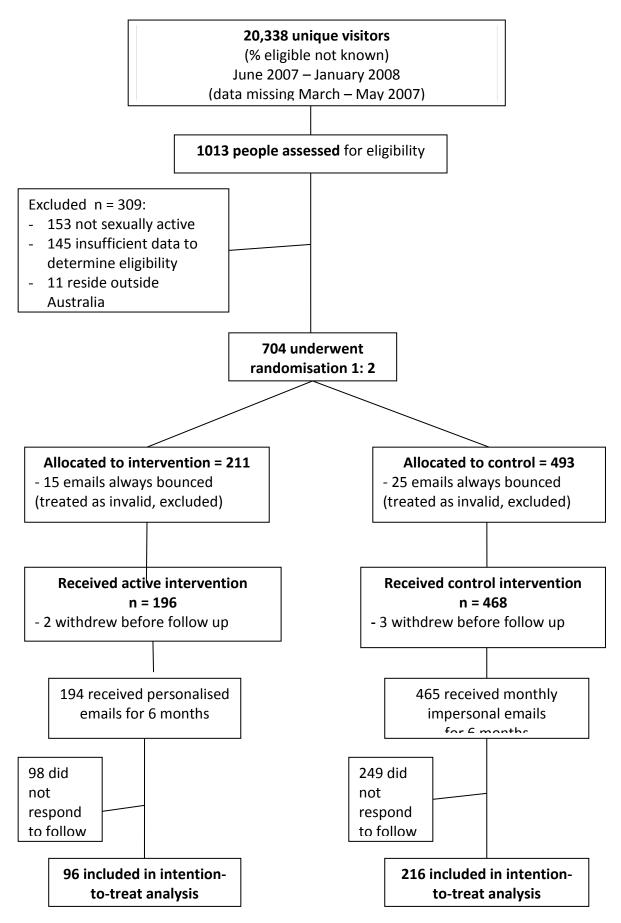
Responding to just one question of the baseline questionnaire led to a data download from *getcluedup*. One hundred and forty-five such downloads occurred over the study period that did not contain enough data to be used. Often only an email address was provided and no other questions were answered. Sometimes minimal demographic data was provided but no information about sexual history, making it impossible to determine eligibility for the study. All these website visitors were emailed, using the address they had provided, asking if they had intended to participate in the study, but none responded and some emails bounced back and were likely to have been invalid. This data was completely excluded and the visitors deemed ineligible. Of the remaining questionnaires downloaded over the study period, 153<sup>\*</sup> were not sexually active and 11 resided outside of Australia. The remaining 704 were enrolled into the randomised controlled trial between March 2007 and January 2008. Although the target sample size was 1000, budget and time constraints prevented further recruitment.

Of the 704 young people enrolled, 211 were randomly allocated to the Intervention group and 493 to the Control group. Forty young people were subsequently excluded because their email addresses were deemed invalid (all sent emails bounced). Five withdrew prior to follow up. Three hundred and forty-seven participants did not respond to the six-month follow up request. The remaining 312 completed follow up questionnaires.

Figure 11.1 summarises the number of young people who provided data for analysis.

\*Note that I reported in Chapter 10 that the number of young people who were not sexually active was 152, not 153. This is because I analysed and published the data for the RCT first, prior to publishing baseline data. When I prepared baseline data analysis for publication I realised that one of the data records in this group was in fact a duplicate and should have been excluded. The correct number of young people in the 'not sexually group' is 152. Since these young people were excluded from the RCT this did not affect the analysis for this chapter or publication.

Figure 11.1 RCT flowchart



#### 11.1 Considerations in statistical analysis

Consistent with CONSORT statement guidelines<sup>340</sup> about the conduct of randomised controlled trials, statistical analysis by intention-to-treat (ITT) was planned. Due to the setting in cyberspace, a number of real-life challenges emerged over the life of the study that had to be addressed to maintain the rigour and integrity of the RCT design. The most important of these challenges was the delivery and uptake of the intervention, which is described later. This required careful consideration of the most meaningful ways to analyse the data, and additional per protocol and sensitivity analyses were done. In this section, statistical analysis in RCTs will be discussed.

#### 11.1.1 Intention-to-treat analysis

Intention-to-treat (ITT) analysis is a strategy that compares outcomes among research participants according to the group(s) to which they were initially assigned. Ideally, all study participants adhere to the protocols in the groups to which they are assigned and complete follow-up. In reality, research participants may deviate from study protocols by non-adherence or non-completion and researchers and clinicians may deviate from protocols through various errors, such as administering the incorrect intervention. ITT analysis thus aims to evaluate the *pragmatic* effect of a treatment on a population as it allows for real-life departures from protocols, but assumes these are random. ITT includes everybody who was randomised, regardless of what occurs after randomisation.<sup>341</sup>

There has been wide variation in the application of the ITT concept and definition in published RCTs. In their survey of randomised controlled trials (RCTs) published in four major medical journals (Lancet, British Medical Journal, New England Journal of Medicine and the Journal of the American Medical Association), Hollis and Campbell describe adherence to intention to treat analyses among 119 RCTs. They found three broad types of departure from ITT analysis that were nevertheless reported as being ITT analysis. These were (1) excluding those who failed to start the intervention (2) excluding missing outcome data and (3) false inclusions and exclusions.<sup>342</sup>

In a systematic review of RCTs reporting ITT analysis to explore the ways in which missing outcome data were handled, Alshurafa et al<sup>343</sup> found "no consensus" on the definition of ITT analysis in relation to missing outcome data. They also noted that, due to the wide variation in what is reported as ITT analysis and the perennial problem with missing outcome data, the 2010

revision of the CONSORT statement guidelines have removed the term 'TTT analysis'. Instead, the most recent guidelines ask explicitly for information about the number of participants retained and analysed according to their original assigned groups.<sup>344</sup> Alshurafa et al recommend that researchers report clearly on how they handle missing outcome data, explaining the strategies they have selected. Strategies include complete case analysis only, data imputation through a variety of measures or sensitivity analysis.<sup>343</sup>

A further consideration is that ITT analysis is deemed preferable for superiority trials,<sup>341,345</sup> but, on its own, might not be for non-inferiority trials. Non-inferiority trials should however calculate sample sizes based on power of 90% because the non-inferiority margin is smaller than the treatment effect margin of superiority trials.<sup>345</sup>

#### 11.1.2 Engagement with the intervention as a key factor in statistical analysis

An unanticipated issue emerged within the first three months of data collection. Contrary to expectations, many young people in the Intervention group did not respond at all to their personalised emails, ie they did not *engage* in any email interaction. Engagement was defined as having had a minimum of <u>one</u> response of any type from the young person. The Youth Consultants were approached for advice and it was decided to pursue engagement with these young people intensively via weekly personalised emails. The Youth Consultants felt that receiving emails more frequently than this would have been regarded as annoying by participants. After three months of non-response, the participants were considered as having *not engaged*. The young people in the Intervention group who did not engage continued to receive personalised emails after three months, but at one-month intervals. Follow-up remained at six months.

It should be noted that non-engagement was not the same as non-completion. There were young people in the Intervention group who did not engage but who completed follow up, and those who engaged but did not complete follow up. All young people in the Intervention group who engaged did so within three months.

As expected, due to the impersonal nature of the emails sent to young people in the Control group, none of the young people in the Control group responded to emails.

The absence of engagement was an unforeseen issue and can be regarded as a 'failure to start the intervention'.<sup>342</sup> Hollis and Campbell suggest that to avoid this problem, randomisation should

take place after the necessary event for inclusion in the RCT has occurred.<sup>342</sup> Even in hindsight, it is difficult to know how this could have been overcome within the study design. Emails were only sent by participants to the research clinician, signifying engagement, on the receipt of a personalised email – this intervention was probably correctly assumed to have been, at the time, a requirement for engagement and interaction. The reverse proved not to be true – a personalised email did not guarantee engagement. The recruitment process could have been modified such that participants had to email the research clinicians as a first step, before completing the baseline questionnaire, but this would have added an additional step in the recruitment process and would not have guaranteed higher engagement in the Intervention group since it was a response to that initial *personalised* email after randomisation that constituted engagement.

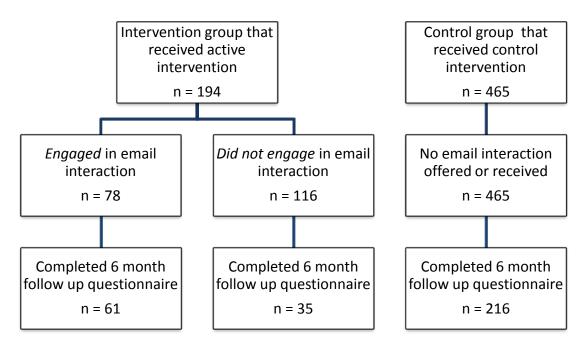
#### 11.1.3 Per protocol analysis

A per protocol (PP) analysis has been defined as a 'subset of the ITT population who completed the study without any major protocol violations'.<sup>341</sup> It has been argued that a PP analysis more accurately reflects treatment differences<sup>341</sup> and that it provides higher estimates of effect than an ITT analysis.<sup>346</sup> Hollis and Campbell<sup>342</sup> refer to an 'explanatory investigation of efficacy' which, in *this* study, involves the analysis of the sub-group that engaged with the intervention and compares it with the Control group. This is because the intervention was only deliverable where engagement occurred.

#### 11.1.4 Summary of decisions about statistical analysis applied to this study

- a. Participants whose emails always bounced were deemed to have invalid email addresses and were excluded from the RCT, even though this occurred after randomisation. Due to the recruitment occurring in cyberspace, this was an inclusion criterion that could not be determined pre-randomisation. The proportion of invalid emails was the same in each group.
- b. Participants who withdrew from the trial and asked for their data to be removed were excluded from analysis.
- c. Intention-to-treat analysis was performed on all randomised participants minus those in (a) and (b)
- d. Analysis was performed on all completed cases
- e. Per protocol analysis was performed on the subset that engaged with the intervention
- f. A sensitivity analysis comparing (c), (d) and (e) was conducted

Results will be reported for Intervention (All), Engaged and Control groups. Figure 11.2 shows the numbers for these three groups.



#### Figure 11.2 Intervention, Engaged and Control groups flow chart

#### 11.2 Baseline data comparing Intervention, Engaged and Control groups

Baseline information was compared between Intervention (All), Engaged and Control groups. Table 11.1 describes their demographic and sexual history characteristics. Of the baseline sample of 664 young people, 78.2% were female. The mean age of female participants (20.0 years) was significantly lower than the mean age of male participants (21.5 years), p < 0.0001. There was a small significant difference between the Engaged and Intervention groups with respect to being born overseas. Those who engaged were more likely to have been born in Australia. However of those born overseas in both groups, most were born in English-speaking countries. At baseline, 111/664 (16.7%, 95% CI 13.9% - 19.6%) reported having ever had chlamydia.

## **Demographic and sexual history characteristics of sample at baseline** NB total n in each group includes young people who withdrew between baseline and follow up (2 in Intervention –including 1 Engaged – and 3 in Control groups) <u>Table 11.1</u>

	Intervention (All) n = 196	Intervention (Engaged) n = 79	Control n = 468	p value Intervention (All) vs Engaged	p value Interventio n All vs Control
Mean Age (years)	20.5	20.7	20.3	0.50	0.42
Female (%)	154 (78.6)	65 (82.3)	365 (78.0)	0.46	0.97
Not born in Australia (%)	21 (10.7)	4 (5.1)	60 (12·8)	0.06	0.53
Aboriginal/ Torres Strait Islander (%)	4 (2.0)	2 (2.5)	14 (3.0)	1.00	0.70
Region of Residence				0.29	0.21
Major City (%)	147 (75.0)	54 (68.4)	317 (67.7)		
Inner Regional (%)	33 (16.8)	17 (21.5)	88 (18.8)		
Outer Regional (%)	12 (6.1)	5 (6.3)	43 (9·2)		
Remote (%)	0 (0.0)	0 (0.0)	4 (0.9)		
Very Remote (%)	0 (0.0)	0 (0.0)	0 (0.0)		
Occupation				0.70	0.42
School (%)	35 (17.9)	11 (13.9)	98 (20.9)		
University/ Tertiary (%)	60 (30.6)	26 (32.9)	128 (27.4)		
Full time work (%)	62 (31.6)	27 (34.2)	149 (31.8)		
Part time or casual work (%)	23 (11.7)	7 (8.8)	37 (7.9)		
Looking for work (%)	8 (40.8)	3 (3.8)	31 (6.6)		
Work + study (%)	4 (2.0)	3 (3.8)	4 (0.9)		
Parenting/ Domestic (%)	2 (1.0)	1 (1.3)	12 (2.6)		
Other $(%)$	2 (1.0)	1 (1.3)	7 (1.5)		
Sexual History					
Mean age of first intercourse (years)	16.2	16.5	16.3	0.15	0.42
Mean no. of sexual partners ever	3.1	3.2	3.1	0.83	0.57
Mean no. of sexual partners last 12	2.0	1.9	2.0	0.31	0.88
months					
Use condoms always (%)	41 (20.9)	20 (25.3)	100 (21.4)	0.62	0.95
Had Chlamydia test in past 6 months	60 (30.6)	26 (32.9)	127 (27.1)	0.49	0.57
(%)					
Had a previous diagnosis of chlamydia	26 (13.3)	13 (16.5)	85 (18.2)	0.56	0.21
( <sup>0</sup> / <sub>0</sub> )					
Substance use history					
Daily smoker past 12 months (%)	37 (18.9)	17 (21.5)	102 (21.8)	0.80	0.44
Drink 5 or more standard drinks at a	93 (47.4)	47 (59.5)	201(42.9)	0.67	0.95
time (%) past 2 weeks		. /	. /		
Marijuana use (any) past month (%)	30 (15.3)	10 (13.9)	81 (17.3)	0.45	0.66
Other illicit drug use (any) past month	23 (11.7)	10 (13.9)	52 (11.1)	0.60	0.83
(%)					

#### 11.3 Completion rate

Completion rates were calculated after subtracting the number of young people who withdrew in each group from the denominators (Intervention = 2, including one Engaged; Control = 3). The completion rate was  $47\cdot3\%$  (312/659) overall. There were no differences in demographic (mean age, sex) or baseline sexual history characteristics (number of sexual partners ever, condom use) between those who completed follow up questionnaires and those who did not. There was no difference in completion rate between the intervention (49.5%; 96/194) and control (46.5%; 216/465) groups, however completion rate for the 'engaged' group (78.2%; 61/78) was significantly higher compared to the 'non-engaged' group (30.7%; 35/114), p<0.0001 and compared to the control group (46.6%, 216/464), p <0.0001.

#### 11.4 Primary outcome

The primary outcome was self-report of having had a chlamydia test in the previous six months (between baseline and follow up). A sensitivity analysis compared the primary outcome measurement between:

- The Intervention (All) and Control groups using completed cases (intention-to-treat)
- The Engaged and Control groups using completed cases (per protocol)
- The Intervention (All) and Control groups imputing missing data. Data was imputed to allow for two possibilities (1) assumption that all those lost to follow-up did not have a chlamydia test and (2) assumption that all those lost to follow-up did have a chlamydia test.

A higher proportion of young people in the Intervention group reported a chlamydia test compared to the control group (40.6% vs 31.0%) but this was not significant. However, the difference between the *engaged* intervention and control groups was significant (52.5% vs 31.0%, p = 0.002).

Intervention		
marvenuon	39/96	0.07
	(40.6; 30.7–51.1)	
Control	67/216	
	(31.0; 24.8– 37.2)	
Engaged	32/61	0.002
	(52.5; 39.3–65.4)	
Control	67/216	
Control	(31.0; 24.8–37.2)	
Intervention	39/194	0.09
	(20.1; 14.7 - 26.4)	
Control	67/465	
	(14.4; 11.3 - 17.9)	
Intervention	137/194	0.34
	(70.6; 63.7 - 76.9)	
Control	316/465	
Control	(68.0; 63.5 - 72.2)	
	Engaged Control Intervention Control	Control $67/216$ $(31.0; 24.8-37.2)$ Engaged $32/61$ $(52.5; 39.3-65.4)$ Control $67/216$ $(31.0; 24.8-37.2)$ Intervention $39/194$ $(20.1; 14.7 - 26.4)$ Control $67/465$ $(14.4; 11.3 - 17.9)$ Intervention $137/194$ $(70.6; 63.7 - 76.9)$ Control $316/465$

## Table 11.2:Self-reported chlamydia test in past 6 months by group allocation<br/>(sensitivity analysis)

#### 11.4.1 Chlamydia prevalence

Of those who reported having had a chlamydia test at follow up, a total of 14/99 ( $14\cdot1\%$ , 95% CI  $7\cdot95\%$  -  $22\cdot6\%$ ) young people reported their tests were positive for chlamydia. Three (9.4%) were from the engaged group and eleven (16.4%) from the control group. This difference was not significant using the Fisher Exact test.

#### 11.5 Secondary outcomes

#### 11.5.1 Change in condom use

The proportion of young people who reported using condoms every time they had sex increased in all groups (Intervention, Engaged and Control), however the increases were not significant. Table 11.3 shows the change from baseline to follow up in proportion who used condoms every time they had sex within each group.

	Baseline used	Follow up used	McNemar
	condoms every time	condoms every time had	p value
	had sex (%)	sex (%)	
Intervention	21.7	30.4	0.10
Engaged	20.7	32.8	0.07
Control	22.2	27.8	0.12

Table 11.3Proportion in each group who used condoms always at baseline and followup

Each group was analysed for change in condom use from never, sometimes or usually, to always. There were 43 young people who reported using condoms always at baseline and at follow up, therefore this was not included as a change in condom use. Overall there was approximately a 14% change to always using condoms across all groups, there was no difference between Intervention and Control or Engaged and Control groups. Table 11.4 shows differences between groups in change in condom use to always.

	Change in condom	No change in	Pearson's chi-	p value
	use to always at	condom use to	square statistic	
	follow up (%)	always at follow up	(df)	
		(%)		
Intervention	13/96	83/96	0.036	p=0.85
(All) n = 96	(13.5)	(86.5)	(1)	
Control	31/216	185/216		
n = 216	(14.4)	(85.6)		
Engaged	9/61	52/61	0.006	p =1.0
n = 61	(14.8)	(85.2)	(1)	
Control	31/216	185/216		
n = 216				

<u>Table 11.4</u> Change in condom use from never, sometimes or usually to always

#### 11.5.2 Change in knowledge

Change in knowledge from baseline to follow up was analysed for 312 young people who completed follow up. Change in knowledge was analysed within groups and between groups using mean composite knowledge score. Change in knowledge was also measured question by question by analysing percentage correct at baseline and follow up.

The mean score for the whole group increased from 6.2/7 to 6.4/7, which was not significant. There was no difference between change in knowledge within the Intervention (All), Engaged and Control groups (Table 11.5) and no difference between the Intervention (All) and Control or Engaged and Control groups (Table 11.6). Change in percentage correct question by question is shown in Table 11.7. There was a significant increase in percentage correct for the question about chlamydia being preventable by condom use.

	Mean baseline knowledge	Mean follow up knowledge score	Statistical test	Statistic (df)	p value
	score				
Intervention	6.2/7	6.4/7	Paired	-1.615 (92)	0.11
(All) n = 96			samples t-test		
Engaged	6.1/7	6.4/7	Paired	-1.856 (57)	0.07
n = 61			samples t-test		
Control	6.1/7	6.3/7	Paired	-1.771 (208)	0.08
n = 216			samples t-test		

<u>Table 11.5</u> Within-group change in composite knowledge score

<u>Table 11.6</u>	Between-group	change in	composite	knowledge score

	Mean change in composite knowledge	Statistical test	Statistic (df)	p value
	score			
Intervention	+0.22	Independent samples t-test	0.218	0.83
n = 96			(200)	
Control	+0.18		(300)	
n = 216				
Engaged	+0.31	Independent samples t-test	0.637	0.53
n = 61				
Control	+0.18		(265)	
n = 216				

Question	Valid % correct at baseline	Valid % correct at follow up	McNemar test p value
Chlamydia is a sexually transmissible infection	92.0	94.9	0.163
that affects only women			
Chlamydia can lead to sterility among women	85.9	90.1	0.085
A woman can have chlamydia without any	92.9	96.1	0.110
obvious symptoms			
A man can have chlamydia without any obvious	88.3	89.6	0.689
symptoms			
Chlamydia is curable	85.8	86.5	0.888
Chlamydia can be prevented by using condoms	91.6	96.8	0.005
when you have sex			
Chlamydia can be tested for with a urine sample	77.8	81.0	0.282

### <u>Table 11.7</u> Question by question changes in knowledge for whole group (n = 312)

#### 11.5.3 Change in attitudes

Attitudes were reported by participants using a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree). Change in attitude was computed for each of the eighteen attitude questions by subtracting *either* the baseline from follow-up score *or* the follow-up from baseline score, depending on which direction represented an "improvement" in attitude. Improvement in attitude was based on several assumptions, which are described in Table 11.8. There was very little mean change in attitude scores in all groups (Intervention, Engaged and Control). Table 11.9 shows changes in attitudes from baseline to follow up and compares them between Intervention and Control, and Engaged and Control groups. There were no differences between groups. A table showing the actual change in attitude scores within each group between baseline and follow up, and independent t-test analysis comparing these groups can be found in **Appendix G (i)**.

Differences between groups at follow up were analysed by comparing scoring ranks using the Mann-Whitney U test. There was a significant difference between the Intervention and Control group for the attitude 'I don't know how to get a chlamydia test' where the Intervention group was more likely to disagree (median = 1.0 for each group, mean rank Intervention 137.88, Control 157.66; z-value = -2.098, p value = 0.04). Statistical data reporting mean ranks at follow up for the three groups and compare Intervention and Control and Engaged and Control groups can be found in **Appendix G (ii)**.

$\mathbf{T}_{\mathbf{a}}$	Table 11.8 Assumptions about improvement in attitude	
	Attitude	Improvement in attitude = change:
-	I think I am at risk for Chlamydia	Towards agreement
2	I don't think I have Chlamydia	Towards agreement
3	I don't care whether I have chlamydia or not	Towards disagreement
4	I don't know how to get a chlamydia test	Towards disagreement
ы	I would be too embarrassed to see a doctor or nurse to talk about Chlamydia	Towards disagreement
0	I would not see a doctor or nurse about chlamydia <u>because</u> I am worried about confidentiality	Towards disagreement
2	It is difficult for me to see a doctor or nurse about chlamydia because of transport	Towards disagreement
œ	I would prefer to see a doctor or nurse who is the same sex as me for a chlamydia test	Towards disagreement
6	It is difficult for me to see a doctor or nurse about chlamydia because of cost	Towards disagreement
10	I would feel comfortable visiting a doctor or nurse to get a chlamydia test	Towards agreement
11	I do not want to talk to a doctor or nurse about my sexual history	Towards disagreement
12	I can't get a chlamydia test because I don't have a Medicare card	Towards disagreement
13	I don't want a chlamydia test because I'm scared of what it might show	Towards disagreement
14	I don't want a chlamydia test because my partner/s might find out	Towards disagreement
15	I would have a chlamydia test if my partner/s wanted me to	Towards agreement
16	I would have a chlamydia test if my doctor recommended it	Towards agreement
17	I want to have a chlamydia test because I would want to prevent any long term health problems from Chlamydia	
18	I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	Towards agreement

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<u>Table 11.9</u> Changes in attitudes from baseline to follow-up comparing Intervention and Control, and Engaged and Control groups

-		vention		Engaged	Control
	I think I am at risk for Chlamydia	worsened	worsened	worsened	worsened
	I don't think I have Chlamydia	improved	improved	improved	improved
+	I don't care whether I have chlamydia or not	improved	improved	improved	improved
	I don't know how to get a chlamydia test	improved*	improved	improved	improved
	I would be too embarrassed to see a doctor or nurse to talk about Chlamydia	improved	improved	improved	improved
+	I would not see a doctor or nurse about chlamydia <u>because</u> I am worried about confidentiality	improved	improved	improved	improved
	It is difficult for me to see a doctor or nurse about chlamydia because of transport	improved	improved	worsened	improved
	I would prefer to see a doctor or nurse who is the same sex as me for a chlamydia test	improved	improved	improved	improved
	It is difficult for me to see a doctor or nurse about chlamydia because of cost	improved	improved	worsened	improved
+	I would feel comfortable visiting a doctor or nurse to get a chlamydia test	improved	improved	improved	improved
	I do not want to talk to a doctor or nurse about my sexual history	improved	worsened	improved	worsened
	I can't get a chlamydia test because I don't have a Medicare card	worsened	improved	no change	improved
+	I don't want a chlamydia test because I'm scared of what it might show	improved	improved	improved	improved
	I don't want a chlamydia test because my partner/s might find out	improved	improved	improved	improved
-	I would have a chlamydia test if my partner/s wanted me to	improved	improved	improved	improved
	I would have a chlamydia test if my doctor recommended it	improved	worsened	improved	worsened
	I want to have a chlamydia test because I would want to prevent any long term health problems from Chlamydia	worsened	worsened	improved	worsened
	I want to have a chlamydia test because I don't want to give chlamydia to my partner/s if I have it	worsened	worsened	improved	worsened

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#### **11.6 Discussion**

At the time (2007), this was a novel way to implement a strategy to try to change health seeking behaviour in young people. To design a randomised controlled trial that would take place wholly online was even more novel, and this was possibly the first RCT of an intervention to increase chlamydia testing implemented entirely in cyberspace. The primary outcome was self-report of having had a chlamydia test between baseline and follow-up (six months) and we found that this was more likely among the young people who engaged in email interaction with a clinician than for those who were not offered such contact. Knowledge, attitudes and condom use did not change.

Recruitment to the trial was slower than anticipated, and this was probably mostly due to the modest reach of the website. On the other hand, delivering the intervention was relatively simple, efficient and we (the research nurse and I) were able to provide clear information about testing, treatment and relevant services to those young people who engaged in email interaction. We also answered any of the questions that the young people had, regardless of the topic/s of their enquiries. The sending of impersonal emails to the Control group participants was quick and simple as well, even though done manually.

The completion rate of just under 50% created difficulties with analysis and reduced power; however the unanimous view of our youth consultants was that this was an excellent retention rate. Internet based trials have high attrition rates, especially when there is no clinician contact at the outset.<sup>347</sup> Attrition can occur either at uptake of an intervention or with failure to complete follow up. This introduces dilemmas with analysing intention-to-treat populations in exactly the way we found. To improve validity it has been suggested that individuals who do not take up an intervention be removed and that the remaining participants in the intervention group undergo a second randomization process.<sup>348</sup> Given our time frame this was not feasible. It is possible that participants who are symptomatic are more likely to take up an intervention, but also to drop out if no benefit is perceived. Our trial involved an intervention that was not therapeutic, and targeted a behaviour change for an asymptomatic condition. If anything we would expect a much higher drop-out rate compared to therapeutic interventions, which was not the case. Nevertheless we must be cautious about how to interpret our findings. A fuller discussion of the methods including external and internal validity and ethical considerations, will be provided in the final chapter of this thesis.

*Engagement* seemed to be an important phenomenon. The young people who engaged were much more likely to complete follow-up and to report that they had had a chlamydia test. Although there were no measurable differences in attitudes between these subgroups, it is possible that those who engaged were more concerned about chlamydia, more engaged with the health system, or wanted to please the clinician or avoid embarrassment. Content analysis of the emails of those who engaged (Chapter 13) may or may not shed light as to what occurred in those interactions to motivate completion and/ or testing. Interviews with participants (the subsequent study, see Chapters 15 and 16) could also help understand what factors came into play for those young people who engaged or didn't engage, and for those from the Control group.

Fourteen per cent of the young people who had had a chlamydia test at follow up had a positive result. This is unsurprising given our self-selected sample, and is higher than various estimates calculated in a meta-analysis of Australian prevalence data published in 2011 which found a prevalence of 5.0% for women under 25 years and 3.9% for men under 30 years in community or general practice settings, and 6.2% among women under 25 years attending sexual health, family planning or youth clinics (10.2% for young men).<sup>194</sup>

There were no significant changes in knowledge, attitudes or condom use. However, baseline knowledge was high and might have been positively impacted simply from navigating the website. That reported condom use was low and did not increase significantly highlights the complexities of this behaviour and relationship dynamics at the point of sexual encounter.<sup>349</sup> Furthermore heterosexual couples using other contraceptive methods are less likely to use condoms,<sup>349,350</sup> or pregnancy might be desired. The only attitude that changed was really a knowledge question about how to get a chlamydia test. This knowledge improved in the Intervention group compared to the Control group but not when the Engaged group was compared to the Control group. It is puzzling as to why this would be the case, except that perhaps the personalised emails, regardless of whether they elicited a response/ engagement, did generate some active thinking about the test (but not necessarily the wish or motivation to have one).

In summary, the outcomes of the study and methodological considerations suggest that the use of e-technology to deliver an intervention to change health-seeking behaviour is feasible. There is a need to understand what could facilitate engagement (or what might be a barrier to it) and whether an intervention such as this can be 'scaled up' without a significant increase in cost. The findings from this randomised controlled trial were published in the following paper:

**Kang** M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Facilitating chlamydia testing among young people: a randomised controlled trial in cyberspace. *Sexually Transmitted Infections* 2012; 88:568-573.

They were also published in an abstract from conference proceedings in the following paper:

Kang M, Rochford A, Skinner SR, Mindel A, Webb M, Usherwood T. Getting Clued Up in cyberspace about chlamydia: a randomised controlled trial of an internet-based intervention [abstract]. *Journal of Adolescent Health* 2009; 44(2): Supplement:S22

A copy of these publications and statements from all authors verifying my contribution to the publication can be found in **Appendix H**.

## CHAPTER 12 NON-SEXUALLY ACTIVE PARTICIPANTS AT FOLLOW UP

#### Introduction

One hundred and fifty-two young people provided complete baseline records, but were not eligible for enrolment in the trial because they had never had sexual intercourse ('NSA group'). Rather than exclude them and delete the data, they were treated like Controls in that they were sent impersonal monthly emails and then asked to complete follow-up questionnaires at six months. Seventy-four young people (48.7%) in this group completed follow-up questionnaires, a follow-up rate higher than either the Intervention or Control groups.

The primary outcome in the RCT (having a chlamydia test) was not relevant in this cohort and none of the participants received the RCT intervention relating to chlamydia testing. However, of interest was self-report of having had sexual intercourse at follow up and whether any baseline factors predicted this.

#### 12.1 Follow-up rate

The young people in the NSA group who completed follow-up were more likely to be older (mean age 18.7 years) than those who did not complete follow-up (mean age 17.0 years). They were also more likely to be living in a metropolitan or inner regional area (94.6% vs 76.9%). Table 12.1 summarises demographic factors in those who did, and did not, complete follow up questionnaires.

	Completed	Did not	Statistical test	Statistic	p value	
	follow-up	complete		(degrees of		
	n = 74	follow-up		freedom)		
		n = 78				
Mean age	10.7	17.0	Independent	4.954 (150)	<0.0001	
	18.7 years	17.0 years	samples t-test	4.854 (150)	< 0.0001	
Sex = female	(1 (92 40/)	(0, (07, 20/))	Yate's continuity	0.2(2.(1))	0.55	
	61 (82.4%)	68 (87.2%)	correction	0.363 (1)	0.55	
Born in Australia	((90.20))	(0 (00 E0/)	Yate's continuity	0.000 (1)	1.00	
	66 (89.2%)	69 (88.5%)	correction	0.000 (1)	1.00	
Speak English at	(0, (0,2, 20/))	(0, (07, 20/))	Yate's continuity	0.592 (1)	0.45	
home	69 (93.2%)	68 (87.2%)	correction	0.583 (1)	0.45	
Aboriginal and/ or			Fisher's Exact			
Torres Strait	2 (2.7%)	2 (2.6%)	Test		1.00	
Islander			Test			
Major city/ inner	70(04.6%)	60 (76.9%)	Fisher's Exact		0.04	
regional	70 (94.6%)	00 (70.970)	Test		0.04	
Studying (school	65 (87.8%)	69 (88.5%)	Yate's continuity	0.008 (1)	0.93	
or tertiary)	03 (07.070)	09 (00.370)	correction	0.008 (1)	0.93	

# Table 12.1:Differences between non-sexually active young people who completed<br/>follow up and those who did not complete follow up

# 12.2 Young people who reported sexual intercourse at follow up compared to those who did not

Demographic factors and substance use at baseline were examined to see whether these were associated with reporting of sexual activity at follow up. Specifically, after six months, were young people who had initiated sex, compared to those who had not, more, or less, likely to be:

- Older?
- Female or male?
- Born in Australia?
- Speaking English as their main language?
- Aboriginal and/or Torres Strait Islander?
- Living in metropolitan or rural/remote areas?
- Studying or not studying?
- Daily or regular smokers?
- Drinking alcohol more than once a week?
- Drinking at risky levels (5 or more drinks at a time)?
- Using marijuana and/ or illicit substances?

Sixteen out of 74 young people (21.6%) who were not sexually active at baseline, and who completed follow up, reported having had sexual intercourse at follow up. There were no differences between these 16 young people and the 58 who reported not having had sexual intercourse at follow up with respect to age, sex or any other demographic factors including occupation. Young people who had reported having had sex at follow up were more likely to have reported drinking 5 or more drinks usually or in the past two weeks at baseline. Table 12.2 summarises demographic and substance use factors according to self-report at follow up of having had sexual intercourse.

	Had had sex at follow up	Had not had sex at follow up	Statistical test performed	Value of test (degrees of freedom)	p value
<u> </u>	n = 16	n = 58			
<b>Demographics</b> Mean age at baseline	18.0 years	18.8 years	Independent samples t-test	1.090 (72)	0.28
Sex (female)	13 (81.3%)	48 (82.8%)	Fisher's Exact		0.72
Born in Australia	15 (93.8%)	51 (87.9%)	Fisher's Exact		0.68
English spoken at home	15 (93.8%)	54 (93.1%)	Fisher's Exact		1.000
Aboriginal	0 (0.0%)	2 (3.4%)	Fisher's Exact		1.000
Metro/InnerRegional	14 (87.5%)	56 (96.6%)	Fisher's Exact		0.20
Studying	14 (87.5%)	51 (87.9%)	Fisher's Exact		1.000
Substance use					
Regular smoker at baseline	1 (6.3%)	1 (1.7%)	Fisher's Exact		0.37
Drinks weekly or more at baseline	3 (18.8%)	5 (8.6%)	Fisher's Exact		0.36
Drinks 5 or more at a time at baseline	5 (31.3%)	5 (8.6%)	Chi square	3.729 (1)	0.05
Drank 5 or more in past 2 weeks at baseline	5 (31.3%)	3 (5.2%)	Fisher's Exact		0.01
Used marijuana at all in past 30 days at baseline	0 (0.0%)	1 (1.7%)	Fisher's Exact		1.0
Used illicit drugs at all in past 30 days at baseline	0 (0.0%)	0 (0.0%)	-	-	-

Table 12.2:Demographic characteristics and substance use history at baseline for<br/>young people who reported sexual intercourse at follow up compared with<br/>those who did not

# 12.3 Young people who reported having had sexual intercourse at follow-up

Data provided by the sixteen young people who reported having had sexual intercourse at follow-up were analysed with respect to demographic characteristics, sexual histories and change in knowledge about chlamydia and attitudes towards testing. No statistical tests were conducted due to the small number of young people who made up this group. Summary data are presented below.

#### 12.3.1 Demographic characteristics

Thirteen females and three males reported having had sexual intercourse at follow up. Age ranged from 16 to 24 years. All but one were born in Australia and all but one spoke English as their main language.

#### 12.3.2 Sexual histories

Most of the young people reported one sexual partner in the preceding six months (range 1 - 3 partners) and most reported using condoms always. None had had a chlamydia test and none reported a diagnosis over the preceding six months of chlamydia, gonorrhoea, genital herpes, human papillomavirus, HIV or any other sexually transmitted infection.

Table 12.3 summarises demographic and sexual history information.

#### 12.3.3 Change in knowledge about chlamydia

Baseline knowledge was quite high (mean score 5.4/7) but the mean score did improve at follow up (6.0/7). The question where knowledge improved for the most number of young people was about how to test for chlamydia. Five of the 16 young people who were incorrect at baseline subsequently gave a correct answer at follow up for the question 'a man can have chlamydia without any symptoms', all of these were female. However one young person out of sixteen went from the correct answer at baseline to an incorrect answer at follow-up for the same question. Table 12.4 presents the number of young people who gave correct answers to the seven knowledge questions at baseline and follow up and the percentage change at follow up.

Had CT test	No	No	No	No	No	No	No	No	No	No	No	No	No	No	No	
Condoms	Always	Always	Always	Always	Always	Usually	Sometimes	Always	Usually 1	Usually ]	Always 1	Usually ]	Always 1	Sometimes	Always	
No. ( partners	1 A	1	1 A	3 A	1 A	1 U	2 S	1 A	1	1 U	1 A	2 C	1 A	2 S	1 A	
Educational Level	Completed Yr12	Completed Yr10	Completed Yr10	Completed Yr12	Completed Yr12	Completed Yr12	Missing	Completed Yr10	Completed University	Completed Yr10	Completed Yr10	Completed Yr10	Completed Yr12	Completed Yr10	Completed Yr10	
Occupation	Tertiary study	Tertiary study	School	Tertiary study	Tertiary study	Tertiary study	School	School	Full time work	School	School	School	Tertiary study	School	School	
Geographic region	Major City	Major City	Major City	Inner Reg	Major City	Major City	Inner Reg	Major City	Outer Reg	Outer Reg						
State	NSW	Vic	MSW	MSW	Vic	QId	MSW	WSW	NSW	ACT	Vic	WA	NSW	QId	Tas	
Main Language	Nepalese	English	English	English	English	English	English	English	English	English	English	English	English	English	English	
CoB Father	Nepal	Aust	Poland	Aust	Aust	Aust	Aust	Aust	Aust	Aust	Aust	UK	Aust	Aust	Aust	
CoB Mother	Nepal	Aust	Poland	India	New Zealand	Aust	Germany	Ireland	Aust	Phillipines	Nauru	Aust	Aust	Aust	Aust	
CoB	Nepal	Aust	Aust	Aust	Aust	Aust	Aust	Aust	Aust	Aust	Aust	Aust	Aust	Aust	Aust	
Sex	ц	ц	ц	ц	ц	ц	ц	ц	Μ	ц	ц	Μ	н	ц	ц	
Age	20	18	16	19	21	18	18	16	24	17	16	16	19	16	16	
D is	11	33	91	216	317	377	536	599	709	740	818	868	954	966	978	

Chapter 12

Knowledge question	No. correct at	No. correct at	%
	baseline n = 16	follow up $n = 16$	change
Chlamydia is a sexually transmissible	14	13	-6.3%
infection that affects only women			
Chlamydia can lead to sterility among	13	14	+6.3%
women			
A woman can have chlamydia without	13	14	+6.3%
any obvious symptoms			
A man can have chlamydia without any	8	12	+25.0%
obvious symptoms			
Chlamydia is curable	14	13	-6.3%
Chlamydia can be prevented by using	15	15	0.0%
condoms when you have sex			
Chlamydia can be tested for with a urine	10	15	+31.3%
sample			

#### Table 12.4: Knowledge at baseline and follow up and percentage change

#### 12.3.4 Change in attitudes towards chlamydia testing

Four of the 16 young people who had become sexually active at follow up changed their attitude from 'not being at risk' to 'being at risk' of chlamydia, four reported exactly the reverse in attitude and the remainder did not change.

Several of the attitude questions that addressed barriers to chlamydia testing improved from baseline to follow up, 'improvement' meaning that more of the 16 young people at follow up compared to baseline: knew how to get a chlamydia test, did not feel embarrassed about getting a chlamydia test, and were not worried about confidentiality, cost, having a Medicare card or having a sexual history taken.

Conversely, fewer of the 16 young people at follow up compared to baseline cared whether they had chlamydia or reported that they would have a chlamydia test to protect their longer term health or to protect their partner's sexual health.

#### **12.4 Discussion**

The proportion of young people in the NSA group who completed follow up was higher than the RCT group, which suggests that they were as engaged in the study as those in the RCT. Within the NSA group, those who completed follow up were significantly older than those who did not. This was not the case in the RCT group, where there was no difference in age between completors and non-completors. However the NSA group was significantly younger than the RCT group.

Twenty-one percent of the NSA group had become sexually active after six months. These young people were more likely to have binge-drunk at baseline, but were not more likely to be smokers or to have used been illicit substances at baseline. While it is possible that this small number of young people were more likely to be at 'higher risk' with respect to various health behaviours, these differences could also reflect natural developmental processes: those who were developmentally ready to become sexually active were also more likely to be engaging in other adolescent health risk behaviours. Although binge drinking is a harmful behaviour, it has become normative among Australian young people. The great majority of the 16 young people who were sexually active at follow up used condoms always or mostly, and most had had one sexual partner. It is not surprising that none reported an STI, or having had a chlamydia test, since they had been sexually active for six months or less. The two knowledge questions that were least correctly answered at baseline also improved the most over six months. Of particular note was the improvement in knowledge about how chlamydia could be tested for with a urine sample. This combined with apparent improvements in attitudes towards some of the barriers to testing (eg confidentiality, embarrassment) suggests there are favourable pre-conditions for these young people seeking testing in the future. It would be useful to be able to track these young people further to explore the factors that eventually lead to behaviour change (testing).

## CHAPTER 13 ANALYSIS OF EMAILS SENT BY YOUNG PEOPLE IN THE INTERVENTION GROUP WHO *ENGAGED*

#### Introduction

Of 192 young people who received the allocated intervention within the Intervention group in the RCT, 78 (40.6%) responded at least once to the personalised email/s sent to them as part of the intervention (ie they '*engaged*'). None of the 468 young people allocated to the Control group who received the Control intervention (monthly, non-personalised emails) responded to any emails at all during the six month period between baseline and follow up. This chapter examines the content of the emails sent by young people who *engaged* using simple thematic analysis. Specific objectives were to understand the sexual health concerns young people expressed via email interaction, and to identify barriers and facilitators to chlamydia testing. A secondary objective was to gauge young people's level of engagement with a sexual health professional via email interaction.

#### 13.1 Method

As soon as a young person was allocated to the Intervention group, the research nurse or doctor (myself) sent them a personalised email (as described in Chapter 8). If there was no response, we continued to send personalised emails once a week for the first three months and then monthly for a further three months. Follow up (completion of the online follow-up questionnaire) took place at six months.

*Engagement* was defined as one or more email responses from a young person, regardless of the content of the email response. Email transcripts of the 78 young people who sent one or more email responses were saved and formed the units for content analysis. The transcripts were read twice-through to glean the range of topics and questions raised, as well as to gain a sense of the tone of the communication (eg formal, casual, disinterested, friendly). Broader themes were then identified after third and fourth readings of the transcripts. Particular attention was paid to themes according to whether the young person reported a change in testing behaviour from baseline to follow up (the primary outcome of the RCT).

#### 13.2 Results

#### 13.2.1 Characteristics of the young people who engaged in email interaction

Detailed demographic characteristics of the whole RCT sample, including comparisons between the Engaged group and the Intervention (All) and Control groups, were described in Chapter 11. Basic demographic data for the Engaged group are presented again below:

Female 65/78 (83.3%) Male 13/78 (16.7%) Mean age 20.6 years Born in Australia 74/78 (94.9%) English main language 76/78 (97.4%) Aboriginal and/ or Torres Strait Islander 2/78 (2.6%)

#### 13.2.2 Number of email responses

The majority of young people who engaged in email interaction only responded once. Table 13.1 shows the number of email responses for females and males.

No. of email	No. of females	No. of males	Total no. of
responses	young people		
1	41	8	49
2	16	2	18
3	2	2	4
4	1	0	1
5	3	1	4
6	1	0	1
12	1	0	1
	65	13	78

#### Table 13.1Number of email responses from females and males who engaged

Most responded after one or two emails from the research nurse or doctor, and all responded within the first three months:

46/78 responded after the first email

21/78 responded after two emails

2/78 after 3 emails

2/78 after 4 emails (i.e. 4 weeks after the intervention began)7/78 after 5 emails, but within three months of the intervention

Thus, the overwhelming majority (91%) who engaged responded within the first month. Once engagement occurred, the time between email exchanges was short. The research nurse or doctor always replied to a response within one business day. For those young people who emailed twice or more, response time was never longer than a few days.

Of the 11 young people who emailed three or more times, seven (63.6%) completed follow up and of these seven, three (42.9%) reported having had a chlamydia test between baseline and follow up. Of 67 who emailed only once or twice, 54 (80.6%) completed follow up, and of these 29 (43.3%) reported having a chlamydia test. While these numbers are too small to reach significance, it does *not* appear that a greater number of email exchanges increased the likelihood of either completion of the follow-up questionnaire or reporting a chlamydia test at follow-up.

#### 13.2.3 Tone of email interactions

As reported above, most young people who engaged responded after one or two personalised emails. These personalised emails were based on templates created for the study, so that each young person received an identical email in terms of tone and wording. The tone of the outgoing emails sent by a nurse or doctor was friendly but professional, with links to the University of Sydney staff directory for verification and contact details (See Appendix D for examples or personalised emails).

A number of different tones and styles were displayed in emails received from participants.

The overwhelming majority of email responses from young people were polite and expressed gratitude for the nurse or doctor's interest and concern, even if they did not want any further information.

"...thanks for your emails, but at the moment I don't have any questions." [Female, 25 years]

"... Thanks for the support and I will write you if I want to know something or feel worried about something. Thanks." [Female, 21 years]

"...I think this program is really good, and I think there should be more... for young people to ask questions... I feel I know enough about chlamydia. If I had any concerns I would consult my GP... Thank you very much for your concern."

[Male, 22 years]

Many emails were friendly and casual in their tone:

'*Hi Arlie [research nurse], no questions! Cheers,* [name] ' [Female, 25 years]

'Hi Arlie, sounds like a pretty cool job. Nope, I can honestly say I think I'm pretty clued up about this kinda stuff....Keep rockin' [name]' [Female, 16 years]

"...I'm sure I'll think of something to ask in relation to health somewhere along the lines, when I do I'll remember to give you a buzz. Ta, take care, [name]." [Male, 19 years]

A sense of altruism was also conveyed in many emails:

'I'm happy to help out, and chat with you via email. Let me know what you need. Cheers, [name]' [Female, 24 years]

'Hey. I have no worries with talking to you about chlamydia...I've already been diagnosed..I just wanted to find out more info on it and then found your questionnaire... but yeah happy to chat.' [Female, 20 years]

Many who responded to the second email were apologetic:

'Hi, sorry I haven't writtin (sic) back to you, have been very busy! ... Thank you for your concern but I'm good.' [Female, 16 years] 'Thanks for the emails, sorry I haven't had a chance to respond I've been really busy at work...' [Female, 19 years]

A few displayed a degree of caution in their initial response:

'I'm quite happy to chat via email, as long as I remain study no. [xxx], and only this email address is used.' [Female, 18 years]

'I only want replies via email no phone calls, but questions I have are: ...' [Female, 22 years]

Finally, several young people were humorous in their interactions:

"...p.s. Apart from the normal stigma that is attached to chlamydia – it is also the only word I know of that rhymes with my name!" [Female, 23 years]

'I have just one question... how on earth does one fill an 80GB iPod? Cheers, [name].' [Male, 24 years]

There were no hostile emails. Two young people did express confusion about why there were receiving emails.

#### 13.2.4 Sexual health concerns other than chlamydia

Where young people had specific questions, most were about chlamydia. However there was a range of other concerns, all relating to sexual and reproductive health. All of these were personal, that is, they arose from personal experience (eg symptoms, situation, partner or friend's experience).

The specific topics asked about were Pap smears (2 queries) and one query each about the following: local sexual health services, questioning own sexual orientation, age of consent law, emergency contraception, condoms (how to avoid breakage), vaginal discharge, genital lump, anal lesion, thrush, genital herpes, genital warts. Most of these questions were posed during the

first email, even though the outgoing email specifically offered to answer questions about chlamydia.

There were an additional 7 young people who stated that they had come across the website and the study through their professional or academic work. None of these young people had personal questions about chlamydia or other STIs, but one asked for suggestions of other sexual health promotion websites, one asked the research nurse if she would participate in a community radio interview to educate young listeners about chlamydia and one asked for assistance with an assignment about chlamydia.

#### 13.2.5 Questions about chlamydia

Of the 78 young people who engaged, 24 asked specific questions about chlamydia. The style of questioning took one of two approaches: (1) 'impersonal' specific, factual questions and (2) questions based on a personal narrative. In the first group, it was common for several questions to be asked at once:

'How do you know if you have it? What are the symptoms? Can u have kids? Is it contagious?' [Female, 20 years]

'I just wanted to know what the symptoms are for chlamydia, and how you are able to get tested.' [Female, 17 years]

'How do I know if I have it? How do I get tested? How will my partner be effected? (sic) Does it cause infertility? Can it be treated? Thanks' [Female, 22 years]

The second group of questions covered similar topics as the first group (such as symptoms, testing, partners, consequences), but took a narrative form with some degree of personal disclosure. Some young people had recently been diagnosed with chlamydia or had recently had a test (and did not yet know the result) and asked further questions, while others were more concerned about their current risk and what they could do about it.

"... is it true when they test for clamidia (sic) they need to take a swab from inside the penis?... I had unprotected sex because I was drunk and decided to take the risk (not a good idea) because it feels better, and she said she was on the pill."

[Male, 22 years]

'I just went to get tested for chlamydia! I am wondering about the confidentiality regarding this test, particularly as I live in a small rural town... what stops them from discussing my results? I know they're not supposed to, but really, how do you know?' [Female, 23 years]

"...As for getting myself tested, i believe it would be a good idea. I am 20 atm, and being young and not having gotten myself tested after one partner (who had sex with people before myself...) Would this then mean if I had chlamydia that I wouldn't be able to become cured?" [Male, 20 years]

"...I had a severe pelvic infection and they thought that chlamydia had caused it. I was tested for chlamydia and I tested negative...I was just wondering if I did have chlamydia which caused my pelvic infection how likely is it that i will get chlamydia back?

[Female, 17 years]

#### 13.2.5.1 Barriers to chlamydia testing

Within the second group of questions about chlamydia based on personal experiences, several barriers to testing were identified. These fell into 3 broad categories: (1) service logistics of testing (2) personal / emotional barriers (embarrassment, shame, fear), and (3) qualities of the doctor/ service (personal attributes of doctor, attitudes),

#### The logistics of testing

"...I would like to know where I can get tested for this and I would need someone to come with me like my ex boyfriend are you allowed to have someone come with you for these tests?" [Female, 17 years]

'Can any public hospital offer sexual health services or are the specialist sexual health centres better? And where is it around the inner city?' [Male, 24 years] *Will the test be able to be part of just a normal appointment? That's the only thing I've really been worried about for it...'* 

[Female, 18 years]

Ten young people interacted further about testing logistics and were given specific contact details for appropriate services within their local area.

#### Personal/ emotional factors

A few young people expressed concern about the actual test (eg pain, discomfort) while others expressed more general embarrassment.

"...would a test for chlamydia be a swab taken from the cervix? I find that really embarrassing and uncomfortable and would prefer a simple urine sample or something like that." [Female, 20 years]

"...I've heard that getting tested is putting a swab down the urethra, giving it a twirl or not, and pulling it out, sounds like it hurts, so, no thanks I don't want to get tested that way." [Male, 24 years]

#### Qualities of the doctor/ service

Interestingly there were very few young people who expressed concerns about confidentiality, which is one of the most important barriers for young people accessing health care generally. In fact, the majority explicitly stated that they were *not* concerned about confidentiality, and understood that having a chlamydia test would be confidential. However, several young people expressed preferences for certain types of services (eg sexual health or Family Planning or student health clinics) because they felt more confident in their ability to be sensitive and maintain confidentiality. Others also expressed concerns and preferences for certain attributes of the doctor or the service.

"...I hesitate when thinking of going to my GP as he is a male, and I just prefer not to be tested by a male." [Female, 18 years] 'I am sure that I am able to get tested at my local GP – not that I would want to.. although I know he is a professional, I don't want him to know my sexual orientation. He is a Christian and I feel that it would make him uncomfortable/ judgemental of me.' [Male, 21 years]

'Doctors I have been to in the past have always made me feel rushed and unimportant. My current doctor is very supportive and doesn't make me feel like the clock is ticking. .. I had some symptoms... they kept coming back so I eventually went to the doctor... I probably would have put it off for longer if I hadn't found my current doctor...' [Female, 23 years]

'I generally go to the Family Planning Clinic that's free of charge for all my sexual health needs... I'd prefer to go to the FPA to be tested over a normal GP ... as I feel they possibly understand more and are a bit more sensitive about the subject.'

[Female, 19 years]

#### 13.2.6 Young people who reported having a chlamydia test at follow up

Of the 78 young people who engaged in email interaction, 61 completed follow up questionnaires and reported on whether they had had a chlamydia test in the previous six months (ie the study period). Thirty-two of the 61 (52.5%) reported having had a test at follow up.

Of these thirty-two:

- 19 had not had a test at baseline
- 13 had also had a test at baseline

Of interest were the 19 whose testing behaviour might have changed as a result of the study. Those 19 emails transcripts were studied again carefully.

Four of the 19 young people stated they had no questions and gave no information about themselves, and only responded once.

Five reported in their initial email that the website itself had motivated them to have a test since they first came across it (after completing the baseline questionnaire but prior to receiving the first intervention email). The remainder asked questions that covered the range of topics described in the previous section. Four of these young people were given specific service contact/referral details while the others nominated services they already knew (including their GP).

#### **13.3 Discussion**

Only 78 of 192 young people who received the study intervention (personalised emails) engaged in any email interaction. However, this subgroup (Engaged) were significantly more likely to complete follow up and to report having had a chlamydia test at follow up compared to the Control group (78.2% cf 46.6% p <0.0001, see Chapter 11). Importantly, even the most fleeting interaction appeared to have an impact. Furthermore, the input required from the clinicians (a sexual health research nurse and myself) was minimal, even when there were many questions being asked by any one young person. Most questions could be answered directly as though in conversation, some clinician email replies involved sending website links to factsheets, and the most time-consuming replies involved making enquiries about health services in local areas in order to provide contact details. Given our existing professional networks, this was not particularly time consuming.

This intervention appeared to be highly scalable, where for no or only minimal increase in resources, an exponentially greater number of young people could be reached and engaged. An outstanding feature of the email interactions from the participants was their tone, which was variously friendly, polite, grateful, humorous and/ or altruistic. While this was a self-selected group of engaged study participants, the fact that there were no negative or hostile responses from any young people suggests that there is a substantial group of young people who will respond to contact with a clinician through the internet and who can become motivated to engage in health seeking behaviour.

The fact that several young people asked questions about other sexual and reproductive health topics beyond chlamydia, despite the very specific wording of the emails they received, implies a willingness to use the opportunity they were being offered to interact with a clinician to address their own broader concerns.

The level of personal disclosures in many emails suggests a degree of trust in the virtual clinician. Barriers to and facilitators of chlamydia testing tended to focus on logistics, including requests for specific referral information. Mention of well-known barriers to health care for young people, such as confidentiality concerns,<sup>61</sup> was remarkably infrequent. This probably reflects the self-selected nature of the sample, many of whom were already 'clued up' about sexual health.

In summary, personalised, internet-based health advice can be simple and is not time-intensive. This is a scalable intervention that can help probe and address concerns and barriers young people have about chlamydia and other sexual health issues, and can have a useful role in facilitating access to testing and health care.

## CHAPTER 14 RESULTS (RCT): ADDITIONAL DATA

#### Introduction

A secondary aim of launching the website <u>www.getcluedup.com.au</u> and promoting it through paid advertising and through links with the *ReachOut* website was to raise awareness among young people about genital chlamydia infection and testing. Indirect measures of awareness included website traffic to *getcluedup* and to *ReachOut*, quiz questions on the *getcluedup* website itself, and quiz-like surveys in *Dolly* magazine and through the *Act Now* website. This latter strategy did not materialise, due to other website content taking priority at the time, however all the other strategies were implemented. Website traffic data have already been reported in Chapter 9. This chapter presents the *getcluedup* quiz data and results from the two *Dolly* magazine surveys about chlamydia.

#### 14.1 getcluedup quiz data

From the launch of <u>www.getcluedup.com.au</u> on 7 March 2007, until 3 December 2008, a small number of short quiz questions requiring yes/no responses were rotated on the home page. Only one quiz question could appear at a time. 'Programming' of the quiz questions was done manually by me. An awareness question was programmed to appear regularly throughout the 21-month quiz period. An attitude question about chlamydia testing was added in the final 12 months. In addition there were five knowledge questions. The main reason for having knowledge questions was to add variety and an interactive element to the website. Once a visitor submitted a response to a quiz question, the website generated a percentage figure, which appeared on the screen, indicating the proportion of other respondents who answered yes or no to the same question. There was no particular order in which questions appeared, and some knowledge questions only appeared for a few weeks and were then 'inactivated'.

Data was downloaded at four time periods (March to May 2007; May to August 2007; September to December 2007 and December 2007 to December 2008). Data was downloaded via the .csv file and exported into a Microsoft Excel file, as described in Chapter 8. Over the 21 month period, the following quiz questions were rotated through the website's homepage:

#### Awareness questions:

Have you ever heard of chlamydia? (March to August 2007) Have you previously heard of chlamydia? (September 2007 – December 2008)

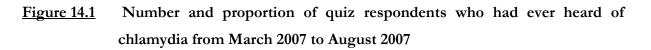
#### Attitude question:

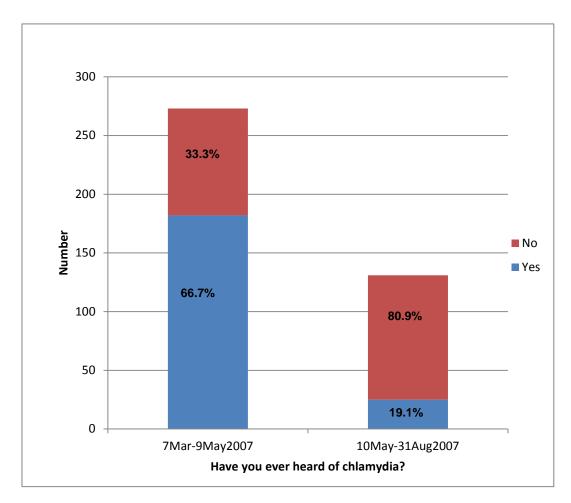
I'd feel OK asking for a chlamydia test from a GP (December 2007 – December 2008)

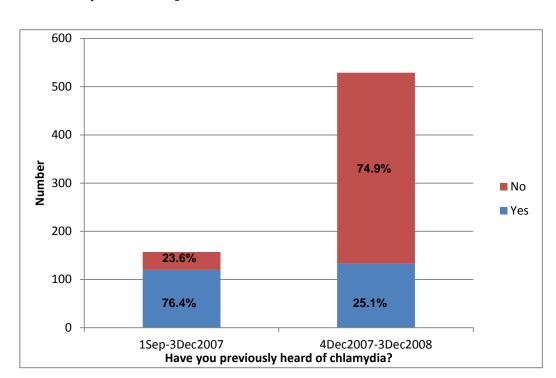
#### Knowledge questions:

Most people with chlamydia don't have symptoms (March 2007 – December 2008) Chlamydia can be cured (March 2007 – December 2008) Chlamydia can cause infertility (March – May 2007) Chlamydia affects men as well as women (March – August 2007)

Figures 14.1 and 14.2 show the proportions of quiz respondents who had ever heard or previously heard of chlamydia.



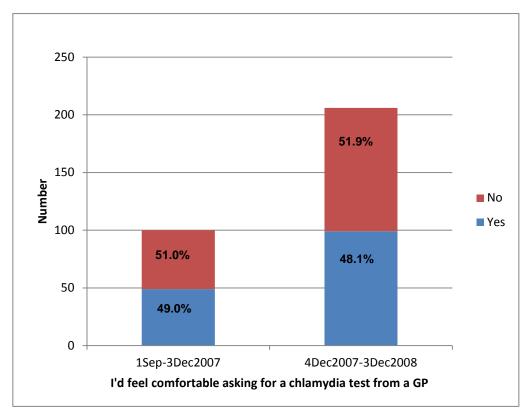




## Figure 14.2Number and proportion of quiz respondents who had previously heard of<br/>chlamydia from September 2007 to December 2008

The proportion of quiz respondents who felt comfortable asking for a chlamydia test from a GP over the 21 month quiz period remained steady at about 50% (see Figure 14.3)

## Figure 14.3Number and proportion of quiz respondents who would feel comfortable<br/>asking for a chlamydia test from a GP from March 2007 – December 2008



Only two quiz knowledge questions ('Most people with chlamydia don't have symptoms' and 'Chlamydia can be cured') were rotated on the homepage for the whole duration of the quiz period. The proportion of correct answers was generally high. Figure 14.4 shows the proportion quiz respondents who gave correct answers.

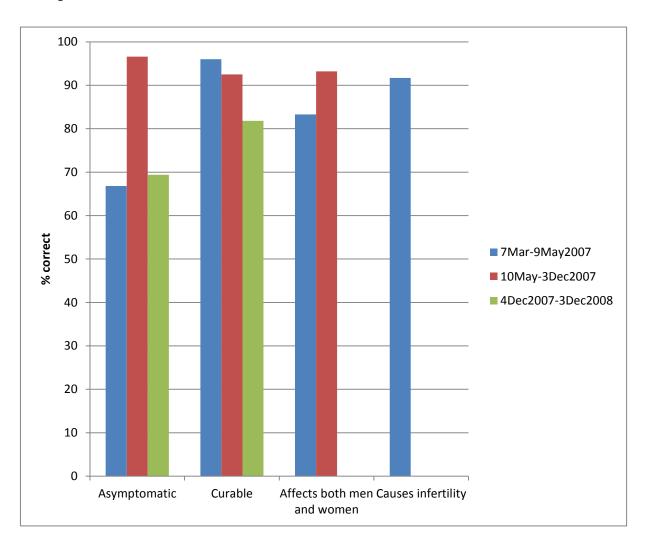


Figure 14.4 Proportion of correct answers for four knowledge quiz questions at different time periods

#### 14.2 Dolly online surveys

The *Dolly* magazine editor and *Dolly* website producers agreed to include questions about chlamydia in two 'sex surveys' conducted by the *Dolly* website twelve months apart (December 2006 and December 2007). This came about through negotiation when buying advertising space in the magazine and website in late 2006. Results were collated by the *Dolly* website producer. Only those relevant to the *getcluedup* project are reported in Table 14.1. There was no change in the proportion of survey respondents who had heard of chlamydia over the 12 month period.

## Table 14.1Chlamydia awareness among *Dolly* online survey respondents December2006 to December 2007

	December 2006	December 2007
	n = 8465	n = 12234
	0/0	0/0
Age		
12 – 13 years	20.6	20.1
14 – 15 years	38.4	37.3
16 17 years	25.2	26.0
18 years and over	15.8	16.6
Ever had penile/vaginal		
intercourse		
Yes	40.6	40.9
No	59.4	59.1
Ever heard of chlamydia		
Yes	72.8	73.8
No	27.2	26.2
Where have you heard of		
chlamydia		
Magazine	45.3	50.8
School	44.2	44.5
Friends	23.1	23.6
Health professional	21.3	22.5
The internet	12.9	14.1
Parents	6.7	7.2

#### 14.3 Contact and Feedback Form data from getcluedup

The *getcluedup* website had a Contact and Feedback utility which allowed visitors to request contact with or provide feedback to those managing the website (myself and the research nurse). When the 'submit' button was clicked, an email was generated to the <u>cluedup@usyd.edu.au</u> email address with a transcript of the visitor's text. From the launch date in March 2007 until December 2008, there were eighteen Contact Forms and seven Feedback Forms submitted. In general these Forms were utilised appropriately, in that visitors submitting a Contact Form were requesting specific personal contact for a range of reasons, and those submitting a Feedback Form were providing feedback about website content.

Among the 18 Contact Forms submitted (11 from females, five from males, two where gender was not specified) three were from youth or health promotion workers requesting professional contact to discuss the website and the study, two were reporting on errors in website links, one was from a student asking how to cite the website in an academic work, one provided positive feedback on the website, one was promoting their own website and the remaining 10 were personal sexual health questions requesting clinical information. Despite the Contact Form webpage specifically stating that an email address needed to be provided if a response was wanted, half of the Forms submitted did not contain any contact information. However one critical incident occurred early, in March 2007. A visitor who provided a name, mailing address and fax number, requested specific information on sexually transmitted infections to be sent to them by mail or fax. Some factsheets were faxed soon after this, and a few days later our Department was contacted by the Federal Police saying that this person had been the subject of a hoax and had received copious material relating to sexuality and sexual health from a range of services. Having this incident occur early fortunately alerted us to potential hoaxes and we responded to future requests for contact by sending a neutral email initially asking whether the person had in fact intended to contact getcluedup for sexual health information. There were no other incidents.

Of the seven Feedback Forms submitted (five from females, one from a male, one not specified), one was a personal question that appeared spurious, one mentioned a technical problem with a link and one provided overall positive feedback about the website. The remaining four people requested more information to be posted on the website regarding a range of issues, such as condom use, lesbian sex and risk of STIs and more information about the risk of acquiring chlamydia from different sexual practices.

We responded to all Contact and Feedback where feasible and appropriate. Because website content appearing on each webpage could not be changed (without cost), additional information was added via factsheets and links. Where professional contact was sought, it was made.

#### **14.4 Discussion**

The additional data collected over the study period provides interesting, but very limited, information to support the other findings of the RCT. Measures of awareness were quite disparate between time periods on the *getcluedup* quiz and between the quiz and *Dolly* survey. The very limited data on chlamydia knowledge suggests that knowledge was high among quiz respondents. The small number of Contact and Feedback Forms submitted over a 21 month period did not add any new information.

The stark differences in chlamydia awareness among quiz respondents from the March – May 2007 and the May – August 2007 time period and again between the September to December 2007 and December 2007 to December 2008 time period could reflect fluctuations in visitor numbers to the website and their reasons for visiting the website. For example, there could have been more visitors to *getcluedup* who responded that they had not previously heard of chlamydia, but who had in fact recently become aware of it, reflecting an increase rather than a decrease in awareness. Because each block of downloaded data covered several months' worth of data that was not dated (unlike the baseline and follow up questionnaires which contained the date that the data was submitted), the data could not be closely matched against website traffic or other potential promotional activities. The wording of the awareness and the data unreliable.

The static findings from the *Dolly* survey data, measured 12 months apart, is of more interest. The large number of respondents and the reach of the *Dolly* website make the findings somewhat more robust. Chlamydia awareness did not appear to change, suggesting that the two surveys sampled two different cohorts of *Dolly* website visitors, whose overall awareness of chlamydia was reasonably high. The advertisements for *getcluedup* were featured on the *Dolly* website from March to June 2007, and the surveys occurred in December 2006 and December 2007. It is unclear whether the absence of increase in awareness of chlamydia therefore is because six months had lapsed from the appearance of the advertisements to the second survey or whether the readership and survey respondents changed rapidly. The increase, albeit small, in the proportion of survey respondents stating that they heard about chlamydia from magazines and

the internet does support the use of these media for providing health related information to young women. School (presumably formal curricula) is also clearly a very important source of information about chlamydia for young women.

The very small number of *getcluedup* visitors who submitted Contact and Feedback Forms suggests that this facility was under-utilised. On the other hand, the website was mostly static and did not seek to encourage interaction other than through the RCT.

# CHAPTER 15 METHOD (IN-DEPTH INTERVIEWS)

In the wonderment of this taxonomy, the thing we apprehend in one great leap, the thing that, by means of the fable, is demonstrated as the exotic charm of another system of thought, is the limitation of our own, the stark impossibility of thinking that.

- Michel Foucault, The Order of Things, Preface p.xvi

# Introduction

The qualitative component of this research was designed to complement and enrich findings from the RCT. I wanted to talk with young people directly, preferably face to face, to ask about their experiences of the RCT and the meanings of STIs to them. I also wanted to find different ways of *interpreting* what young people had to say.

What I wanted to do was to cast aside, or perhaps to blow apart (and reassemble) fixed notions about young people's understandings of STIs. Indeed, a randomized controlled trial whose primary outcome is the act of receiving a chlamydia test presupposes fixed ideas, or truths. The primary outcome is regarded as a certainty, a measure of health, an ideal goal and one that young people have, or should have. It presupposes that young people hold to those same truths, and that there can be simple ways of understanding and reshaping attitudes and contextualizing the barriers to, and facilitators of, the behavioural goal.

The premise of this study was that we do not know what truths young people uphold about sexually transmitted infections. The medical discourse is but one set of 'truths' and I wanted to explore where young people see themselves in relation to that discourse or whether they adhere to other discourses. For example, medicine delivers health messages to young people about the health dangers of unprotected sex. If there are other discourses that compete with this one, such as a morality discourse about being young and sexually active, as suggested by some of the literature reviewed in Chapter 3, then it would be useful to look for how these discourses intersect and the points of resistance that young people find that might shift their thinking and their behavior.

Thus the aims of this study were to enquire about participants' experiences of the RCT and to explore how young people (16 - 25 years) construct meaning around chlamydia and other sexually transmitted infections.

# 15.1 Methodological considerations - a background

Qualitative research methods enable different ways of understanding some of the complexities surrounding behaviours and attitudes, including help-seeking, and help to place quantitative findings within the social contexts of individuals being 'studied'. Qualitative methods used to date in relation to young people and STIs have mostly been semi-structured interviews where data are subjected to thematic analysis. As described in Chapter 3, common themes in relation to chlamydia testing or partner notification about STIs include fears about stigma, confidentiality, denial, and concerns about the impact on relationships.<sup>106,107</sup>

In the first part of my interviews with young people, I wanted to focus on their participation in the RCT, and to look for themes as well as simple reasons that they put forward for how and why they chose to participate in the RCT and how they found the emails they received. This could help shed light on why some of the participants in the Intervention group engaged or didn't engage, and help understand what impact impersonal (Control group) emails had as well.

I then wanted to broaden the discussion to look at STIs and how young people understand them. To do this I wanted to apply Foucauldian discourse analysis to the data. Discourse analysis as a research method in the field of adolescent sexuality offers a valuable way to understand how experiences are constructed by individuals within particular cultural contexts and how individuals position themselves within (often competing) discourses. A discursive approach takes the view that 'constructs are the effects of active social processes which are historically and culturally specific'.<sup>351</sup> Discourse analysis lends itself well to the study of sexual health because of the complex intersections between human sexuality and the cultural institutions of medicine, religion, education and mass media. These institutions all have their own discourses, and young people find their own positions within them to make sense of their own sexuality, sexual health and sexually transmitted infections. As described in Chapter 3, there is relatively little research that has examined the discourses of young people regarding STIs.

In its broadest sense, discourse analysis examines language as the vehicle for the social and cultural phenomena being studied. Historically the very broad field of discourse analysis derives from centuries' old Hermeneutics, but modern discourse analysis emerged in about the 1960s. It germinated from the discipline of Linguistics, but has been far-reaching in its utility as a research tool and conversely, has evolved and diversified both theoretically and in application because of the influence of many other disciplines. Discourse analysis has become an important tool in, and

has been extended by, the discipline of Psychology. Philosophy as a discipline introduced concepts such as the subject, the author within a text, the 'contingency of interpretation' and the 'institutionalizing of discourses'.<sup>352</sup>

# 15.2 Michel Foucault and notions of the self

Foucault studied the ways in which human beings became subjects, a subject being 'an entity which is self-aware and capable of choosing how to act'.<sup>353</sup> Foucault argued against older or accepted wisdom in presenting different ways of conceptualising power, freedom and knowledge. Rather than seeing power as residing solely in larger social groups such as governments or religious institutions, Foucault believed that power operates even at the most micro- levels of social relations. Freedom is thus conceptualised as a practice, rather than an abstract idea or goal, and the practice of freedom can take place at the individual level. The relationship between power, freedom and knowledge is therefore important in understanding how individuals become subjects. Foucault believed that the various mechanisms of power produce different forms of knowledge which in turn reinforces power. The individual is therefore a product of those relations between power and knowledge, and is created by that individual within social relations as they become subjects.<sup>353</sup>

Foucault's theories critiqued, challenged or flew in the face of essentialist notions of the self. Rather than understanding human beings as thinking, autonomous organisms governed by fixed ('essential') human drives (and *a la* Freud, by the subconscious mind, which is also fixed), Foucault believed that all human thinking, acting and being is socially constructed. In spite of human drives such as the sex drive or other biological or emotional needs, these are 'buried so deep beneath elastic and socially constructed interpretations that... human beings are their own product...<sup>354</sup>

Concepts relevant to my study include Foucault's notions of identity, institutions, normalisation and techniques of the self. Foucault argued that identity is a form of subjugation, a result of the exercise of power over individuals that prevented them from moving beyond boundaries. Normalisation was another way that individuals conform, using medical notions rather than legal ones. Foucault very strongly believed that medicine and health had become the social arbiters of 'truth' in human behaviour. Institutions, such as the institution of medicine, are mechanisms for freezing power relations that advantage some and disadvantage others. Technologies are the practical means by which individuals or groups become, or create, constituent selves or subjects. Foucault, having explored technologies of power in his earlier work shifted emphasis later in his life to studying technologies of the self, which he defined as '...operations on their own bodies and souls, thoughts, conduct, and way of being...[to reach a]...state of happiness, purity wisdom, perfection, or immortality'.<sup>355(p.18)</sup> He conceived of 'games of truth' of individuals as 'an ascetic practice of self-formation'.<sup>356</sup> Foucault rejected more traditional views of 'liberation' of the individual from a state of repression of their 'true' self, but, rather, believed that individuals *'become' and 'become'* through ongoing processes of self-formation. Foucault believed this process was something that might include, but was more than 'liberation', and was an ongoing, transformative and dynamic practice.

Foucault's later work closely examined the philosophical notion of 'care of the self' as an ethical principle. Foucault focused his study on the ancient Greeks and Romans to develop his theories of power, truth and subjectivity in relation to the individual and their practice of freedom. An ethical life in ancient Greece involved both taking care of oneself, as described above, and knowing oneself, with the former preceding the latter as a matter of logic.

The shift in western thinking from 'care of the self' to 'know oneself' occurred with the advent of Christianity and the concept of an afterlife, according to Foucault. 'Care of the self' was no longer 'moral', it did not fit with the concept of self-renunciation and salvation, it was too preoccupied with the individual conducting himself through constant processes of self-reflection and awareness. This development of understanding of 'how to be' led to what is described as 'the Cartesian moment',<sup>357</sup> which shifted the concept of 'truth' and, in crude terms, equated truth with knowledge. It placed the individual within a concrete existence and had profound effects on the central importance on science, evidence and the construction (or reduction) of the individual subject according to what is 'known'.

Foucault found contemporary meaning in the ancient notions of ethical living, which involved self-reflection, awareness of one's body, mind and spirit, and life-long cultivation of practices of self in order to participate in society. Rather than seeing an individual's existence as being the result of social forces beyond reach, this notion proposed that the individual practised, at the individual level, ever-changing techniques of the self, ways of finding meaning, and ways of taking charge of one's own identity and personal freedom. Foucault through his study of sexuality (in particular) proposed that in fact individuals continued to practise technologies of the

self throughout the classical and early modern periods and suggested that 'care of the self' had application in the modern world.<sup>358</sup>

# 15.3 The practice of discourse analysis, using Foucault's concepts

"Discourse" can be defined as 'a set of meanings, images and statements that work together to construct an object or a class of people in a particular way".<sup>359</sup> A discourse has the following features:

- 1) A body of knowledge
- 2) An institutional basis
- 3) People involved at a practical level in the discourse <sup>360</sup>

Foucault's suggestion is 'to tackle truth by questioning it as a discursive formation'.<sup>361</sup> In practice, this involves examining texts to look not only for patterns and order but also how these help us understand how the individual is 'making sense of themselves' through 'categorising, accounting and explaining'.<sup>362</sup>

Discourse analysis involves looking at texts for the ways in which individuals 'construct their experiences through language'.<sup>363</sup> Rather than searching for 'meaning' buried within content, or describing an individual's experiences, emotions or thoughts, discourse analysis looks for the active processes that individuals undertake as they use language to position themselves within their own set of understandings of 'their world' at a particular moment. Discourse analysis also examines shifts that take place dynamically during the process of telling itself, as the individual responds to and positions themselves alongside the interviewer and the topics being discussed. A goal of performing this analysis is to be able to describe the individual's subjectivity, which can be defined as a 'product of internalised discursive constructions and positioning, never as an entity that pre-exists discourse'.<sup>363</sup>

Underpinning the analytic process is the premise that power exists in all social relations and that at times individuals will struggle and resist and shift and position themselves within competing discourses to 'find their place'. Texts can therefore represent, or be, 'sites of struggle in that they show traces of differing discourses and ideologies contending and struggling for dominance'.<sup>364</sup> By applying a discursive approach to reading young people's texts about STIs, I hope to understand not only whether previously identified barriers such as stigma and shame emerge or are prominent, but how young people came to locate themselves there and whether and how

they resist their subject positions when faced with the potential to acquire or transmit an STI. To return to an earlier example, if a young person positions themselves as 'good' within a morality discourse by silencing their sexual self, they might have unprotected sex and fail to seek STI testing because this would help maintain that subject position – their sexual activity is 'invisible'. If this then clashes with the medical discourse, which dictates that unprotected sex is risky or bad, how do they reconcile this? Do they reject the medical discourse, or find new ways to position themselves in the morality discourse, or reject the morality discourse? How do young people construct identities and meaning if there are competing discourses? Studying the ways in which young people talk about STIs could help to answer these questions.

# 15.4 Study methods

## 15.4.1 Study Design

I conducted in-depth interviews to collect data from volunteers who had participated in and completed the RCT.

### 15.4.2 Ethical approval

The Human Research Ethics Committee at the University of Sydney was approached in early February 2007 (prior to commencement of the RCT) to slightly revise the approved RCT protocol in order to accommodate this subsequent study. This application was approved without amendments, and it allowed us to modify the Participant Information Statement for the RCT to state that participants in the trial might be approached after follow up and invited to participate in an interview. The HREC was applied to later in 2007 for approval of this qualitative study, and was approved by the Human Research Ethics Committee of the University of Sydney in November 2007. The HREC required minor amendments, such that we state the duration of the interviews and modify the format of the telephone numbers on the Participant Information Sheet.

### 15.4.3 Sampling frame and process

The RCT participants were young people (16 - 25 years) from all over Australia, in metropolitan and rural areas. The final question in the follow-up questionnaire in the online RCT was:

THANK YOU FOR PARTICIPATING IN THIS IMPORTANT STUDY. Please feel free to email us if you would like to offer any feedback about the website or the study.

Would you be willing to be contacted by email or phone to participate in an interview about your views on Chlamydia and other STIs? By answering yes, you are not agreeing to participate, but only to being contacted by email or phone. Participation in an interview will only occur after have been given more information and give full consent.

Yes, you can contact me by email or phone to discuss participation in an interview about my views on Chlamydia and other STIs.

My preferred email address is (if different to the one we have): My phone number is:

No, I do not wish to be contacted about an interview

I'm not sure, ask me again later (if you tick this box we will send you an email in a few weeks)

All young people who completed the follow up questionnaire were invited to participate. A sampling frame was drawn from those who said 'yes' or 'maybe' and sampling was intended to be purposive. It was thought that by including young people who had had different experiences within the RCT (personal email interactions compared with monthly impersonal emails) as well as those who had sought testing and those who had not at follow-up, a breadth of perspectives about STIs and about chlamydia testing would be gained. It was hoped that 10 - 20 young people from each of the Intervention and Control groups would volunteer, and that about half from each group would have achieved the primary outcome (reported that they had had a chlamydia test) and half would not have. It was also hoped that some males would volunteer. The desired final sample size was 20 - 40.

Participants were offered \$30 to reimburse them for travel and other expenses.

Three hundred and twelve young people (of 704) who were enrolled in the RCT completed follow up. One hundred and forty-two said they would be happy to be contacted about

participation in the qualitative study, 60 said maybe, 91 said no and 19 did not respond to the question.

### 15.4.3.1 Final sample – from purposive to convenience

Although 142 young people expressed willingness to be contacted, only 27 lived within a 2-hour drive from Sydney. As there were no financial resources available for travel costs, I also explored the feasibility of audio-recording of telephone interviews. There were no technical supports or resources to achieve this either.

The 27 young people living within a 2-hour drive from Sydney were emailed first, regardless of which group they had been randomized to. The initial email invitation was sent in June 2008. The time from completion of the RCT to receiving an email invitation for interview ranged from nine months to one week. Of the 27, 16 did not reply, 2 declined as they had changed their mind, and 2 were busy or travelling and willing to be contacted later. Seven were sent the Participant Information Statement and agreed to be contacted to organize an interview. Second emails were sent to those living in greater Sydney who had not replied initially, but did not elicit a response.

Thus the final sample was a convenience sample of 7 young people. I did not try to recruit more participants as I did not have the required resources (time, money, technology).

## 15.4.4 Pilot interviews

Interviews were piloted among 2 youth consultants (both female, 17 years and 25 years). Their data was neither recorded nor included in analysis. Feedback from the pilot interviews helped me in better explaining and framing the interviews with study participants. The link between the interview and the RCT was an important one to make, as was explaining the contribution that participation in the study could make to youth sexual health. A few questions were refined, with prompts added, where the youth consultants found them to be too vague.

## 15.4.5 In-depth interviews

The in-depth interviews were conducted in a private office of the University of Sydney at either the Camperdown or Westmead campus.

The interviews were guided by topic prompts but were essentially unstructured, allowing the young person to talk about their experiences freely. The interview guide can be found in **Appendix I.** 

Interviews were digitally recorded and handwritten notes were taken during interviews or made immediately afterwards where I felt the need to note my observations of the interaction, my or the young person's non-verbal cues or to comment on my own techniques in interviewing. I transcribed three interviews, and four were transcribed professionally to save time. However I listened to all 7 audio-files again after transcription to check for errors.

## 15.4.6 Analysis

The units of analysis were the transcripts of young people's speech during the interviews. The digitally recorded interviews were saved as audio files and transcripts were initially read while listening to the audio files. Subsequently, only the transcripts were read. Each transcript was read at least four times, and some sections of some transcripts were read many times.

Notes describing initial emergent themes were made on first and second readings of each transcript. These initial themes were then categorized using simple thematic analysis. These initial categories included themes exploring motivation for participation in the study, reactions to the emails/ intervention, experiences of health services and STI testing (including barriers and facilitators), and attitudes and beliefs about STIs more broadly. This process allowed me to become familiar with the data.

By my third reading of each transcript, I tried to look at the data differently. I found it easier to follow simple guidelines (although somewhat non-Foucauldian!) suggested by practitioners of discourse analysis,<sup>362,365</sup> by asking the data:

- what is the young person representing as 'truth' and how do I know this?
- How are they constructing this 'truth'? What is being said and what is not being said?
- How does their construction of truth allow or deny the young person an identity, or an action?
- Where does the young person position themselves in relation to their constructed truth?
- How and when has that position shifted? Is there any resistance or struggle?

My associate supervisor read four transcripts and we met to discuss these as well. These discussions focused on discourse analysis, addressing the young person's subject positions and areas of struggle or resistance.

Data from the first part of the interviews, about participation and experiences of email interactions, were also analysed using simple content analysis. This intended to provide feedback about the feasibility and acceptability of an internet based intervention.

The transcripts were also imported into NVivo. Only NVivo's most basic utility was used as a peripheral tool for organizing the data under theme and subtheme headings by creating tree and child nodes. This made it easier to subsequently search the data.

The results of my analysis of the seven in-depth interviews will be presented under sub-headings of content analysis, major themes and young people's discourses about STIs.

# CHAPTER 16 RESULTS (IN-DEPTH INTERVIEWS)

To keep the body in good health is a duty, for otherwise we shall not be able to trim the lamp of wisdom, and keep our mind strong and clear. Water surrounds the lotus flower, but does not wet its petals. - Buddha

# 16.1 Profile of the participants

Seven young people (5 female, 2 male; age range 18 - 25) participated in face-to-face, in-depth interviews which were digitally recorded. Six of the seven had been allocated to the Control group and one to the Intervention group. Six were born in Australia; of these one had Spanishborn parents and another had one Malaysian-born (Chinese) and one Australian-born parent. The others all had Australian-born parents. One was born in Malaysia but had Australian-born parents. One identified as Aboriginal. All spoke English at home. Each interview lasted between 60 and 90 minutes.

to use a name, and so they will subsequently be referred to by their interview number.								
Interview	Gender	Age	Sexual	Allocation	No.	History	Chlamydia	Chlamydia
no.			identity		sexual	STI ever	test in past	test in last 6
					partners		6 months at	months at
					ever		baseline	follow up
I1	Female	25	Heterosexual	Control	3	Yes,	Yes, positive	No
						chlamydia		
I2	Female	18	Heterosexual	Control	5	Yes,	Yes, positive	Yes,
						chlamydia		negative
I3	Female	18	Heterosexual	Control	1	No	No	No
14	E 1	01	TT . 1		2	N/	X7	X7
I4	Female	21	Heterosexual	Control	3	Yes,	Yes, positive	Yes,
						chlamydia		negative
15	Male	20	Heterosexual	Intervention	1	No	No	No
				(did not				
				engage)				
I6	Female	25	Heterosexual	Control	3	No	No	No
I7	Male	21	Gay	Control	4	Yes, HPV	No	Yes,
								negative

The table below describes the profile of the seven participants. None of the participants wished to use a name, and so they will subsequently be referred to by their interview number.

# 16.2 Experiences of participation in the study: content analysis

The first part of all interviews enquired about how the young person discovered the *getcluedup* website, their views on the website itself (content and style), and why they decided to participate in the study. Their experiences of receiving emails over the six month study period were also explored. Their responses as transcribed were subjected to content analysis.

# 16.2.1 Accessing the getcluedup website and participating in the RCT

Two young people actively sought information on the internet due to a recent diagnosis of chlamydia, and the *getcluedup* website came up in their search. Another was also searching for information about STIs due to concern about symptoms (but who did not have an STI). Three of the young people (including both young men) received emails with a link to *getcluedup* via work or educational networks. These emails were associated with promotion of the study that occurred through web-based strategies outlined in Chapter 8.4. One young person found *getcluedup* through a friend's myspace page, which was serendipitous, as she had had a diagnosis of chlamydia one month earlier.

The young people interviewed found *getcluedup* accessible. Most stated that the information was simple, 'not intimidating' and provided useful and relevant knowledge ("*it woke me up*"). One young person stated that some of the text was too technical in some parts. The name and appearance of the website made it feel 'young' and one described it as 'funky'.

There was a range of reasons cited for participation in the RCT. Some young people expressed a desire to be 'helpful' or to 'contribute' to a bigger cause, often expressed in overt altruistic terms:

"...I thought well you know maybe I could like help maybe with all the information I'd been given maybe I could give something back..." [12, Female, 18 years]

while others expressed a more 'passive' approach, a sense of 'why not':

'...[I] thought there's no harm in getting involved in this, it seemed really simple... it seems really harmless... [I] just jumped on board...' [I1, Female 25 years]

The decision to participate appeared to be associated with curiosity about the questionnaire and its perceived relevance to them. The chance of winning a prize (either an iPod or aa CD voucher) was mentioned as a partial incentive by two of the young people.

### 16.2.2 Experience of receiving emails as part of the RCT

One young person of the seven interviewed had been allocated to the Intervention group, and he had not engaged in email interaction (zero responses throughout the study period to personalised emails). He described receiving personalised emails as '... *a little bit weird, but ... it's all confidential... it didn't worry [me] too much.*" He was aware that the email sender was a sexual health nurse.

The remaining six people interviewed were from the Control group. All of them stated that anonymity was important in deciding both to participate and to remain in the study. The monthly email reminders over the study period were perceived as creating a connection between them and either a clinician, researchers or a group of other anonymous young people. Emails occupied a space that felt safe and trustworthy, they represented an entity that was caring and professional yet remained unknown, and the young people had no desire for the email sender to become known. The monthly impersonal emails functioned in a variety of ways:

#### Utilitarian:

"...they were just sort of like you know here's just a little reminder and you go thank god my brain couldn't have remembered stuff" [I2, Female 18 years]

"...[emails were]... just reminding me that there was another part coming up, and I think it told me when as well, which is good, so I knew." [I7, Male 21 years]

Created a sense of connection to the study: *...I remember getting...just this email every now and then. I quite liked it.*' [I6, Female 25 years]

"...even though it was impersonal it was a bit of a 'hey we're still thinking about you, this is still going on, don't completely drop us off your radar', so that was good...' [I3, Female 18 years]

The young people found email an acceptable form of contact from a health professional about sexual health. All six young people from the Control group stated that they understood that credible health professionals were involved indirectly, but they were not sure whether the emails they received were automated or not. This ambiguity created a safe distance between their sexual health issues and the 'real' professional:

"...it was just like, like having this informed friend there but via the internet..." [I2, Female 18 years]

## 16.3 Major themes

After two to three readings of each transcript, major themes emerged. These themes were discussed with my associate supervisor, who had also read and analysed four of the transcripts. These themes emerged independently of my analysis of discourses, but also intersected with the young people's subject positions. I found the themes another useful way to understand the data.

### Proximity and distance

*Proximity and distance* was a recurring theme throughout all seven interviews. The anonymity of emails was an important factor in creating a safe distance while feeling connected to the researchers.

*Proximity and distance* emerged as a theme in relation to young people's discussions about STIs. Most young people first learned about STIs through school education programs, where the information presented was seen as formal, which in turn made it distant. Young people's roles were as passive learners, content was part of a larger mass of academic knowledge that had to be learned but was distant, impersonal or irrelevant. Other early sources of STI information came from teen magazines and books. Information from school was seen as irrelevant and distant because young people were not engaging in any sexual activity, rather than because of the content and its delivery. This reinforced a sense of distance between STIs and young people's real lives.

Young people formed understandings about connections between STIs and sexual activity from a young age. As young people or their friends began to encounter personal experiences of STIs, notions of *proximity and distance* became more prominent. They either perceived, or actively placed, themselves as proximal to or distant from information and/ or discussions about STIs and sought information about STIs privately and anonymously – distance between them and the informant was important. The young people were more comfortable discussing STIs with close friends than with sexual partners and took up a subject position of *caring for others* in doing so. This position itself created a safe distance from the 'reality' of STIs, while simultaneously making

STI information and help-seeking more proximal for them through the care of others. Discussing STIs with parents or family members was uniformly absent and unacceptable. The medical consulting room was seen as the most appropriate place to get personal information and advice about STIs, but even within the confidential confines of a consulting room, proximity and distance played out. Where doctors were perceived as 'distant', discussion about STIs remained absent, incomplete or unfulfilling; where doctors were perceived as able to be 'close and personal', discussion about STIs was able to take place more freely.

STIs were unanimously constructed as negative entities in young people's lives, regardless of their proximity to or distance from them. However as young people's proximity to STIs increased, their struggle to resist these negative beliefs led to all of them taking up a new subject position of *caring for self*. This struggle came only with a personal diagnosis or perceived need for an STI test, where no such need arose, an STI diagnosis remained a source of shame either through 'stupidity' (not caring for self) or 'un-morality'.

### The deeply gendered nature of STI stigma

The young people interviewed unanimously attributed the negative beliefs that they, and other young people, and society at large, have about STIs to sexual activity itself. They perceived that sexual activity among young people was taboo, and STIs were a product of this taboo, only more intense - a reinforcement of the shame of being young and sexually active. These beliefs were deeply gendered, being female and sexually active was more uncomfortable for society (and young people themselves). All seven young people held these beliefs about gender.

I think women have more of a stigma and... if they've got STDs then they might seem that they're promiscuous and that's bad for women only...' [I6, Female 25 years]

#### The multiple subjectivities of STIs

Young people produced subject positions for individual STIs. For only one young person were STIs seen as the result of a microorganism infection that could be treated or managed. For all others, each STI had particular meaning, all negative. These positions were influenced by physical manifestations of the infections, their curability, and their historical associations.

# 16.4 Young people's discourses about STIs

The analysis presented here derives from an assumption that the young people interviewed have played an active role in producing their own subject positions through discourse.<sup>122</sup> These subject positions involve the construction of an identity as well as a 'way to exist' meaningfully and truthfully in the particular time and space during which the interviews took place. These subject positions illustrate the choices that young people are able to make as they produce and reproduce discourses.

# 16.4.1 The safety-risk (medical) discourse

All seven young people constructed meanings about STIs through the discursive field of medicine. Furthermore, this was a dichotomy, where one took up a position of being 'safe' or being 'risky'. This dichotomy contributed to the sense of absolutism that the medical discourse held for each young person. The truth-bearers within the safety-risk discourse came into each young person's life at different stages of their adolescence – prior to this, STIs were not part of any discourse. The first point of contact for most young people with the safety-risk discourse and STIs was via school curricula and teachers. These truths were disseminated in formal and impersonal classroom settings, and perceived by most of the young people as irrelevant to their personal lives. Despite describing their experiences of learning as passive, each young person clearly retained basic information, including the 'single truth' about risk and safety being mediated through condom use, which suggests that their earliest constructions of STI meaning were formed through active academic engagement at some level.

Despite the absolutism of the safety-risk discourse, when probed, most young people believed that this was gendered and that males were privileged over females. Even for the most rigid adherent to the safety-risk discourse [I3, female 18 years], there was a concession that young women might not always have the power to negotiate being safe (by insisting on male partners wearing condoms):

"... guys have to wear [condoms] ... even though I've heard all these messages about all bad things can happen to me and I'm the one who has to be in control - in the moment of passion, he can refuse. And... a lot of young women, myself included, aren't necessarily likely to say no if he turns. And there is also the fact that guys are still on average bigger than girls... you are unconsciously aware of, "He's bigger than me. He can overpower me." And I could get stuck... Which is a big fear thing I think and it's hard because there is so much more responsibility placed on girls and yet to a certain extent the choice is out of our hands. We can only do so much.'

[I3; Female, 18 years]

The young man who identified as gay described gay young men as being privileged compared to heterosexual young people when it came to the safety-risk discourse:

I think with a same-sex couple, there's no, "Who should bring the condom?" Because you just both bring the condom... in terms of whose responsibility it is in the first place, it's just both people. Whereas I think with a heterosexual couple, they're more, "I don't want to bring the condoms, because then it looks like I'm trying to come onto him," and the guys like, "Well, I don't want to bring the condoms because she thinks I'm trying to come on to her and she's going to get the wrong idea." [I7; Male, 21 years]

As each young person progressed through adolescence and began to encounter their own sexual experiences, medicine remained a prominent, although not the only, discourse surrounding STIs. Truth-bearers expanded to include mass media (such as magazines, health promotion advertisements and campaigns) and doctors, who were regarded as the most privileged practitioners of the truth. As young people matured beyond school years, concepts of safety and risk expanded beyond the condom, to include being tested for STIs by medical professionals, who would verify your status as one who was 'safe'. For some young people, STI testing provided a 'second chance' at reinforcing their position as a 'safe' person. The singular condom truth was found to falter in producing a 'safe person' all the time, which meant that other producers of safety had to be found. Testing tied STIs ever more firmly to the medical discourse.

"...it's great that the message is getting out there now, that yes, you wear condoms when you're having sex, but that it's not the only thing that protects you... I think that [getting tested] needs to be pushed a lot more...that that becomes part of the next culture. You wear condoms and you get regular check-ups." [15; Male, 20 years]

Some young people took up the mantle of truth-bearers themselves and became champions of the *safety versus risk* discourse. All of the young people to some extent took up a subject position of 'caring for others' by disseminating the safety-risk truth. Some constructed identities as educators, even authorities, on the safety-risk medical discourse while others took up identities as confidantes and facilitators. For many the subject position of caring for others evolved after a personal diagnosis of an STI.

Myself, I did know a fair bit. But I'm different, though, had a different upbringing. Sexual health in itself has been drummed into me from a very young age, but just because I have a lot of mates out doing a lot of stupid things, and I try to go 'No, it doesn't work like that'" [15; Male, 20 years] It's definitely nice to be able to kind of pass my knowledge on, because ...it would to have been nice for someone to have pointed that out to me. I don't really see it as my role ...it's more I'll tell them about my experience... so to them it's not so much ...actively teaching them. [I4; Female, 21 years]

While the medical discourse allowed young people to take up positions of safety and risk, these were not free of judgement. Young people who were not 'safe' could be labelled as 'stupid':

'I have a lot of mates out doing a lot of stupid things, and I try to go, "No, it doesn't work like that."'

[I5; Male 21 years]

For one young woman, this subject position was particularly rigid:

*[STIs are] Infections that happen through sex... when you've been stupid enough to not use condoms and let it happen to you... I mean I am not religious at all, but I guess it is ,,.the biblical idea of punishment for not thinking about it right?* [I3; Female, 18years]

After further probing, she did shift a little and conceded that sometimes other factors influenced young people's decisions, including people she knew:

"...with physical things because you know how to not jump off a cliff for example. You know how to not paralyse yourself. There's a survival instinct. With sexual stuff there is an element of desire and also possibly intoxication. I know a lot of my friends have been in that experience..." [13; Female, 18years]

In summary the medical safety versus risk discourse was dominant, and all young people took up subject positions of being, or aspiring to be, safe.

## 16.4.2 The morality-shame discourse

All seven young people described a discourse that centred on *morality and shame*. In this discourse, a diagnosis of an STI implied some degree of immorality about the person diagnosed, who was then shamed by others, or who should feel ashamed of themselves. This discourse had multiple and ever-shifting subject positions; it was evident that almost all the young people had tried or were still trying to resist their own subject position that placed *morality and shame* at the heart of an STI diagnosis.

The shame associated with STIs were linked to, and an extension of, the immorality and shame of young people's sexuality generally. This was seen as a societal issue, something 'external' to the young people, yet it impacted on their identities as sexual beings as they struggled to find subject positions that did not make them feel morally wrong. There was a sense of being misjudged:

'They [in adult society] feel that we're all very promiscuous and all going out for one night stands and that kind of thing. And that's not necessarily the case.' [15, Male 20 years]

For some, it was possible for someone's behaviour to be immoral, without the person themselves being so; this was particularly true for young women:

"...I'm not against going out and you know having fun but within reason... don't do it all the time, like but that's just my moral value systems, you know someone else's idea of.. having fun might be doing it every single night but you need to acknowledge the fact that...females who are just sexually liberated who just don't give a fuck what anyone thinks... as a result of that, like I've heard people put them down...' [I2, Female 18 years]

For two of the young women, morality was closely tied to religion. Although neither of these young women practised religion, they believed that their views about STIs had become entrenched in the religious-morality discourse.

"...I'm not a very religious person, pretty much an atheist but... there's still...if you're being brought up in a certain religion ...there's definitely a stigma there... and you feel that Catholic guilt...' [11, Female 25 years]

"...I had a bit of a religious school as well so they were a bit that it was wrong to have sex before marriage and stuff..." [I6, Female 25 years]

The *morality and shame* discourse was deeply gendered, yet for all seven young people this was a source of ambivalence and discomfort. It was generally acknowledged that there was a double standard, that women with an STI were more immoral, or shameful, than men. For example, I3 described herself as a feminist and decried the 'hangover from the 1950s' that she believed subjugated women yet acknowledged that even she was more likely to attribute shame to a female than a male:

"...[there were] two friends, they both cheated on each other... but my male friend was still kept as part of the friendship group... she was certainly blackened more because she'd had sex with another guy... one of the crucial things that came into deciding that ... was she'd had unprotected sex... I don't think we ever inquired the same question about our male friend." [I3, Female 18 years]

For one of the young men interviewed, there was an attempt to deal with this ambivalence by creating a temporal distance and reflecting on attitudes of peers from school days (three years earlier):

"...as a boy -- this is where the double standards really come out -- as a popular guy, then you'd be sort of put up on people's shoulders for promiscuous behaviour. But as a popular girl, the tall poppy syndrome cut in so fast. As soon as there was any talk of you being promiscuous, or rumours about pregnancy or STI, then you were just gone." [17, Male 21 years]

Being sexually active and female was likely to bring your morality into question, but this could be mitigated by being safe when it came to STIs – buying into the medical discourse:

"...I know a girl who does it [has sex] just to get the attention off the guys... she... refers to herself as a slut. I know a mate who goes home with a different bloke every weekend but she's in control. .. and always wears protection, doesn't have that mentality around it, you know, no one so much as questions it.' [15, Male 20 years]

In fact, for some young people, the diagnosis of an STI brought equal shame on males and females, and this was linked to the separate medical discourse of safety versus risk. Thus, both males and females could be equally 'stupid':

'The whole thing about 'guys sleep around more' and that's more acceptable, I don't think that [that notion]... correlates with as a male, having an STI [being] more acceptable, I don't think it's like that...'

[I4, Female 21 years]

Morality and shame could also be mitigated by age and maturity:

Probably, when I was younger there would be more of a stigma... I have felt a bit more, like maybe they [young people] are promiscuous, a little bit more that way, or judge that anyway.' [I6, Female 25 years]

"... you see [STIs] differently, you've got a more mature attitudes towards sex and issues involved in it and I think with time you have more experiences and people around you have had more experiences." [I4 Female, 21 years]

Within the *morality and shame* discourse, young people found ways to resist being positioned in negative ways by carefully choosing others with whom they could discuss sex and STIs and gradually rejecting notions of guilt, shame or immorality. Interestingly two of the young women expressed the view that gay men were particularly good people to confide in about STIs, as they were knowledgeable about STIs and often more responsible about STI protection. Young people were beginning to resist gendered discourses of shame by rejecting 'girls are sluts, boys are studs' labels and replacing these with notions that young women are more trusting (and therefore vulnerable), and conversely are better at taking care of themselves (and therefore more open). However all young people still remained with the struggle to a greater or lesser extent.

# 16.4.3 The contamination discourse

The contamination discourse was also universal among the seven young people. It was distinctly separate from the morality-shame discourse, in that it was specific to STIs, and did not pertain to sexual behaviour more generally:

'STIs were like, "Oh yuck. How gross." Whereas pregnancy was like a big giant 'oops' at the end of the night.' [I7, Male 21 years]

The contamination discourse positioned young people as 'dirty' or 'clean'. 'I remember that it [having an STI] was about being sort of dirty. Not so much... about ... sluttiness or promiscuous behavior. But it was more like dirty ... I guess...' [17; Male, 21 years]

I felt sort of dirty and weird [asking for an STI test] ...' [I6; Female, 25 years]

In the contamination discourse, contagiousness was important, but could take on a mythical quality.

"...a lot of people aren't informed and they freak out because they think you're contagious or they don't know what's going on with it you know it's kinda just like don't treat them like a leper sort of feeling that's the embarrassment. Like leprosy, it's equal to leprosy." [12; Female, 18 years]

The contamination discourse was also gendered, although not as strongly as the morality-shame discourse:

"...females don't want to be seen as you know this contaminated thing and it'd make them you know unpleasing to other partners whereas males are just like 'neh! It's nothing, you know, my body will get over it' it's like a cold, they're just really nonchalant about it and they'll continue to give it to other girls ...' [I2; Female, 18 years]

# **16.5** Subjectivities

Subjectivity' refers to that aspect of an individual's psyche by means of which the person identifies themselves and their place in the world. This entails the person 'inserting' themselves into a particular 'subject position' within a chosen 'discourse'.

Chris Weedon, Feminist Practice and Poststructuralist Theory, 1987 <sup>366(p.71)</sup>

### 16.5.1 STIs have their own individual subjectivity

The young people produced subject positions for individual STIs. While on the surface, STIs collectively represented 'risk', 'shame' or 'contamination', when probed, it emerged that not all STIs were equally negative. Different STIs had different meanings. Interestingly, when describing individual STIs, the medical discourse often loosened, or even vanished, being replaced in some instances by concepts that were vague but powerful. This was true for syphilis and gonorrhoea, the latter simply because of its name.

"...syphilis ... I think of myself of a bit of a wench... obviously there's medieval connotations of no not very pleasant connotations ...' [I 1; Female, 25 years]

There's gonorrhoea, yep sure is! I don't know enough about the illness see I would probably have to go look it up but the name in itself is not a pleasant one you know... gonorrhoea might be used in a joke and therefore you know it's got this kind of icky connotation to it in fact I actually got teased got my name rhymed with it and along with a few other medical terms um so yeah I just don't have a pleasant kinda connotation I don't think you can.'

[I 1; Female; 25 years]

'Gonorrhoea... I don't know much about it to be honest but even the word sounds ...gross.. it sounds like diarrhoea, it's just not a nice sounding word! I don't know much about it.' [I 4; Female, 21 years]

The contamination discourse became more raw, or base, for some STIs. STIs that were associated with visual skin lesions (warts, genital herpes) were more 'gross' or 'disgusting'

I guess there are stigmas about different ones - like having crabs or the warts. I think warts would be a bit more embarrassing for me. It just sounds like a bit more disgusting.' [16; Female, 25 years]

I think it's a bit gross, I'm kind of cringeing. I think because, like genital warts and stuff, it's like a visible thing, it's something that's external, it's something you can see...' [I4; Female 21, years]

Chlamydia had a double meaning for most of the young people. It was the STI that they were all familiar with, and most acknowledged that it was 'preferable' because it was invisible, curable and preventable. On the other hand, its invisibility made it more ominous,

"...it's kinda like the better std because there's no symptoms but it's also the worst one because of that you kinda like 'well you know I could have it and I could not know and it could be really bad' [I2; Female, 18 years]

It's the long term damage and the no visual symptoms ...what if I did have it, what damage could it be doing?' [15; Male, 20 years]

All young people had heard of HIV/ AIDS and nominated this as the 'ultimate scary' STI, although this perception was historical and based on memories of media campaigns about 'bowling balls' and the grim reaper. Despite these powerful memories, the young people were less concerned about its seriousness in their own lives. Even for the young gay man, HIV was an STI that could be 'managed' if someone had it.

The young gay man was the only young person who did not give different STIs different subjectivities. Except when he was younger, when he felt that HIV was the STI that gave him part of his sexual identity:

'I was under the impression that HIV was for gay men, and I was coming to terms with the fact that I am a gay man, and that's my STI. How exciting! And then so it turns out that that's not the case.' [I7; Male, 21years]

### He summarised STIs in the following way:

'Herpes is a strange one ...everyone's very concerned about herpes.... Herpes is a big deal. People cry when they get herpes.... It's just a cold sore... HIV obviously has a stigma, and I look at chlamydia and gonorrhea ...Not too concerned. Pubic lice is annoying, I think. That went around our peer group for a little while, so I feel like, "Boo." Warts - No, it's just warts. It's just herpes, but with warts.' [17; Male, 21years]

# 16.5.2 STIs, care of the self and care of others

When, in the practice of the care of the self, one appealed to another person in whom one recognised an aptitude for guidance and counselling, one was exercising a right. And it was a duty that one was performing when one lavished one's assistance on another, or when one gratefully received the lessons the other might give.

-Michel Foucault<sup>367(p.53)</sup>

A personal diagnosis of an STI was a transformative event in many of the young people's lives. Initially an STI diagnosis represented a critical incident in their sexual relationship(s) that brought into question issues such as trust and fidelity.

It can happen to you. It can happen to anyone. I trusted him, but trust is nothing if they lie to you?

[I5 (quoting a close female friend)]

'It depends on the couple, if you honestly have trust and you know that there is no one else and there is no possibility of that then you could possibly come you know to terms with that, it's very hard if you have got a bit of a suspicion though.' [I1; Female, 25 years]

An STI diagnosis also forced a re-evaluation of the young person's subject position/s within all the discourses they had constructed around STIs. This also held true for young people who had had at some point worried that they might have an STI, or who had a friend or relative with an STI.

Most of these young people, including all who had had a diagnosis of chlamydia, had taken up a new subject position of *care of the self*. These young people reconciled themselves with their previously held positions of being 'safe', 'moral' or 'clean' by discovering that they could be responsible and ethical people through caring for themselves.

As I2 found, 'It's my own health hey I think like that's just my maturity and responsibility for myself kicking in I'm just like um well no one else is going to look after my body for me so I'm definitely gonna go and take care of it.' [I2; Female 18 years]

For I6, after worrying that she had had an STI (but had negative tests), she felt that she had developed:

*"more respect for your own body and your health and understanding that sexual health is part of your complete health and there's nothing wrong with looking after your body."* [I6; Female, 25 years]

*Care of the self* involved deeper resolve to practise safe sex (using condoms) and get STI testing, it buried the young person deeper into the medical discourse. The limitations of condoms and STI testing were acknowledged however, but care of the self could extend into magical thinking:

'I've recently become a big fan of learning to heal yourself so I was like, I'm not even gonna contract it so it's not even an issue I refuse to get this [cervical cancer] vaccination? [I2; Female 18 years]

To care for one's self, one also had to care for others, and this was true for all seven young people. Like care of the self, care for others involved positioning oneself within the medical discourse, and usually encouraging friends or peers to seek medical advice. Personal experiences were shared to demystify and destigmatise the experience of seeking STI testing.

It's definitely nice to be able to kind of pass my knowledge on, because it would have been nice for someone to say "Do you know how many people these people have slept with and do you know how many people those people have slept with?", do you know what I mean, it would to have been nice for someone to have pointed that out to me." [I4; Female, 21 years]

I1 offered advice to a friend who stated that she trusted her partner and did not need to worry about STIs:

'And she started to think a bit more about those things and the week after that went and got an STD check I gave her my situation last year and she got the courage to go the GP and get a test done and she was clear which is lucky but she's starting to rethink the condom use, definitely, definitely.' [I1; Female, 25 years]

I try and pull them [friends] up on it [unprotected sex], but ultimately it's their decision and I can't force them into anything, but saying "they're mates, always look out for them" whether it's a bar fight or they're getting lucky'. [I5; Male, 20 years]

# **16.6 Discussion**

Despite the small sample size, which was disappointing, the data was rich and there were three clear and dominant discourses about STIs: risk-safety, morality-shame and contamination. *Care of the self* emerged as a dominant subject position that all young people took up to some extent, and

did so across discourses. *Care of others* was a natural corollary to care of the self for all young people, for some this took place in intimate discussions with friends and confidantes, for others they became champions of the truths about STIs. Proximity and distance, gender and multiple subjectivities were themes that cut across all three dominant discourses.

It is unfortunate that only one young person had been allocated to the Intervention group. The six young people who were interviewed and who had been allocated to the Control group described receiving impersonal emails as either neutral or reassuring and expressed the view that anything more personal might have felt intrusive. This was interesting in view of the fact that in the RCT, young people who engaged in the Intervention group were more likely to complete follow up and to have had a chlamydia test at follow up. This probably reflects the preferences of different young people, with the main cautionary tale being that for some young people, personalised emails could be seen as intrusive.

It would also have been good to have interviewed young people of diverse sexualities, as the one gay young man did present subject positions that appeared to differ from the other six young people (in relation to the privileging of gay young men and condom use and in relation to the subjectivities of STIs in particular).

Cultural background did not emerge strongly in these interviews. Religion (Catholicism) was raised by two of the young women, but ethnicity, Aboriginality and other cultural factors were not mentioned. This could be because all seven were either born or raised in Australia and lived in Sydney.

The dominance of the medical discourse in the lives of the seven young people I interviewed supports Foucault's ideas about how institutions become powerful by creating knowledge that is accepted as 'truth', and how this truth is then adopted, maintained and perpetuated by other institutions and individuals. Foucault described the way that 'regimes of truth' arise out of institutions (in this case medicine) and are then reinforced through other institutions such as the education system (which was clearly articulated in my interviews), the media and others. Foucault argued that there is no 'battle for absolute truth' but rather a 'battle about the rules according to which the true and false are separated and specific effects of power are attached to the true... a battle about 'the status of truth and the economic and political role it plays'.<sup>368</sup>

Further to this, Foucault's theory about discourses, power and truth proposes that they make people act, ie they influence behaviour. The decisions that individuals make that lead them to act are linked to the subject positions they take up within discourses, and these can be in constant flux, or relatively stable. Foucault also proposes that individuals 'practice ethics' - that they form an identity that makes them the 'moral subject of their own actions'.<sup>353</sup> Thus, individuals play out, sometimes constantly, ways to challenge power 'by detaching the power of truth from the forms of hegemony, social, economic, and cultural, within which it operates at the present time'.<sup>368</sup> Their discourses become the sites of power and resistance simultaneously; this could be seen in my interviews to some degree within the medical discourse and more extensively in the moralityshame discourse. The subject positions of care of self and care of others that the young people I interviewed found, suggest that these were the identities they were able to construct for themselves within discourses that uniformly held that STIs were 'bad'; ie they were able to find an ethical way to exist despite being young and sexually active and potentially vulnerable to STIs, because they would take care of their bodies and help take care of others. The multiple subjectivities of STIs is particularly interesting and has implications for education and clinical practice. A more detailed discussion about discourses, subject positions multiple subjectivities as well as their policy, practice and research implications will be found in the next chapter (Chapter 17). In brief summary however, by emphasising 'risks' associated with sexual activity, health and education professionals could be reinforcing negative discourses about shame. Instead, approaches to STIs could acknowledge the struggle young people face in resisting negative discourses about their own sexual activity. By focusing on positive concepts such as caring for self and caring for others, young people might find safer spaces to seek help and discuss STIs with their partner/s and health care providers.

Findings from the thematic and discourse analyses were published as an abstract from conference proceedings in the following paper:

**Kang** M, Hillier L. Medieval wenches and other icky connotations: how young people's constructions of sexually transmitted infections deepen our understanding of their sexual health [abstract]. *Journal of Adolescent Health* 2014; 54(2) Supplement:S65.

A copy of this abstract and a signed statement from my co-author verifying my contribution can be found in **Appendix J**.

### **CHAPTER 17**

### DISCUSSION

Seldom, very seldom, does complete truth belong to any human disclosure...

Jane Austen, *Emma*, 1815.

This chapter seeks to interpret, synthesise and bring applied meaning to the findings from this research. A discussion of the methods of both studies, including their strengths and weaknesses, will explore different approximations of 'truth'. First, how the uncontrollable nature of the internet created challenges in reconciling traditional beliefs about approaching 'truth' in randomised controlled trials, especially notions of validity. Second, how learning about young people's 'truths' can have the potential to alter those of others, particularly researchers and health professionals. I will attempt to find a place for this research within the myriad of other studies, programs and activities that aim to reduce the impact of chlamydia infection among young people, by examining what might be new or different, or adds fresh insight. I will briefly discuss the application of these findings and their relevance to local policy and practice, as well as recommendations for future research, policy and practice.

#### 17.1 Summary of main findings

The purpose of this two-part research project was to use a randomised controlled trial (RCT) conducted via a website (*getcluedup*) to evaluate an email intervention to increase chlamydia testing among sexually active young people (16 - 25 years) living in Australia, and to contextualise the evaluation by exploring, via in-depth interviews and content, thematic and discourse analyses, young people's experiences of the RCT and how young people understand sexually transmitted infections (STIs) more broadly.

The intervention, which relied on email interaction between a nurse or doctor and a young person, was effective in increasing the likelihood of chlamydia testing as long as there was engagement (at least one email response by the young person to the nurse or doctor). Where there was no engagement (and therefore no interaction), testing rates did not improve compared to the control group.

To understand what might facilitate engagement, in-depth interviews were conducted with a convenience sample of RCT participants. An insufficient number of participants was recruited to be able to adequately address this question, and it seemed that while email interaction might be

valued by some, unsolicited emails from a 'researcher' might not be valued by others. Insights were gained into understanding some of the discourses surrounding STIs that might be helpful for enhancing the relevance for young people of educational and health-seeking strategies about chlamydia, STIs and testing.

## 17.1.1 Findings from the getcluedup data

The RCT setting was the purpose-built website, *getcluedup*, which was launched in March 2007. A group of 20 young people aged 16 – 25 years provided feedback on the website's content and style during its development stage. A second group of 17 Youth Consultants provided ongoing advice and feedback to the study about website promotion, study interventions, recruitment and follow up strategies, and preliminary findings. The website had features that enabled a small amount of visitor interaction with it, such as a rotating series of quiz questions, downloadable factsheets and Contact and Feedback forms. Promoting the website occurred through various means, but securing a 'Google Grant' (allowing *getcluedup* to appear first in Google searches using a range of search terms) and having links to *getcluedup* from the *ReachOut!* website and the *Dolly* website made these the top three referral sources. Website traffic data showed that *getcluedup* averaged a few thousand unique visitors per month during the study period, which was extremely modest compared to three separate Australian State government media campaign websites about STIs which targeted young people that ran over a similar time period.

Despite the number of unique visitors to *getcluedup* each month, less than three per cent of these visitors, on average, commenced the baseline questionnaire. Recruitment into the RCT, which depended predominantly on eligible people visiting the website and then deciding to participate, was therefore slow and had to stop before the target sample of 1000 sexually active young people was reached.

By the end of the recruitment period (January 2008), a total of 856 young people (16 - 25 years) completed baseline data records that were available for analysis. Of these, 704 were enrolled in the RCT; the other 152 were not sexually active at baseline and therefore not eligible for the RCT, but were followed up after six months. The baseline data provided information about a unique national sample of young people that, compared to Census data, was overrepresented in those born in Australia, living in major cities and speaking English at home. The young people who had had sex at baseline were more likely than the non-sexually active young people to speak

English at home, smoke regularly, drink alcohol, binge drink and use marijuana and other illicit substances. Their knowledge about chlamydia and chlamydia testing was also greater.

Barriers to chlamydia testing among the baseline sample included embarrassment, concerns about confidentiality, cost, not having one's own Medicare card and transport. Yet the great majority supported the statement that they would be willing to have a chlamydia test if their doctor or nurse recommended it and most also stated that they would have a test to protect their own, or their partner's health.

Of the 704 young people enrolled in the RCT, (211 allocated to the Intervention group, 493 allocated to Control group), only 664 were included in the intention-to-treat analysis (196 Intervention; 468 Control) due mainly to invalid emails, making them ineligible *post*-allocation. This was a phenomenon unique to our recruitment and enrolment method, whereby the validity of email addresses could not be known prior to allocation.

A subset (40.2%) of the Intervention group consisted of those young people who responded to the email intervention delivered by the research nurse or by me. This group was termed 'Engaged', because they engaged in email interaction. Because it was this very interaction that was the intended intervention, a *per protocol* analysis was conducted that treated the Engaged group as the Intervention group, and compared it with the Control group. The primary outcome was a self-reported chlamydia test by six-month follow up. Secondary outcomes were selfreported changes in condom use, chlamydia knowledge and attitudes to chlamydia testing.

The follow-up rate for the whole sample was 47.3% and did not differ between Intervention and Control groups. However, those in the Engaged group were much more likely to complete the follow-up questionnaire than those in the Control group (78.2% cf 46.6%; p<0.0001). A sensitivity analysis allowed us to compare outcomes between the Intervention and Control groups and the Engaged and Control groups, and between Intervention and Control groups assuming that all those lost to follow up did, and did not, have a chlamydia test.

Of the 194 young people in the Intervention group, 40.6% reported having had a chlamydia test at follow up compared with 31.0% of those in the Control group (n=465), which was not significant (p=0.07). However, those in the Engaged group (n=78) were significantly more likely to report a chlamydia test at follow up compared to the Control group (52.5% cf 31.0%; p = 0.002). There was no difference between the Intervention and Control, or the Engaged and Control, groups for any of the secondary outcomes.

A content analysis of the emails from the young people in the Engaged group (n=78) found a surprising degree of openness among them. Questions asked by the young people were not limited to chlamydia, but included a range of sexual and reproductive health topics and many were willing to disclose sensitive and personal information. The main barriers to chlamydia testing identified by content analysis were logistic in nature such as which services were available in certain areas and what the test involved. The tone of the emails was strikingly friendly, polite, grateful, humorous and/ or altruistic (in that they wanted to assist the study). Sixty-one of these 78 young people completed the follow up questionnaire, and 32 of them (52.5%) reported a chlamydia test at follow up. However, close study of their email transcripts did not provide any particular insight into why they sought testing compared with the remaining young people from the Engaged group who did not report testing at follow up.

At baseline, 152 young people had never had penetrative sex and were not eligible to enter the RCT, however we followed them up after six months. Seventy-four (48.7%) completed the follow up questionnaire and of these, 16 (21%) had had sex by follow up. Most of these 16 sexually active young people reported using condoms mostly or always, but none had had a chlamydia test by follow up. Among the whole group at follow up (n=74), some knowledge and attitudes improved, particularly relating to how to get tested and being less concerned about confidentiality or embarrassment.

The *getcluedup* website had a quiz facility that was primarily developed to increase the interactivity of the website, but whose secondary function could have provided information about chlamydia awareness. However analysis of quiz data was unhelpful in showing any changes in awareness over time.

### 17.1.2 Findings from the in-depth interviews

Seven young people who completed the RCT were interviewed in a second study which aimed to deepen our understanding of the RCT findings and provide insights into how young people understand STIs. Six out of the seven interview participants had been allocated to the Control group, and the one allocated to the Intervention group had not engaged in email interaction. Only three of these participants had a chlamydia test at six month follow up, even though based

broadly on the sexual histories provided in the follow up questionnaires, testing might have been recommended for all seven. However the interviews (intentionally) did not probe into whether testing 'should' or 'should not' have occurred (and there may have been several reasons why it might not have been clinically indicated). Rather, the interviews sought to enquire as to how the six Control group participants perceived the monthly impersonal emails, and whether they thought personalised emails might have felt different. All six stated that personalised emails might have felt intrusive. The one participant from the Intervention group also mentioned that the personalised emails felt 'a bit weird' (and he had not had a chlamydia test at follow up). Due to the small sample, it was not possible to tease apart the factors that might facilitate testing for young people who did engage with emails compared with those who did not, or those who were not offered personal interaction via email.

There were three dominant discourses about STIs: risk-safety, morality-shame and contamination. All seven interview participants were strong proponents of the safety-risk discourse in understanding STIs. Being 'safe' was equated initially with always using condoms during penetrative sex, this was expanded to include being tested for STIs as a 'back up' measure, such as when condoms were not used consistently. The morality-shame discourse surrounding STIs stemmed from sexual activity itself, where being young and sexually active was associated with shame, regardless of STI status. It became possible to resist these subject positions of being 'risky' and 'shameful' or 'immoral' by taking up a new position of caring for self, and/ or caring for others. Individual STIs had different meanings and subjectivities, with those causing visible symptoms such as genital warts and genital herpes being mo re negative and undesirable.

Care of the self emerged as a dominant subject position that all young people took up to some extent, and did so across discourses, while care of others was a subject position that was also adopted by most participants. Proximity and distance, gender and multiple subjectivities were themes that cut across all three dominant discourses.

# 17.2 Reflection on methods, strengths and limitations

# 17.2.1 RCT methods

### 17.2.1.1 External validity

Data from the study of a nationally representative sample of secondary students surveyed in 2008 found that about 50% of students in Year 12 (17 – 18 years) were sexually active.<sup>325</sup> The national household survey of Australian Sexual Health and Relationships conducted in 2002

found the median age of first intercourse in young people was 16 years for both females and males.<sup>328</sup> Interestingly, this median age for first vaginal intercourse among heterosexuallyidentified young people increased to 17 years for females and males in the second national household survey in 2012.<sup>71</sup> Our target group was *sexually active* young people, 16 – 25 years, residing in Australia and we recruited from March 2007 – January 2008, almost concurrent with the 2008 school survey and about mid-way between the two national household surveys. 'Sexually active' was defined as ever having had penetrative intercourse (vaginal or anal). Our focus was thus on a subsample of Australian young people, acknowledging that many young people, particularly those under 18, are not yet sexually active. This differed from the other national surveys which did not exclude participants who had never had intercourse. The participation of 152 young people who were not sexually active suggests that sex, sexual health and STIs is of interest to many young people even if they have not had sex.

Our recruitment strategy and sampling method raise concerns about external validity. External validity is defined here as the generalisability of the findings to the whole target population,<sup>340</sup> and not just the study population. Our study population was the subset of sexually active young people who accessed *getcluedup*. Because both recruitment and sampling occurred via *getcluedup*, a dedicated website about chlamydia, we are likely to have attracted young people who were more interested in chlamydia, STIs and sexual health, and the sample was self-selected rather than random.

Experimental design in research and the importance of various types of validity were set out and described by Campbell and Stanley in 1963<sup>369</sup> and this seminal work remains a key reference for researchers seeking to discover whether an intervention 'truly' works or not. In recent years, commentators on experimental design have stated that considerations about and / or reporting of external validity are often neglected or sub-optimal.<sup>370,371</sup> External validity has been described as complex since it relies on a combination of factors such as eligibility/ inclusion criteria, prior knowledge of the topic being studied and how this informs generalisability, statistical considerations and biological plausibility.<sup>371</sup> External validity has been highlighted as particularly important in the evaluation of public health interventions, and renewed calls have been made for external validity to be adequately described and discussed before public health research is published.<sup>372</sup>

The generalisability of our findings was the major criticism by one (out of two) reviewers when we submitted our baseline data manuscript to the journal *BMC Public Health*.<sup>373</sup> This reviewer echoed the concerns of many critics of online research and external validity is a well-accepted limitation of online research due to factors such as self-selection bias and the absence of a clear sampling frame.<sup>374,375</sup>

However, the internet and the rapidity with which online research has occurred since the early 2000s adds new challenges to the way we conceptualise external (as well as internal) validity. In a *Lancet* paper published only 10 years ago<sup>376</sup> that presented a 'checklist for clinicians' to be able to assess the quality of the external validity of RCTs and systematic reviews, the internet as a research setting was not even listed. Similarly, the 2010 CONSORT statement's explanatory paper<sup>377</sup> gives exquisite detail about reporting all components of a randomised controlled trial, including how to describe recruitment, setting, participants and external validity, but the internet as a setting is not mentioned.

One of the main difficulties conceptually with the internet is that it is a network, rather than a single setting. Further, the internet can offer both 'real' and 'virtual' experiences simultaneously, and internet users themselves can have multiple and shifting identities. One researcher has described this as the 'multiple possibilities for arriving at the same location' in internet research and the threat to external validity that is imposed by 'networked effects'.<sup>378</sup> This phenomenon can be due to the multiple, simultaneous, electronic 'tasks' that individual internet users can engage with, such that many stimuli, influences or information sources can be reaching an individual at the same time when they are participating in online research. Self-selection is also thought to be more problematic than non-internet research because of the multiple and networked ways in which an individual can arrive at an online study.<sup>378</sup>

In their systematic review of internet-based randomised controlled trials, Mathieu et al reported that the first primarily online RCT was conducted in 2000 and published in 2006, and the first fully online RCT conducted in 2002 and published in 2003. In total there had been 50 online RCTs published up until September 2011. In their discussion on external validity Mathieu et al suggest that it is not always compromised, and can sometimes be enhanced. For example, the issue of internet access and internet use creating distinctions between a sample and a target population has become less problematic as the internet becomes ubiquitous across demographic, geographic and cultural boundaries. Indeed, internet research can allow for reach into geographically remote areas that conventional research could not. Finally, Mathieu et al state that self-selection bias has the potential to be reduced by online trials that target non-clinical populations.<sup>375</sup> Supporting this counter-argument, Murray et al suggest that self-referral to an online trial bypasses a health professional (or researcher) which can improve external validity. They also suggest that internet based health information and interventions offer convenience and anonymity which is important for stigmatised conditions and populations.<sup>379</sup>

In our RCT, promotion of *getcluedup* consisted of both systematic and *ad hoc* strategies, but even when taken together, fell far short of saturating the online 'market' of our target population. Website referral data (see Chapter 9.4) provide some information about the parameters of our sampling frame – since we know that most referrals came via a Google search (using search terms that all related to chlamydia, STIs and sexual health), and that other referrals came via the *Dolly* and *ReachOut!* websites. These latter are not sexual health websites, and *Dolly* is not related to health or health promotion. The in-depth interviews gave interesting, but limited, insight into the motivations behind participation (mainly due to the small sample size) so that we could not draw conclusions about how our RCT sample might differ from the general youth population in terms of self-selection. Over one-quarter of the sample at baseline had had a chlamydia test in the past six months, suggesting that the website or trial or both attracted young people actively seeking information about chlamydia; however three quarters of our sample had not had a recent test.

#### 17.2.1.2 Internal validity

Internal validity is the ability of a study to show cause and effect: – that an intervention does or does not lead to one or more outcomes, with minimal or no bias. Many commentators on the conduct of RCTs state that internal validity is a pre-requisite for external validity – that an intervention must first be shown to 'truly' have an effect (or not) before it can mean anything outside the study boundaries.<sup>371,376</sup> There are many components of an RCT that influence internal validity, and these are important to consider in reflecting on the strengths and limitations of our study.

#### Randomisation, allocation concealment and blinding

Randomisation, allocation concealment and blinding are procedures that can be easier to achieve in internet based compared to conventional RCTs.<sup>375,379</sup> For trials that are fully online, randomisation can be computer generated leaving little, if any, room for error. Allocation concealment can also potentially be supported in online trials if allocation is generated by a computer or web server. In our study, we had to complete a manual step before randomisation and allocation. Data from the server were downloaded into an Excel spreadsheet (see Chapter 8.12) and either a research nurse or I checked the four columns that related to eligibility criteria (age, email address, Australian postcode and whether there was a 'yes' response to the question 'have you ever had sexual intercourse?'). If these criteria were satisfied, we used a computergenerated number to allocate them into either the Intervention or the Control group. We completed these steps without looking at other data, although hypothetically we could have, since they were not 'concealed'. To remove or reduce any bias that might have been introduced in either randomisation or allocation concealment, we could have involved another person to perform these steps, however we did not have any other staff to call upon to do this. Similarly, automating the process would have required much more sophisticated technology that allowed the server or a computer program to determine eligibility. As the project manager who directly supervised the research nurse, I was always satisfied that randomisation and allocation were concealed. Blinding is potentially less problematic in online RCTs because the researchers or clinicians are likely not to meet participants face to face. In our study, nearly all participants remained anonymous or identified themselves by first name only.

### The Intervention

Our intervention was email interaction, defined as having at least one response by a participant to a personalised email sent by the researcher; this participant was then considered 'engaged'. Although interaction was facilitated via *getcluedup*, the intervention depended entirely on a separate process of engagement by the young person with a clinician by email. To standardise the intervention, the texts for personalised emails sent to young people in the Intervention group (initial email followed by weekly emails for three months for non-respondents, see Chapter 11.1.2) were based on templates written by the research nurse and me. Once the young person responded, content necessarily changed, but tone (professional but friendly) remained consistent. Our intervention was more like one in a conventional trial in that fidelity depended on the individual clinician<sup>379</sup> and our particular way of interacting on any given day or time, as well as how we might have responded to any given young person's tone, questions or comments. The research nurse and I regularly discussed these email interactions and reflected on questions and responses, to maintain a degree of consistency in tone as well as content. Our aim was to assure confidentiality / anonymity, offer clinical advice in an objective and non-judgemental manner

and answer all questions regardless of topic. Nevertheless, different young people receiving these emails may have reacted differently, depending on their own circumstances and personality.

Thus, two important issues arise in considering internal validity with regard to the intervention. First, what led some and not others to engage in email interaction? It is important to address this question, even though we felt justified to conduct a per protocol analysis comparing only the Engaged group with the Control group to measure the impact of the 'true' intervention (see Chapter 11). In particular we need to consider whether the proportion of young people in the Intervention group who did *not* engage were negatively impacted by the attempted intervention. Our one interview participant who fitted into this group simply commented that receiving personalised emails 'felt a bit weird'. However, only one in the 'non-engaged' group actively withdrew from the study during the intervention phase and no complaints or any other communication expressing a negative view were made by them or by any other study participant in either the engaged or non-engaged group. We could consider those who did not engage as 'non compliers' which introduces another form of bias<sup>380</sup> but this would be making assumptions about compliance that cannot be justified. Consenting to participate in the RCT only involved giving consent to receive emails, not an undertaking to respond. We cannot make comparisons with an RCT that involves compliance with a medication regime or other treatment program. Content analysis of the email transcripts of the Engaged group (Chapter 13) might suggest that those young people were motivated to interact because of a sense of altruism or because they had genuine concerns about their sexual health and were seeking answers. Yet the converse does not necessarily apply – we cannot assume that those who did not engage did *not* have these characteristics, rather, they may have overlooked emails, been too busy to respond, felt apprehensive/ mistrusting of the researchers, not have had any questions or wish to discuss chlamydia and sexual health in this way, or any number of reasons. Our Youth Consultants concurred with these suggestions and also advised us not to send personalised emails any more frequently than once a week. Data from the in-depth interviews in the second study were insufficient to help us understand why some young people engaged and others didn't, but the fact that several young people said that receiving personalised emails might have felt intrusive might give us some clues. Perhaps email interaction with an unknown health professional is a comfortable environment in which to discuss sensitive or personal information for some young people but not others.

The fact that the majority of young people in the Intervention group did not engage adds complexity to the design of future interventions that require an interaction in the 'virtual' world. Several alternative strategies for online engagement could be considered, but whether one would prove more effective than any other is unknown. For example, initial procedures (randomisation, allocation and initial email) could be automated so that a personalised email was sent at the point of baseline questionnaire completion, and the initial email could request a response (such as a simple acknowledgement of receipt). This would immediately eliminate most or all false email addresses, and might enhance, but would not guarantee, a response. Another option would be to be more explicit in the Participant Information Statement as well as in the initial personalised email, requesting email response, even if just acknowledgement. Even so, these automated steps might not be any more effective at engaging participants, since the act of engaging in our study required a conscious decision to respond to a 'real' person. Young people interact online constantly with 'virtual' others whom they might not actually have met face to face: friends, potential partners, people in their social networks. It is not implausible to imagine that they could engage with a 'virtual' health professional, but being cautious, sceptical or disinterested is reasonable.

The second issue relating to the intervention is that it did not offer a direct clinical service, and because our primary outcome was the self-report of having a chlamydia test in the six months between baseline and follow up questionnaires, our intervention had to focus on addressing the more intangible barriers to testing, such as awareness and knowledge about testing, embarrassment and concerns about confidentiality. The fact that the young people in the Engaged group were more likely than Controls to have had a test suggests we had some success in delivering this intervention, but it is also possible, given all the factors discussed above, that this group was more motivated or more concerned about chlamydia in the first place. This suggests another form of self-selection bias that occurred after allocation. On the other hand, the fact that none of the Controls responded to a 'Control (impersonal) email' suggests that making a personalised approach had an effect for some young people.

In hindsight, it would have been helpful to include a brief online or email-delivered questionnaire as part of the second study, rather than relying on face to face interviews, to specifically enquire into the factors that facilitated engagement.

### Data quality

Quantitative questionnaires that can be completed online can have some advantages over paper and pencil questionnaires, for example, non-responses can be reduced if software does not allow progression through the questionnaire and forces a response; and questionnaires can be designed to be easy to navigate, by having explanatory terms in pop-up boxes or by allowing steps to be skipped easily. It has been suggested that if questionnaires are designed or adapted appropriately for online use, there is less missing data.<sup>381</sup> Reliability and validity of questionnaires depend on metric properties, and to maximise these and allow for comparisons with other national datasets, all our questions about knowledge, sexual history and substance use history were taken from existing national questionnaires (see Chapter 8.11.2). Although it is likely that pencil and paper questionnaires that are valid and reliable can probably be transferred to an online format, it has been advised not to make this assumption and to assess this prior to recruitment and data collection.<sup>382</sup> We piloted our online baseline questionnaire among our Youth Consultants prior to the website launch, and although we did not formally assess reliability and validity, we were satisfied that the instrument was user-friendly, questions were easy to understand and the time taken to complete the questionnaire was reasonable.

Our primary outcome relied on self-report and could not be independently verified, and our methods have the same limitations as other studies that rely on self-reporting of behaviour that might be seen as sensitive or taboo.

#### Retention

Our retention rate was 47.3%, and online trials are reported to have lower retention than conventional trials.<sup>379</sup> A systematic review of online RCTs found the average follow up rate of fully-online trials was 53%.<sup>375</sup> Having multiple strategies to improve follow up (such as telephone, SMS or postal reminders in addition to email) have been used in some online studies.<sup>375,379</sup> In our RCT, asking for other contact details in order to potentially improve retention would have been contrary to our original hypothesis – that email-only interaction (and the perception of anonymity) would increase testing. Our Youth Consultants expressed surprise at what they considered a high follow up rate!

### Intention to treat analysis

Our decision to present intention to treat and per protocol analyses separately attracted concern and criticism by reviewers of our manuscript to the journal *Sexually Transmitted Infections*.<sup>383</sup> This concern was also linked to the retention rate which was under 50%. We conducted a sensitivity analysis (see Chapter 11.4) with imputed data<sup>375</sup> but do accept that at best our findings are suggestive of an effect but nowhere near conclusive.

### 17.2.1.3 Other issues with online research

Duplication – the same person entering a study more than once - is a potential problem with online research and is something we did encounter. Others have suggested monitoring of the Internet Protocol (IP) address using software<sup>379,382</sup> but this is not failsafe, since IP addresses can by dynamic and change with each log in to a network; alternatively, two individuals might use the same computer/ network that would record the same IP address.<sup>379</sup> In our study, we removed duplicate datasets which were recognised by email address. Most of the duplicates were consecutive, where the first dataset was incomplete, suggesting that the young person did not get time to finish the questionnaire and returned to it later the same day. There are other strategies for minimising or preventing duplication – such as removing incentives, having software that recognises when the same email address has been entered (however this would have jeopardised our study, since any data entered including just the email address, constitute a dataset), or providing unique log in details to individuals on receipt of an email address (or other 'identifier').

Spamming and cybersquatting have been described as potential problems that are unique to online research. Spam refers to mass emails that have not been solicited by the recipient, or emails that have a clear benefit to the sender rather than the recipient. To overcome legal barriers to spam, unsolicited bulk emails must have an unsubscribe facility. Emails sent as part of online research could hypothetically be seen as spam, or might even technically constitute spam. This was not an issue in our study, as our consent procedures and information statement made it clear that emails would be sent, however our Youth Consultants did caution us about the frequency of emails and how they could become perceived as spam. Cybersquatting is the practice of registering a domain name that deliberately causes confusion in bad faith, or infringes on trademarks, for the purposes of commercial gain. (www.domainregistration.com.au) . This has been described in a online study about harmful drinking in the United Kingdom, where multiple websites using the same name but with different domains drove visitors to advertisements.<sup>379</sup> Cybersquatting could be avoided or minimised by buying several domain names (eg .org .com .net). We only registered one domain name (.com.au) however to our knowledge no cybersquatting issues arose during or after the completion of the RCT.

### 17.2.1.4 Ethics

There is a 'mature minor' clause in the Australian National Statement on Ethical Conduct in Human Research<sup>384</sup> which allows researchers or clinicians to assess young people under 18 years as competent to consent to participate, and its application was very familiar to me and my coinvestigators in both clinical and research environments. However human research conducted in the virtual world without ever meeting, seeing, hearing or speaking to research participants intuitively raises ethical questions. The principles of respect, justice, weighing up benefits and risks, privacy, security of data, confidentiality, voluntarism and free choice apply equally online as they do offline, but tensions may arise with issues such as the blurring of public and private spaces, ambiguities surrounding 'personhood' and multiple identities, as well as the inability to verify information (such as age, particularly of minors, where vulnerability might be greater).<sup>385,386</sup> There is no reference to online research or the internet as a research setting in the National Statement, however it is mentioned in some individual research institutions, such as the Children's Bioethics Centre in Melbourne.<sup>387</sup> On review of our application to conduct the RCT, the Human Research Ethics Committee at the University of Sydney wanted assurances about anonymity and confidentiality, expressing concern that email addresses would potentially be identifying. We did not experience any ethical issues over the duration of the RCT.

### 17.2.2 Qualitative study reflection on methods

The overwhelming limitation of the qualitative study was the small sample size, the reasons for which were described in Chapter 15, see *Chapter 15.4.3.1*. As discussed in Chapter 16.6, this affected the ability to draw conclusions about young people's experiences of the RCT, their engagement and non-engagement with the intervention, and ultimately to understand in much more depth what the barriers and facilitators to chlamydia testing were. The other aim of the study – the exploration of meanings of STIs and discourses - would also have been enhanced with a larger sample, particularly more males and more people under 18 years. For example, broader assumptions about how young people see the gendered nature of STI stigma cannot be made, even though clearly articulated by all seven interview participants. It would also be interesting to explore how meanings of STIs change with age and experience of relationships and sex. All five young women were heterosexual, and all seven lived in Sydney. Thus geography, sexual (and gender) diversity, ethnic and cultural background and education and employment experience are all factors that could influence young people's understandings of STIs that could not be fully explored due to the small sample. It was not possible to achieve a larger and more diverse sample within the constraints of the recruitment strategy (ie via the RCT) and the study

resources (eg no capacity to travel for face to face interviews and inadequate technology to audiorecord telephone interviews). To prevent or overcome these difficulties we could have commenced the interviews earlier, that is, closer to the time the young person completed the RCT. The interview requests were made by email, and these were not sent until June 2008, regardless of when the young person completed the RCT. This was due to my own lack of time and having no further project resources. Some RCT participants in the sampling frame (ie those who indicated they would be willing to be contacted for an interview and who lived within a 2 hour drive of Sydney) had completed the RCT as early as September 2007, which meant that they had had no contact with the study for several months by the time they received an email inviting them to participate in an interview. It is possible that this time delay contributed to a lack of response to the invitation, although among the seven young people who completed interviews the dates of completion of the RCT were: September 2007, November 2007, January 2008, February 2008, March 2008 and June 2008 (x2). In addition, it would have been useful to have discussed technological issues ahead of time with IT services to explore the feasibility of telephone or Skype interviews. A study into meanings of STIs could have been conducted separately from the RCT and would be of interest in the future.

The in-depth, semi-structured interviews themselves were an appropriate method for collecting the data I was interested in, particularly in relation to STI meanings. However on reflection, it seems likely that the enquiry into engagement and RCT experience could have taken place in other ways than face to face interviews, including telephone interviews, Skype, email or chat. In fact there could have been a few questions at the end of the follow-up questionnaire as part of the RCT itself.

As in all qualitative research, analysis and interpretation are subjective, even when conducted through a theoretical framework. Analysis was enhanced by having two researchers (myself and my associate supervisor) examine transcripts together and separately.

### 17.3 Weaving the tapestry: a synthesis of findings

Despite the global reach of the internet, the practical application of findings from our studies are best understood within an Australian context: our health system, our education system and the cultural meanings that our young people attribute to sexuality and sexual health. The lessons learned from our international colleagues doing similar work can be of value where they have local applicability or where we can advocate for change within our existing systems and test new ideas. Our ultimate goal was to reduce the impact of chlamydia infection in sexually active young people. While several studies in Australia and internationally have had similar goals, there is a multitude of studies evaluating programs to address other aspects of young people's sexual behaviour more broadly that might also have applicability.

### 17.3.1 Chlamydia on the internet, decision-making and discourses

Several studies have evaluated the use of the internet as the primary means to facilitate chlamydia testing among young people; two (including ours) were RCTs, while others include uncontrolled intervention studies or descriptive studies of web-based or web-facilitated chlamydia testing strategies. Four studies, including one in Australia, evaluated the utility of a postal chlamydia test kit. In these, websites were the main vehicle for promoting the test and ordering a kit; kits were mailed, samples collected at home and returned by mail to a laboratory, and results communicated in various ways (email, logging in to the website, SMS or telephone).<sup>294,295,388,389</sup> In all but one,<sup>388</sup> there were other ways of obtaining a test kit including picking one up from various community locations (such as youth centres and pharmacies) but the great majority were ordered online. In these studies there was also a range of methods in which the kit was advertised besides a website, including print and other media. A pilot RCT in the United Kingdom has evaluated the impact on both 3-month retention rates and returned postal chlamydia test samples of an interactive website compared to a non-interactive website. The 'interactivity' of the intervention website involved quizzes that gave respondents feedback, and activities that involved entering personal information and reflecting on decisions.<sup>292</sup> Participants were randomised in three ways: into the intervention or control website groups, to receive or not receive a home-based chlamydia testing kit in the mail, and to receive a  $f_{10}$  or  $f_{20}$  voucher incentive for completing all parts of the trial. Being allocated to the intervention website increased retention rates significantly, but receiving a home-test kit significantly reduced them. This intervention was somewhat complex since it included multiple components but the study's intention is to inform a full RCT of the interactive website. The return rate of postal test kits ranged from 13.2%<sup>389</sup> to just under 65%388 with the total number of tests done never exceeding a few hundred over several months.

Two other studies, including one from Australia, involved promoting a website with downloadable chlamydia test request forms which could be taken to a participating laboratory collection centre. Results were sent back to a coordinating centre for facilitation of treatment and follow up for those with positive tests.<sup>297,390</sup> In Western Australia, over 50% of form downloads

over a 15 month period resulted in a test, with total number of 377 tests done. About 70% of these tests were among the target group (those under 30 years).<sup>390</sup> In Ottawa, Canada, 104 tests were done over a 12 month period, with just over 57% being from the target group (15 - 29 year olds).<sup>297</sup>

An intervention study in Illinois, USA used a Facebook page to deliver information and measured before and after intentions to seek testing, and local health district testing data, to measure impact. Although intention to seek testing increased, testing data showed a decline in testing over the study period.<sup>296</sup>

Most of the above studies describe similar challenges to ours with recruitment and employed a range of promotional strategies of either the website, the study, or both, including paid advertising on Facebook, radio advertising, links from other websites, Facebook pages and Twitter accounts, print advertising such as pamphlets and posters. Only the UK-based RCT found recruitment easy via Facebook, exceeding their target sample size, and achieved very good retention rates.<sup>292</sup> However it seems likely that the financial incentives contributed significantly to this, which might not be practical as a sustainable chlamydia testing strategy.

Our study differs from these others in that the intervention involved direct, targeted interaction between a young person and a health professional, and the subsequent act of obtaining a chlamydia test required conventional contact with the health system. All but one<sup>296</sup> of the studies described above allowed for the bypassing of a health professional/service either until a test result was obtained (for postal tests) or on presentation to a collection centre to submit a sample for testing (for downloadable test request forms). The key question appears to be: *at what point along the spectrum in the virtual world does the decision to have a chlamydia test in the real world occur?* Young people might order a postal test kit online or download a test request form, but might not return a sample. In the UK trial, receiving an unsolicited postal kit (albeit as part of an intervention previously consented to) had a significant impact on retention in the trial, mitigated to some extent by a substantial financial reward. Perhaps the reality of having a test requires the presence of other favourable 'conditions'. Some of the studies above explicitly describe theory-based approaches to influencing decision-making, including Pender's Health Promotion Model,<sup>391</sup> based itself on Bandura's Social Cognitive Theory,<sup>392</sup> the Theories of Reasoned Action and Planned Behaviour,<sup>393</sup> Motivational Interviewing<sup>394</sup> and Cognitive Behaviour Therapy.<sup>395,396</sup>

Despite this, the yield for chlamydia testing seemed at best modest in all these studies, including ours.

The researchers in the UK pilot RCT conducted a subsequent qualitative study to explore participants' experiences of the RCT and found that they preferred having email contact with a researcher than telephone or face to face contact. The researchers were also able to explore participants' reactions to receiving a postal testing kit and found that some found it 'routine' and appropriate while others found it intrusive and preferred to have a test at a health service. Participants sometimes emailed the researchers prior to returning a postal sample to ask whether or why they needed to submit a sample.<sup>293</sup> Thus they were able to interact with a 'real' person to discuss testing, as in our study. Being able to know which young people would feel negatively or 'intruded upon' prior to receiving a direct approach to have a chlamydia test is unrealistic in this setting, and was a lesson from our studies as well. What is unclear is whether such an approach is potentially harmful. In the UK RCT and ours, young people consented to the range of interventions, no critical incidents or complaints occurred, and there was no strong evidence from either RCT to suggest that making direct approaches about testing in the virtual world is unethical. As with our own small qualitative study, it is not clear what the processes were that prompted the decision to proceed with a test. In our study, less than half our Intervention group engaged, and when they did so, they were more likely than Controls to proceed to have a test, yet only half of them did. In many of the studies, including ours, where the information was sought, a significant minority of participants had already had experience of having an STI, or a chlamydia test, or had had sexual contact with an infected person. For those people who are testnaive and unaware or unconcerned about chlamydia risk (who are in fact the majority of our target group), any strategies need to firstly raise awareness and then attempt to shift perceptions of risk and provide motivation for reaching a decision about testing.<sup>397</sup>

Another way of understanding decision-making might be to look at discourses. Foucault's theory is that people adopt or resist discourses as a means of altering the relationships between power, truth and subjectivity and in doing so, find their own personal freedom to exist. These 'actions' require what he called 'critique', which he described as: *the movement through which the subject gives itself the right to question truth concerning its power effects and to question power about its discourses of truth. Critique will be the art of voluntary inservitude, of reflective indocility.<sup>398(p.386)</sup> In our qualitative study, the medical, or 'safety-risk' discourse seemed 'tied-down', that is, firmly held as 'truth' by all those I interviewed. However, as individual young people found themselves exposed to 'risk' (of STIs)* 

through unprotected sex, they found other ways of being 'safe' such as having STI testing. For some, educating others about the importance of STI testing reinforced the truth. This ability to care for self and care for others was the pathway to being responsible and reclaiming goodness. Although my sample was small, I was able to see some of these young people adopting what is known as "Foucauldian dividing practices" – among their peers, they had adopted the medical labels of 'risky' and 'safe' which dictated which behaviours would be accepted as 'good' and which would marginalise. This discourse was described as the dominant one concerning youth sexual health that arose out of public health responses to the HIV epidemic and has been adopted and promulgated by young people themselves.<sup>124</sup>

The findings from my interviews are interesting to contrast with those from a much earlier study in Australia, published in 1999, among homeless young people who inject drugs. In this study, young injecting drug users were similarly seen to have taken on identities of responsible people by not only adopting safe injecting practices, but by educating other young people about them. These young people were adamant about distinguishing their identities as 'druggies', who were responsible and ethical in relation to their injecting practices, from 'junkies' who were not. However these same young people had much more blurry notions of 'safety' when it came to sex without condoms, and unlike the findings about injecting practices as well as my own findings, subject positions of care of self and care of others did not emerge in relation to sexual practices.<sup>399</sup> Whether this is because of the very different samples, or temporal changes in beliefs, or both, is unclear, but both studies highlight the role that young people themselves take on as educators or 'champions' when they adopt a particular discourse – and this may have useful implications for practice.

Our findings also suggest that STI testing, which takes place outside the potentially unpredictable moment of the sexual encounter, can reduce some of the problem with gendered power relations. Women were seen as better at visiting health services than men, and this could mitigate the difficulties they might experience in negotiating safe sex with male partners, by positioning themselves as good health service consumers which in turn made them responsible citizens.

The discourse of morality and shame, which was highly gendered but also a function of being young generally, could be partially navigated by positioning oneself as a good carer of self or others, if one took care of one's health and did not put others at risk. However there were multiple contradictions in many of the subject positions described by most interviewees in the morality-shame discourse – in contrast to the safety-risk discourse which was rigid, this discourse was more 'agitated'. There appeared to be resistance and small movements within the discourse, but a prevailing sense that young people, particularly young women, are marginalised by wider society for being sexually active, and this impacted on how STI testing could be negotiated. Many of the young people interviewed would therefore describe the sexual double standard as unacceptable and sexist, while simultaneously acknowledging that they saw some young women as behaving immorally, usually because they didn't practise safe sex or seek STI testing, therefore putting their (male) sexual partners at risk; a judgement that some admitted did not apply as readily to young men. These contradictions were not straightforward, and resemble what others have also described about the sexual agency of young women as being 'free within constraints'.<sup>125</sup>

The contamination discourse was more difficult to locate oneself in, and perhaps this is because most of the young people interviewed had not had any symptomatic STIs. For six out of seven young people, STIs had their own distinct subjectivities. Those which caused visible skin lesions (HPV and HSV) were rigidly tied to a contamination discourse. Gonorrhoea and syphilis had negative associations beyond straightforward contamination, and were placed into a historical or mythical context imbued with shame or promiscuity for some, even though most of the young people admitted they did not know much about these infections. HIV was seen as serious and scary, but somehow distant or theoretical for six out of seven heterosexual young people. One gay young man described HIV as 'his disease', associated with his identity as a gay man, but saw it as the cause of a chronic illness and not linked with contamination or shame. This young man, who had had a past diagnosis of HPV infection, was unique in that he saw all STIs as emotionally neutral, and no different from each other subjectively. He associated all STIs with microorganisms than could cause symptoms or lead to disease, but they did not have any other "meaning" or connotation. Chlamydia was the STI most familiar to the interviewees, and three out of seven had ever been diagnosed with chlamydia. Whether this experience of a diagnosis shifted the infection's subjectivity or whether its asymptomatic and curable nature made it more neutral is uncertain, but chlamydia was the least stigmatised STI. Our findings concur with those of others who have found that different STIs are associated with different levels of stigma or fear with chlamydia being the least stigmatised.<sup>90,125</sup> A recent literature review of studies conducted in developed, English-speaking countries (including Australia) explored lay understandings of infection transmission. The review described key themes that resonate strongly with our qualitative findings and the way in which "biomedical models of disease transmission are subsumed into frameworks that use fuzzy dichotomies such as 'clean/dirty' and

'safe/diseased".<sup>400(p.67)</sup> As in our study, this review found that it was possible for individuals to hold 'multiple and ambivalent views outside the biomedical model'.<sup>400(p.78)</sup> Even though these authors were talking specifically about infection *transmission* and described 'magical' notions that could exist simultaneously with biomedical models of transmission, these understandings add weight to our findings about the multiple meanings of *contamination* and individual STI subjectivities.

### 17.3.2 Other settings and broader goals

Most research evaluating chlamydia testing strategies has been conducted in the real, not the virtual, world. The internet functions as a non-health setting, rather than a virtual setting, since the act of having a test must materially occur. Our RCT therefore ought to be considered in the context of a range of other testing settings within and outside the health system. These settings and their utility, feasibility and effectiveness for chlamydia testing have been described in our published systematic review,<sup>401</sup> systematic reviews of others and a literature review, in Chapter 6.4. These findings are briefly reprised here in order to locate our RCT within the body of literature on settings for chlamydia testing.

General practice and its primary care equivalents in other health systems have been acknowledged as important, if not central, settings for opportunistic chlamydia testing, due to the frequency of contact by young people with them. Indeed, our own RCT outcome required contact with the health system, mainly general practice. However the thrust of our intervention was to motivate, empower and/ or upskill the consumer, or young person, to actively seek and request a chlamydia test from a clinician by helping them overcome a range of barriers. In studies exploring testing in general practice, the central challenge has been to improve opportunistic, clinician-initiated chlamydia testing, and studies have evaluated a number of ways to influence this clinician behaviour. Several studies including ours found that young people either expect or desire that their GP (or practice nurse) offer chlamydia testing or would be willing to undergo a test if the clinician made the suggestion. The strategies most effective at increasing clinicianinitiated chlamydia testing were those which were multi-faceted and involved systemic changes within general practices, these included some but not necessarily all of: introducing practice policies, promotional materials for patients, training and awareness raising among clinicians and other staff, clinician prompts or incentives and linking testing with other preventive care such as Pap smear screening.<sup>275</sup> Our in-depth interviews reinforced the appropriateness of the general practice consultation room setting for facilitating testing and its central place in the medical discourse of safety and risk, but also revealed the importance of proximity and distance that young people experience in understanding STIs. Where there had been negative experiences of doctors (such as feeling judged, or lacking warmth), young people felt more distant from them and discussions about STIs were less likely to take place. While it seems obvious, general practice strategies for increasing chlamydia testing must include an element of interpersonal engagement where young people feel they are not being judged for being sexually active or for having an STI. Clinicians could even go so far as to explore or acknowledge the struggles young people might have within the morality discourse or the contamination discourse and help them find new ways of understanding their experiences that enhance care of self or others.

Home-based chlamydia testing has been evaluated in several studies: apart from those cited above that are facilitated through the internet, others have used population registers, such as Denmark,<sup>402</sup> The Netherlands<sup>299</sup> and Sweden<sup>403</sup> or health registers such as general practice registers in England<sup>404</sup> and managed care registers in the US.<sup>405</sup> In France and the United Kingdom, subsets of representative national household samples participating in surveys on sexual attitudes and behaviours were sent home testing kits;<sup>406,407</sup> these studies aimed to determine prevalence rather than evaluate the home testing strategy, but were able to report on return rates of postal kits. Australian studies using home-based testing were included in our systematic review<sup>408-410</sup> and various studies in other developed countries have distributed home testing kits via outlets such as pharmacies, clinics, the workplace a various other locations. Most of these studies were included in a recent systematic review (which also included some studies from developing countries).<sup>411</sup> The review found that the median specimen return rate (number of specimens divided by number of participants  $\times$  100) among all programs was 51.4%. The median testing rate (number of specimens divided by number of individuals invited  $\times$  100) was 28.8% and the median chlamydia positivity rate (number of positive tests divided by total tests  $\times$ 100) was 3.6%. However there was a wide range, with the highest participation occurring in programs that involved recruitment at home with immediate specimen collection.411 The feasibility of an organised screening program involving home-based testing for chlamydia in Australia is currently limited by cost (Basil Donovan, Professor and Program Head, The Kirby Institute, University of New South Wales, oral communication in a meeting, 7 March 2014). However there is currently a randomised controlled trial underway in Australia to evaluate the effectiveness of home based testing to increase chlamydia retesting rates among clients of two large sexual health clinics.<sup>412</sup> Should home-based testing become a feasible option for Australian young people in the future, the internet - with or without virtual clinicians available - would certainly be a useful vehicle for raising awareness, facilitating testing and providing post-test information and advice.

Other settings for chlamydia testing that have been reported include pharmacies, and a range of non-health settings such as sports clubs, music festivals, beaches and community centres. Two small studies in the pharmacy setting in Australia found reasonable acceptability among young people but low uptake, and increased workload for pharmacists despite a willingness to increase their role in primary health care.<sup>413,414</sup> The current fee structures within our primary health system would make pharmacy settings unviable for widespread chlamydia testing without legislative changes or private billing. Similarly, a recent systematic review<sup>415</sup> that examined chlamydia testing participation rates in non-health settings found, as did we, that the most successful setting was sportsclubs, targeting young men during training sessions in Victoria, achieving over 85% participation.<sup>416</sup> A recently published cluster randomised controlled trial of screening approaches with men within football clubs, conducted in the UK, also found reasonably high uptake of screening but with considerable inter-club variability<sup>417</sup> and a cost and outcome analysis of the same trial found that cost effectiveness of this approach could not be determined without further research.<sup>418</sup> While local programs such as these might achieve good participation rates as part of a focused short-term initiative, it is uncertain that widespread population level reach is feasible.

The secondary school setting would seem to be an ideal one for offering chlamydia testing, although young people's perceptions of privacy and confidentiality would be paramount. The USA has a substantial network of 'School Based Health Centers' (SBHCs) that has grown since the first ones opened in the late 1960s to having over 1500 SBHCs in over 45 states.<sup>419</sup> About half of these serve adolescents (rather than primary school aged children) and the majority of SBHC users are from underserved and underprivileged populations with inadequate health insurance.<sup>420</sup> STI testing is available at the majority of SBHCs and annual chlamydia screening in the SBHC has been found to be feasible and cost effective.<sup>300</sup> It might be argued that, with universal health insurance available in Australia, there is no need for a SBHC model, since cost appears to be the main issue for establishing and maintaining SBHCs in the USA. The feasibility of school-based chlamydia (and other STI and blood-borne virus) testing was evaluated in Australia in the Australian Capital Territory a decade ago, as part of a broader educational program, sexual risk behaviour survey and STI prevalence study. STI testing took place among consenting senior high school students within the school and follow up and treatment of students with STIs occurred within the school setting.<sup>421</sup> Despite the success of this project, it is

unlikely that the school setting in Australia will ever be adopted into a health service model. Suggestions for including high school as a setting for chlamydia screening have never gained traction in any of the Australian national or state STI strategies, and any such services would occur *ad hoc.* Schools however, could play a role in facilitating access to health services, but further, could potentially support virtual clinics that allow students to engage with clinicians online. However we found during our study that some schools had (inadvertently) blocked our website, *getcluedup*, and that education department servers have powerful filters and firewalls to protect students from inadvertently viewing inappropriate sexual material.

Schools might not currently be a realistic setting in Australia for delivering clinical services (including STI screening) on a widespread basis, but certainly could have a role to play in impacting on some of the antecedents of STI risk and protection. Schools in Australia and other western countries are widely accepted as appropriate settings to provide sexuality and sexual health education, and our qualitative study suggests that it is through the formal school curriculum that the medical discourse about safety and risk is first perpetrated. Our interview participants often found that while specific STI knowledge learned at school seemed distant or irrelevant, they absorbed and upheld the dominant discourse about safety and risk associated with STIs and condom use that came from school based education. These findings accord with those of the most recent national survey of secondary students and sexual health, where almost 90% of students (in senior high school years) reported have received some form of sexuality and sexual health education. A qualitative analysis of students' comments about the education they received found that a focus on biology and clinical facts was common, abstinence and safe sex often dominated teaching, while relationship issues and sexual pleasure were absent.<sup>70</sup>

There have been a number of systematic reviews examining the impact of interventions in schools and other community settings on STI risk and protective behaviours among young people. The most recent of these included RCTs from several countries (USA, UK, Netherlands, South Africa, Tanzania). While knowledge was frequently improved by behavioural interventions, improvement in condom use was found in only two studies, and when a meta-analysis was conducted across six RCTs that pooled condom use data into one outcome variable, there were no significant differences between intervention and control groups.<sup>422</sup> A more positive systematic review of USA-only RCTs or quasi-experimental studies conducted in schools published in 2006 found that condom use was the behavioural outcome most likely to be positively impacted. They described four features of successful programs: a focus on skills to

reduce specific risk behaviours, duration and intensity of programs, training of facilitators and being clear about what constitutes a 'program'.<sup>423</sup> In a worldwide review of educational programmes targeting young people in schools, those which were most effective were carefully planned and appropriately implemented, the curriculum content itself had to have clear and specific foci on desired behavioural outcomes and the skills associated with them, while acknowledging and addressing appropriate developmental, psychosocial and cultural contexts.<sup>424</sup>

Despite rhetoric about many sexuality education programmes and curricula addressing broader issues such as communication and relationship skills and other psychosocial factors that influence sexual health, it is not surprising to find that the safety-risk discourse emerges as the dominant, if not the only, discourse about sexuality and young people, given the stronghold that medicine as an institution has over sexuality generally. By the end of their secondary school life, only about half of Australian young people have experienced sexual intercourse<sup>70</sup> but they have firmly adopted the discourse by the time they do.

Over the past one to two decades, a new discourse is emerging that normalises adolescent sexuality and advocates sexual pleasure. In 2009, the United Nations Educational, Scientific and Cultural Organisation (UNESCO) published international technical guidelines on sexuality education, an evidence-informed set of approaches for teachers and educators. In the rationale for sexuality education, HIV prevention features prominently, however these guidelines explicitly include defining 'key elements of sexual pleasure and responsibility' as part of an educational program.<sup>425(p.28)</sup> A literature review on the association between sexual pleasure and a range of behavioural and health outcomes found that sexual satisfaction was associated with dual contraceptive use (condoms + other method); discussing ways to eroticise condoms as well as acknowledging sexual pleasure all increased their use.<sup>426</sup> Some researchers, mainly from sociology or psychology disciplines, have formed what Harden<sup>427</sup> describes as a small but persistent chorus of voices [that] has called for a new paradigm for understanding adolescent sexuality, one in which teenage sexual experiences are regarded as both developmentally normative and potentially healthy. There was little evidence in our qualitative study of a pleasure discourse informing young people's understandings of STIs or of them being able to position themselves within a pleasure discourse when discussing STIs. However, given the resistance at policy levels to address sexual pleasure in any formal educational curricula (based on personal experience as an advisor to the national curriculum on health) this is hardly surprising. In the most recent national survey of secondary students,70 students were asked, for the first time since these surveys began (in 2002) to comment on their

experiences of sexuality education in schools. Two prominent criticisms of school based sexuality education were the irrelevance to young people who identified as lesbian, gay, bisexual, transgender, intersex or queer and the absence of acknowledging sexual pleasure.

Education and awareness raising can and do occur at a population level outside the school setting, and it might be possible to include more sex-positive approaches outside the highly politicised arena of formal education systems. Over the past decade there have been a few state and federal government-led mass media campaigns in Australia targeting young people to raise awareness of STIs and encourage condom use and /or STI testing. I was involved as an advisor for a national campaign that occurred across two waves in 2009 and 2010, and a state (NSW) campaign launched in 2009 and relaunched in 2011. Both these campaigns targeted young heterosexuals, normalised the multiplicity of sexual encounters and partners that young people can have (eg 'sleeping with one is sleeping with many') and focused strongly on getting tested and using condoms. The national campaign also used graphic messages about symptoms of STIs (eg 'ii's like peeing razorblades') and infertility ('an STI could stop you from having a baby') and found that these messages resonated with young men and women respectively. A campaign from the USA was one called 'Get Yourself Tested' which is described as the first, comprehensive, national mass media campaign to raise awareness about STIs and testing among young people in the USA.<sup>428</sup> This is a collaborative campaign involving multiple, mainly non-government, organisations with input from the Center for Diseases Control and Prevention and was incorporated into an existing campaign called It's Your (Sex) Life. The campaign's key message is about STI testing, but the supporting website (http://www.itsyoursexlife.com/stds-testing-gyt) includes more comprehensive information about pregnancy, relationships, and addresses some LGBTQ (lesbian, gay, bisexual, transgender and queer) issues, such as identity and coming out. Despite some information on the website about emotions and relationships, the word 'pleasure' (or equivalent concepts) does not appear.

It would therefore be interesting to further explore whether young people hold discourses of pleasure in relation to STIs specifically, given that the medical (safety-risk) and contamination discourses were so dominant among our small sample.

I have attempted to synthesise the key findings from our quantitative and qualitative studies with other bodies of work that address young people, chlamydia testing strategies and discourses. My point of reference in discussing a diverse group of studies has been chlamydia testing and how this can be increased among sexually active young people in Australia, exploring a range of settings and strategies, while weaving young people's experiences and discourses into these findings to help us understand the multiple 'truths' that exist.

## 17.4 Implications for policy, practice and further research

Chlamydia control involves a number of organised and opportunistic activities, among which the screening of asymptomatic sexually active young people is but one. Following three decades of considerable alarm about epidemic rates of chlamydia infection and the implications for the fertility of future generations of young women, new evidence about screening has been emerging that gives us pause. Firstly, the incidence of pelvic inflammatory disease (PID) is falling, in England, Australia, Sweden and the USA.<sup>429</sup> Early identification and treatment of chlamydia infection is thought to play an important part in this trend, although does not explain the whole.<sup>430</sup> Other possible causes include a change in chlamydia virulence, non-chlamydia causes of PID and more specificity in diagnosing PID due to negative chlamydia tests.<sup>429</sup> Secondly, a RCT of register-based chlamydia screening in Denmark has found that after 9-year follow up, there was no difference between those offered postal home testing kits and controls (usual care, opportunistic screening in the health system) in rates of PID, ectopic pregnancy or epidydimitis.<sup>232</sup> However, low uptake of screening probably accounts for much of this null finding, and studies of a single round of screening may be of limited value in looking at long term outcomes.<sup>431</sup> Thus, the importance of evaluating multiple rounds of screening has come to light, with the endpoints being chlamydia prevalence rather than PID incidence:<sup>432</sup> the Australian Chlamydia Control Effectiveness Pilot (ACCEPt) cluster RCT in general practices is one such study. The intervention in this study includes incentives and annual reminder systems in general practices across four Australian states, with the primary outcome being change in chlamydia prevalence after four years.433

In addition to questions about the benefits of screening, potential harms need to be acknowledged. In Australia, a dual nucleic acid amplification test (NAAT) for gonorrhoea as well as chlamydia was introduced in 2007 and performing both tests on a single specimen has become widespread in the years since, even when only chlamydia has been requested.<sup>434</sup> Similarly a recent paper from the United Kingdom reported on a large increase in dual NAATs being performed between 2007 and 2013, and found that in 2013 over 50% of all local authorities who are commissioned to deliver the national chlamydia screening programme perform dual NAATs.<sup>435</sup> The specificity of NAAT for gonorrhoea is less than culture, and varies by testing platform and

specimen type, which can result in a high proportion of false positives when prevalence is low. Indeed, a study published in 2015 among Australian women in Victoria found that, despite the increase in notifications of gonorrhoea between 2007 and 2013, the prevalence of gonorrhoea remained low and stable, and suggests that the rise in notifications could be explained by false positives from NAATs.<sup>434</sup> The implications of a high false positive rate and low positive predictive value for gonorrhoea are significant, causing not only unnecessary medical treatment and costs, but longer term emotional, relationship and psychological distress.<sup>436</sup>

Another important consideration is the capacity for monitoring of positivity in any screening program, whether opportunistic or proactive. The diverse range of settings in which chlamydia screening has been studied to assess feasibility has focused on one-off participation. However, those settings that achived the highest participation rates might not be the most feasible for managing positive cases with regard to treatment, partner notification and retesting. The sustainability of settings to continue to provide screening also needs to be considered.

Other chlamydia control strategies include retesting of individuals with chlamydia to exclude reinfection, partner notification and partner delivered therapy. The first two of these are part of current Australian clinical guidelines while partner delivered therapy would require changes in prescribing legislation in Australia and advocacy has begun for this.<sup>178</sup> It would be useful at this point in time to explore with young people how partner delivered therapy would influence their perceptions of sexual health and relationships, and to gauge how readily young people would take up such a strategy. A systematic review of chlamydia retesting strategies found that postal testing kits and sending reminders were both 'promising' strategies.<sup>437</sup> A RCT of SMS reminders + postal home testing kits (compared with SMS reminder + clinic attendance) is currently underway in Australia.<sup>412</sup>

Despite the unanswered questions about the long term benefits of universal screening among sexually active young people, current expert opinion remains strongly in favour of it continuing until further evidence is gathered.<sup>438</sup>

A slight shift has occurred in chlamydia notification rates in Australia since 2011, in that rates have plateaued or decreased slightly among 15 - 24 year old females and males, but have continued to increase among 25 - 29 year old females and males. Notification rates remain high however, and chlamydia remains the most common notifiable infection in the country.<sup>248</sup> To

address this epidemiological shift, the most recent national STI strategy now includes those aged 25 - 29 years in the 'young people' priority group<sup>439</sup> and screening sexually active young people in Australia needs to continue.

The getcluedup RCT was one of several studies that attempted to address the question 'how do we make chlamydia testing more accessible for young people in Australia? Despite the innovative range of testing strategies tried and tested in Australia and internationally, general practice in Australia remains the most appropriate primary setting for opportunistic chlamydia screening, and one that the young people in our study strongly endorsed. Efforts and investments should, and are, continuing to be directed towards general practice, and although chlamydia testing in Australian general practice remains low, it is steadily rising. National GP surveillance data showed steady increases in testing from 2000 to 2007, reaching approximately 13 per 1000 encounters for 15 -24 year olds.<sup>333</sup> A national study using Medicare data calculated chlamydia testing rates among 16 - 29 year old Australians over a 12 month period from October 2007 to September 2008 found that the testing rate was 8%, being higher for females (12.5%) than males (3.7%).<sup>334</sup> Testing rates need to reach 30% of the target population in order to impact on prevalence, and early data from the ACCEPt study found an increase from 4.1% to 10.9% after three months in intervention practices.<sup>433</sup> As simple and singular as a chlamydia test is, to increase rates in general practice requires an appreciation that practices are 'complex adaptive systems'<sup>440</sup> and that to engage young people in discussing sensitive topics and consenting to a potentially sensitive procedure requires 'youth-friendliness', itself a complex, multifaceted entity. Two decades of research, policy and practice have already informed youth friendly practice in Australia<sup>270,271,273</sup> but much remains to be done to ensure that all young people entering a general practice are afforded appropriate care, including preventive care.

If accessing health care can also be seen as a dynamic and social interaction, our study, along with the other predominantly online studies evaluating chlamydia testing, introduces the possibility of another dimension to the health system and ways of accessing it. The internet can function as an extension of the consultation room, and new digital technologies including mobile devices and social networking can build on this; it can also become the first point of access into the health system and cyberspace is a world where young people particularly may feel enabled and empowered.

One local example where our research could have such practical application is the "Play Safe" website, a NSW Health initiative (www.playsafe.health.nsw.gov.au) launched in March 2014. This website was a redesign of the state's previous STI campaign's website (with which I was involved, see 17.3.2), currently has 1000 visitors a week and receives about six questions per week to a virtual nurse via a Contact facility. Half the questions come from young people 13 - 22years, and the Contact webpage requires an email address from the visitor so that a response can be sent. (Personal communication in an email, Gemma Hearnshaw, Health Promotion and Programs Manager, STI Program Unit, NSW Health, 22 January 2015) This website is clearly branded as an official NSW Health site; institutions such as health departments and universities were seen as credible by our Youth Consultants who also felt it was important for such branding to be obvious without being overwhelming. In addition to increasing website traffic through a range of marketing strategies, it would be interesting for NSW Health to consider investing in technological and possibly human resources that seek to actively engage visitors within the target group in online interactions to help facilitate testing. With only six questions being sent per week to the online nurse, there is certainly scope to try to increase this number and to engage more of the website's visitors in direct, personal discussions about their sexual health. Based on our experiences with getcluedup participants, there would need to be a balance between being more proactive in trying to engage visitors and not being overly intrusive. Suggestions include offering periodic competitions where prizes can be won, whereby young people provide an email address and agree to be contacted by a sexual health nurse to discuss sexual health; inviting website visitors from the target group (sexually active young people) to invite friends to the website (a snowball strategy) with incentives offered to the inviter and introducing a social networking component to the website. The purpose and parameters of this interaction can be clearly stated at the outset: that Play Safe is running a 'campaign' or 'competition' to increase chlamydia testing among sexually active young people. Young people would need to be involved in developing these strategies, as consultants at the very least, and ideally with deeper involvement, such as developing messages and organising the competitions and being involved in evaluation strategies. It would also be useful for the website to periodically survey its visitors to gather information about demographic factors. Such strategies as these could be added to any sexual health website that invites questions from its visitors about sexual health concerns, with outcomes such as chlamydia testing clearly and specifically stated.

If and when medical technology advances to enable techniques such as rapid (point-of-care) and/ or home-based testing to become both reliable and affordable, the settings in which

chlamydia testing occurs may change again. The combination of medical and digital technologies adds further scope. For example in the UK, the electronic self-testing instruments for STIs ('eSTI2') initiative aims to 'develop, evaluate and facilitate polymicrobial point-of-care (PoC) and self-test mobile-phone networked micro-diagnostics' that will enable 'immediate access to diagnosis and treatment via smartphone enabled diagnostics'. (http://www.esti2.org.uk/node/69) Young people interviewed in the UK about the hypothetical utility of this technology in facilitating STI testing were positive about how it would mitigate certain barriers such as concerns about confidentiality, but also expressed their desire to have integration of such digital technology with 'real' services and clinicians.<sup>441</sup>

Despite the small sample in the qualitative study, our findings do have some implications for practice and policy. Discourse analysis adds to what has already been learned about STI stigma and shame and gives us insights into points of resistance and subject positions that could be exploited. Cyberspace offers possibilities to challenge dominant discourses that schools and clinics currently do not, and cyberspace might be able 'get ahead' of these dominant institutions and gatekeepers of knowledge. A useful starting place would be to continue to advocate for new ways of understanding adolescent sexuality, not as deviant, but as natural, and not as risky, but as - to use language from the medical discourse - 'normal'. Discourses of pleasure can co-exist with discourses of safety where caring for self and others becomes a meaningful, lived reality for the majority of young people. This requires effort directed at providers of health and education services as well as young people. A policy step could be to include multiple discourses, including those of pleasure, in the training of health professionals and educators about young people's sexual health. My own involvement, from 2010 to 2013, in a NSW government health promotion subcommittee that addressed sexual health in priority populations led to a state-wide training forum for senior health promotion officers over two days where I (and others) discussed the importance of acknowledging the pleasure discourse when broadly addressing sexual health promotion among young people. I was able to introduce 'care of the self' as a concept in designing STI testing strategies.

However, more qualitative research into discourses would be particularly useful to help guide this. If the discourse of pleasure, for example, does not exist or resonate among young people when they think about STIs or about STI testing, it would be useful to understand why, given the discourse of pleasure does have traction in other areas of sexuality and sexual health. Perhaps the safety-risk and contamination discourses are specific to STIs and firmly tied-down and unable to accommodate subject positions of pleasure, unlike the morality-shame discourse which does have some points of resistance. Exploring how care of the self (and others) can be exploited within the safety-risk discourse and whether there might be other ways of resisting this discourse would also be useful, and our small sample was probably inadequate to enlighten us further.

Another implication from our qualitative study relates to the personalising of different STIs by young people and how this could inform education. While more research is needed to gain a broader understanding of this, there is a potential need to address different STIs differently rather than assume that young people perceive STIs as an homogenous group of entities. When I was involved as a consultant to the 2009 NSW Health STI media campaign targeting young people, there were two advertising companies who tendered for the contract. The creative concept of the unsuccessful company named different STIs individually, making it clear that STIs are a heterogeneous group. The successful company used the slogan 'Get Tested Play Safe' and used the creative concept of the unsuccessful company. However the other concept also had merit and was favoured by the other consultants, as it attempted to de-stigmatise STI transmission by making the notion of multiple sexual partners value-neutral. Ideally there would be scope to convey both (and other) concepts in a range of educational strategies.

Gender emerged in our discourse analysis as a dominant theme. Gender could be a barrier to STI testing, due to double standards about morality and sex that might prevent young women from seeking health care for fear of being judged, yet also creates opportunities, because females might be seen as more responsible in health seeking. It would be useful to do more interviews and include more males, and more sexually and gender diverse young people. It would be particularly useful to explore discourses of young men who have had chlamydia, or other STIs, and whether care of the self emerges as a subject position as strongly as it did for the young women we interviewed. Our sample in the qualitative study included only one young person who identified as gay, the others were heterosexual. It is important to explore discourses about STIs from a much broader range of same-sex attracted young people.

Internet based research itself continues to open up possibilities, and our experience has many practical and logistic lessons for future research. First, more empirical research around online versus traditional data collection methods (both quantitative and qualitative) could be useful. Concerns about external, and to a lesser extent internal, validity in online research (especially RCTs) will not go away until we have enough information to develop peer-reviewed and widely accepted research protocols for studies done in cyberspace.

Second, and more specific to young people, more research would be useful for understanding engagement in an online or digital environment. Given the diversity of digital technologies now available, understanding both the characteristics of online strategies and mechanisms by which young people engage *and do not engage* with them, is important - particularly what might inadvertently create more barriers to care.

Thirdly, information technology experts could now be considered when assembling a research team, in the same way that statisticians might be. Information technologies continue to evolve rapidly, and our study was conducted in the pre-Facebook era in Australia. To ensure that scientific rigour and quality are maintained in an online research environment, technological expertise is as important as research expertise. Promotion and recruitment strategies could be informed by marketing experts rather than researchers, and selecting keywords for promoting a website could be broadened to include words within the range of discourses that young people inhabit, such as 'caring for my relationship' 'how to care for myself' 'how to be safe and feel good' or 'STI is not a dirty word'. Of course these are somewhat fanciful, but with advice from technical experts about how search engines work, these might be ways to shift all of our thinking.

Significant work has been published and continues that evaluates the impact of different testing settings, practice and systems change and provider education on chlamydia testing. It might now be timely to add to this by focusing research on young people's spaces – not just their physical spaces (including online environments) but their 'headspaces'. By this I mean some real investment in giving voice to young people's understandings of STIs and sexual health, including shifting their engagement with sexual health care from the margins and into the mainstream. This is a lofty goal, since adolescent sexuality remains a challenging area in many western countries, let alone other parts of the world. However, many young people have adopted a medical discourse of safety and risk when it comes to STIs, and do feel that medical and health professionals are the appropriate people to offer advice. Thus equally important would be research into health provider and educator 'headspaces'. The intangible barriers (such as embarrassment, discomfort, feeling it is inappropriate) to addressing chlamydia testing and sexual

health broadly among providers<sup>337</sup> has been studied in cross-sectional research. One approach to future research, therefore, would be to bring young people and health providers into one research space and explore with them together and in depth, the barriers and facilitators to testing. This could inform the development and evaluation of new strategies, loosely conceived as 'changing the conversation' (about STIs and young people) to explore whether (for example) sexual health consultations that discuss how young people wish to care for themselves and/ or their partners increases chlamydia testing and whether the normalising of chlamydia testing improves sexual agency and pleasure.

The capacity to combine medical and digital technologies deserves attention in the Australian setting. Even if, for example, a young person can test themselves, receive treatment and inform and treat their sexual partners in a virtual space using impersonal technology, it is not evident how much this would be taken up given the marginalisation that sexually active young people perceive from broader society. Any research that evaluates new technologies needs to remain mindful of this and explore, in parallel, and using qualitative research whether and how new technology influences young people's capacity to engage with real health professionals and increase their sense of agency in managing their sexual health and relationships.

A third and final broad area for future research would be within the school setting – a setting that is greatly under-utilised in Australia, for both practical and political reasons. This setting could involve parents as well as teachers in providing guidance, but would focus mainly on young people and their learning, and could utilise digital technologies in the classroom to build skills and confidence to engage with sexual health information as well as real sexual health services. An interesting study might be to develop and evaluate a learning program that incorporates curriculum-based lessons with access to online or digital health advice. The lessons would focus on STIs but include discussions exploring and drawing on different discourses, and could be facilitated by an outside sexual health expert educator but delivered in the presence of the classroom teacher. Outcomes could be, for example, student knowledge, teacher knowledge and confidence, utilisation of online advice and chlamydia testing. There are in fact many potential programs that could be developed, but the features worth exploring include the conscious attempt to address discourses while delivering important health messages, simultaneously training teachers and students, and providing direct and measurable linkages with real health services in an online environment.

# 17.5 Conclusion

Research for over ten years in Australia has had the overall aim of normalising the routine testing for chlamydia among sexually active young people such that it is adopted by both providers and consumers alike into everyday consciousness about health care. We have shown that there is potential to engage young people with real health care via a virtual environment and that it can lead to health promoting behaviour. However, many health professionals and researchers remain strongly wedded to a discourse, or 'truth' about chlamydia control among young people, and STIs more broadly which was borrowed from the HIV discourse about risk and safety. Young people also hold this discourse, yet continue to feel marginalised because of perceptions about morality and young people's sexuality. To achieve chlamydia control and reduce chlamydia related burden of disease among young people, efforts to understand the infection, its sequelae and changing epidemiology, to improve medical technology and to facilitate access to testing must all occur in parallel. We also need to better understand young people's behaviour and their underlying beliefs about chlamydia and to do this in the context of broader social and cultural influences. We need to examine and modify our perpetration of discourses that risk continuing to marginalise young people. It will take courage to shift our own discourse, to offer access to the best of medical science while opening corridors to the multiple ways of understanding human sexuality and in particular, young people's sexual health.

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## **APPENDIX A**

## SIGNED STATEMENT

 A1: Signed statement of verification from co-authors regarding the publication: Kang M, Skinner SR, Usherwood T. Interventions for adolescents and young people in Australia to reduce HIV and sexually transmitted infections: a systematic review. *Sexual Health* 2010;7:1-22.

#### In relation to the published article:

**Kang** M, Skinner SR, Usherwood T. Interventions for adolescents and young people in Australia to reduce HIV and sexually transmitted infections: a systematic review. *Sexual Health* 2010; 7: 1 - 22.

We verify that Melissa Kang conducted the majority of the research, under our supervision. Specifically:

Melissa Kang conducted the systematic search as described in the published paper, and retrieved and read all the abstracts and full articles. She developed the matrix for classifying studies by setting and intervention type after preliminary discussion with her supervisors, and wrote the draft manuscript. She completed and submitted the final manuscript following discussion and feedback from her supervisors.

We read the abstracts of all retrieved articles and ten full articles each. We then assisted with classification of studies and provided feedback on the draft manuscripts.

20/2/15

Tim Usherwood (Supervisor)

24/2/15

Rachel Skinner (Associate Supervisor)

## APPENDIX B

## GETCLUEDUP CONTENT

A2:	Sitemap for the website (developed by David Trewern Design)
A3-A18:	<i>getcluedup</i> downloadable factsheets (all written by me and reviewed by 20 young people aged 16 – 25 years)
A19:	Drawings commissioned from Tatiana Davidson, graphic art student (aged 17 years) for <i>getcluedup</i>

## **UoS: Chlamydia**

[20.02.07]

## Sitemap

- 0.0 Home
- 1.0 About Chlamydia Trach
  - 1.1 Symptoms & Consequences
  - 1.2 Prevention & Diagnosis
  - 1.3 Glossary
- 2.0 Chlamydia & You
  - 2.1 Intimate Relationships
  - 2.2 When Sex is Not OK
  - 2.3 FAQ's
  - 2.4 Fact Sheets
  - 2.5 Useful Links
- 3.0 Getting Help
  - 3.1 What the Test Involves
- 4.0 Questionnaire (Invitation to Participate)
  - 4.1 Consent Form & Contact Details
  - 4.2 Questionnaire Steps
  - 4.3 Thank you & Follow-up Details
  - 4.4 Refer a Friend (pop-up)

#### Footer:

- Your Privacy
- Friends of Clued Up
- Acknowledgements
- Feedback & Suggestions
- Contact



# Chlamydia Infection and Symptoms

## How does someone get a Chlamydia infection?

Chlamydia infection in the reproductive system is passed on, or transmitted, by sexual contact. The Chlamydia bacteria survive in semen and vaginal secretions so this is how they 'travel' from one person to another.

Sexual intercourse, meaning penis-vagina intercourse is a very common way that the infection is transmitted. Chlamydia can also be transmitted by anal intercourse (penis-anus and rectum, or back passage) and can cause an infection in the person's back passage. Chlamydia can also cause an infection in a person's throat if they receive oral sex. This is when a penis goes into someone's mouth, or when someone's mouth contacts the vagina and genital area in a woman. Thus it is known as a sexually transmitted infection, or STI. Chlamydia infections are usually caused by sexual contact such as the examples above.

Sometimes a sexually transmitted Chlamydia infection can be passed on in other ways. For example, the Chlamydia bacteria also happen to like infecting a part of the eye called the conjunctiva. This is the lining of the inside of the eyelids. Chlamydia infection of the conjunctiva does not occur directly from sexual contact, but someone with a Chlamydia infection in their genital area could accidentally transmit some of the bacteria to their own eyelids or someone else's from touching their genitals and then their eyes. A pregnant woman with a Chlamydia infection in her cervix can pass this to her baby during childbirth. A baby who gets Chlamydia this way might develop conjunctivitis or pneumonia, but it won't get Chlamydia in its reproductive system or genital area.

## What are the symptoms of Chlamydia infection?

In about 75% of women and up to 50% of men who have Chlamydia infection, there are no symptoms. In other words, it is often an "asymptomatic" infection. This means that the Chlamydia bacteria are happily multiplying away in their chosen reproductive organs but don't give away any clues to their unsuspecting 'host' (that's us women and men) that they're there.

If a person does develop symptoms, this usually happens about 1 - 3 weeks after they get infected (ie 1 - 3 weeks after the sexual contact where the bacteria were transmitted).

In the 25% of women and 50% of men who DO get symptoms, they are usually:

#### For women:

- A vaginal discharge. Chlamydia actually infects the cervix making it inflamed, or swollen, red and producing of a white or yellow discharge. Because the cervix hardly has any pain nerve endings, women don't feel pain the way they would if it were an infected toe or finger, for example. But they will notice a discharge coming from their vagina. This discharge will usually be white or yellow and will not be particularly smelly
- · Pain and itching in the vagina
- Unusual bleeding from the vagina
- A woman might also feel pain on urination
- Pain during sex or pain in the pelvic or lower abdominal area. This is usually a sign that the Chlamydia infection has travelled up into the uterus or Fallopian tubes. It might also be accompanied by a fever and feeling a bit 'flu-ey'
- Chronic pain in the pelvic area. This is a symptom of pelvic inflammatory disease.

#### For men:

- A urethral discharge in men. As with women, the Chlamydia bacteria cause inflammation leading to swelling, redness and a discharge this time in the urethra. A man will notice white or yellow fluid coming from the end of his penis. He may also feel pain or discomfort on urination.
- Pain in the scrotum or pelvic area. This is usually a sign that the Chlamydia infection has travelled back from the urethra into the epididymis or the prostate gland. These organs then get inflamed as well and can become sore.



#### For men or women:

- If Chlamydia infects the rectum (back passage) the person will sometimes get a discharge or bleeding coming from their back passage and it may also be sore or itchy
- · If Chlamydia infects the throat the person may have a sore throat
- Chlamydia can also infect part of the eye called the conjunctiva. This is the lining inside the top and bottom eyelids. An infected conjunctiva is called conjunctivitis. The conjunctiva become sore, swollen and make a sticky discharge. By the way, conjunctivitis is a common condition that is usually caused by another type of bacteria altogether (which has nothing to do with sexual contact).



# Consequences of Untreated Chlamydia Infection

Untreated Chlamydia infection can lead to very serious consequences for women and men. They can become infertile, meaning they can't have kids. Women are more likely to be affected. If a woman or man has a Chlamydia infection, chances are they won't know about it, because it is often asymptomatic.

## Infertility in women

In women, serious problems can arise if the bacteria travel from the cervix into the uterus and Fallopian tubes making them infected and inflamed. The danger of getting an infection here is that scarring can occur in the Fallopian tubes and cause blockage. Eggs released from the ovaries can't travel down the Fallopian tubes and reach sperm so conception can't occur and a baby can't be made. Chlamydia infection in the Fallopian tubes is a common cause of infertility in women.

### Ectopic pregnancy

Sometimes scarring of the Fallopian tubes doesn't completely block them, and an egg can be fertilised by a sperm. But if the tubes are infected and inflamed from a Chlamydia infection, the fertilised egg can have difficulty travelling down the tube to the uterus, and might get stuck in the wall of the tube itself. This can lead to an ectopic pregnancy, which is when a fertilised egg tries to grow into an embryo outside the uterus. An ectopic pregnancy is very dangerous and a woman can die from this.

#### Pelvic inflammatory disease

Sometimes the Chlamydia bacteria go even further than the Fallopian tubes, and into the ovaries and the abdominal cavity itself. When Chlamydia bacteria infect the reproductive system beyond the cervix – and this might include the uterus, Fallopian tubes, ovaries or abdominal cavity – it's known as pelvic inflammatory disease or PID for short. Apart from the scarring and the risk of infertility and ectopic pregnancy, a woman can also become very sick just from having an infection in the upper part of her reproductive system. It's estimated that about 30% of women with a Chlamydia infection of their cervix will develop PID. Chlamydia is also an infection that can keep happening – in other words, the body doesn't become immune to it the way it can with something else, like chicken pox. Women who get repeated infections with Chlamydia are at even greater risk of PID and other complications.

### Infertility in men

If Chlamydia bacteria travel up into the reproductive system of a man, they can infect the epididymis and the testicles. Inflammation here can also cause fertility problems for a man, because they can't produce sperm as efficiently. A small percentage of men with Chlamydia infection in their urethra will develop infection in their epididymis or testicles.

## Arthritis

A rare complication of Chlamydia infection is swollen, painful joints, or arthritis. This is more common in men than women who get Chlamydia. It's not known exactly why this occurs but is thought to be genetically related and due to an unusual immune response by the body to the infection. This condition is called "Reiter's Syndrome" after a doctor who discovered it. Symptoms include painful joints, tiredness and weight loss. Most people who develop Reiter's syndrome recover after a few weeks or months, but some get painful joints on and off over many years.



# Chlamydia testing and treatment

## How can Chlamydia infection be diagnosed?

Over the years scientists have developed more sophisticated ways of testing for Chlamydia (and other infections). In the past the best way to know whether someone had a Chlamydia infection was to actually get a sample of the secretions from the cervix or urethra where the bacteria were living and then try to grow the bacteria in a laboratory using special equipment. This involved having to use swabs to collect secretions from the cervix or urethra, which meant that the woman or man had to have a doctor or nurse inserting the swab into those parts of the body. The more secretion on the swab, the more likely that lots of Chlamydia bacteria would be found. These bacteria had to stay alive long enough to reach the laboratory so they could be grown in the equipment. So, collecting the swab carefully and transporting it to a laboratory quickly was very important. This test can still be used. It is a very accurate test and is called a "Chlamydia culture".

More recently tests have been developed that can detect the presence of the genetic material of the Chlamydia bacteria. (Just like us, bacteria also have genes in the core, or nucleus, of their cells). The test only requires the tiniest amount of genetic material to be present in order for it to show up positive. It's no longer necessary for careful swabs capturing lots of secretions to be taken. Enough genetic material can be found in the tiniest amount of secretion to show up in the test and this will fall into a urine jar when a person urinates. This test is also a very accurate test and is obviously more appealing to most people because it does not involve having swabs inserted into the genital area. This is called a "Chlamydia PCR (polymerase chain reaction)" test.

There are other, slightly less accurate tests that can still be used, especially if the more sophisticated (and more expensive) tests aren't available in some laboratories. These also involve taking swabs from the cervix or the urethra but instead of growing the bacteria, they rely on other techniques to detect the presence of the bacteria. They are slightly less accurate because instead of proving the existence of the bacteria by growing them or by showing their genetic material, they tell us indirectly that the bacteria are present.

A blood test will not accurately tell you if you have a Chlamydia infection of the reproductive system.

### How can it be treated?

Fortunately, treating Chlamydia is also very simple. Chlamydia infection, unlike some other STIs, is curable. One dose of a specific antibiotic will usually kill the Chlamydia bacteria and get rid of the infection. Treating Chlamydia infection of the cervix or urethra will prevent it from travelling further up into the reproductive system and causing more serious consequences.



# Preventing Chlamydia Infection

There are two main ways to prevent Chlamydia. An obvious one is to avoid sexual contact that involves penetration or oral sex. Secondly, condoms are extremely effective at preventing the transmission of Chlamydia from one sexual partner to another.

Condoms and dams are made of latex. Condoms go on a man's penis before intercourse or oral sex and dams are used over a woman's genitals during oral sex. They provide a barrier between a man's urethra and his partner's cervix (if female) or rectum (if male or female) or between the mouth and genitals during oral sex. This stops the Chlamydia bacteria from being able to travel from one partner to another.

You've probably heard a lot about condoms already but just in case you haven't, here are a few tips about how to use a condom.

- · Check the expiry date on the packet first (the latex in condoms wears out)
- Don't use a condom that has been left for many hours in direct sunlight or extreme heat (this weakens the latex and makes the condom more likely to break)
- When putting a condom on, gently squeeze the tip of the condom so that it doesn't fill with air. When a man ejaculates, the semen goes into this part of the condom and if it's full of air beforehand it is more likely to break during ejaculation.
- · Wait until the penis is fully erect before putting the condom on
- Use plenty of water-based lubricant you can put this all over the condom before penetration
- Don't leave the penis inside your partner until it has become completely soft again it should be withdrawn while the penis is still quite hard to prevent leakage of semen from around the condom
- · Hold onto the bottom of the condom when removing it to avoid spillage
- Discard the used condom in a rubbish bin don't flush them down the toilet!
- · Use a condom only once and then discard it
- · Practise using condoms before having sex if you're not sure how to use them!

Condoms can be bought by anyone and are available in supermarkets, pharmacies, petrol stations and lots of other places. There are no age restrictions on who can buy condoms. Condoms can be used on penises, and also on vibrators and other sex toys, to prevent the spread of infections.

Condoms not only prevent the spread of Chlamydia, they also prevent the spread of most other STIs as well as pregnancy!

Another way to prevent the spread of Chlamydia is for sexually active young people to be tested for Chlamydia regularly. Sexual health experts recommend that sexually active young people have a Chlamydia test about once a year even if they have no symptoms.



# Chlamydia and Young People

## The rising rates of Chlamydia

In Australia and around the world, Chlamydia infection has been on the rise for several years. Chlamydia rates in Australia have been going steadily up by about 20% per year since 1998, when proper national statistics started being collected. We only know about the cases of Chlamydia that get diagnosed when people go to a doctor or a sexual health clinic and get tested. There are possibly hundreds, or thousands, of people with Chlamydia infection who have never been tested – if these were also discovered then the numbers would be even higher. The latest figures tell us that in 2006 there were over 40,000 cases of Chlamydia infection notified to health departments around Australia.

## Young people and Chlamydia

Of those 40,000 or so Chlamydia infections notified in Australia in 2006, over 15,000 were young people aged 20 - 24 years and over 9,000 were young people aged 15 - 19 years. These 2 age groups have had the highest numbers of Chlamydia notifications every year. There have been more notifications of females with Chlamydia infection compared to males every year as well. This could partly be explained by the fact that young women are more likely to get tested because they are visiting a doctor for other reasons, such as contraception or Pap smears.

#### Do you love numbers?

If so, you can find out more about Chlamydia statistics at: http://www9.health.gov.au/cda/Source/Rpt\_5.cfm

Why are young people more likely to get a Chlamydia infection? One reason is that, for young women at least, their bodies are physically more susceptible. A young woman's cervix is microscopically different from an older woman's cervix. The cells of a young woman's cervix are easier for the Chlamydia bacteria to penetrate and multiply. Another reason is that young people could be changing partners more frequently. Young people might have more partners because they haven't decided on a long term relationship with one person. These differences between younger and older people aren't true for everyone, but in general they are.

Research shows that young people who are same sex attracted are also more likely to get sexually transmitted infections, including Chlamydia. The reasons for this are thought to be due to number and change of partners. Aboriginal and Torres Strait Islander young people are also at higher risk for Chlamydia infection and some other sexually transmitted infections. The main reason is because they have less access to health care than non-Aboriginal people in Australia, so their overall health is poorer.

Using condoms is therefore extremely important for most sexually active young people. Even if young people use condoms most of the time the number of partners multiplied by the number of occasions of unprotected sex equals a higher chance of getting or transmitting Chlamydia.



# Chlamydia and Health

Every person has their own ideas about what health is, and what makes them healthy. Someone with the 'flu' might have to skip school, Uni, work, sport, or a party and might consider themselves sick. Feeling stressed or depressed about stuff going on in life can also affect how healthy a person feels. Other people regard health as something that is more about well-being – feeling positive about life and in control regardless of whether there is a physical complaint. Having good relationships with family and friends or having a strong sense of spirituality can make someone feel healthy. For many, being healthy is about taking care of the body, mind and spirit. This might include learning to live with chronic health problems or preventing new health problems from occurring. There is no right or wrong way to define health for yourself – it's a very personal thing and it changes over time.

Chlamydia infection is an interesting issue to consider when it comes to health. Most people with Chlamydia don't have symptoms and might feel perfectly healthy. In fact, the only way that they might discover they have it is if they accidentally give their infection to a sexual partner through unprotected sex. Alternatively, it might be diagnosed much later if some of the complications of Chlamydia infection occur. If a person with Chlamydia does get symptoms they might feel quite unwell, and for a while they might not feel like having sex or getting intimate. These relationship issues and longer term consequences might affect how a person sees their health.

### Chlamydia and stigma

#### Did you know that Wikipedia has 20 meanings for the word stigma?

What we mean by stigma is "social disapproval". Stigma is a weird thing. As recently as 50 or 60 years ago in a country like Australia some in society disapproved of women going to work after they were married instead of looking after their husbands and kids full time. It's difficult to imagine that being the case these days. Another example is racism – where one group shows disapproval of another group because of their race.

Sex is an issue that can generate lots of stigma. People often have very strong opinions about whether young, or old, people should have sex, whether sex with someone of the same sex is OK, and whether having a sexually transmitted infection says something 'bad' about a person. Think about whether the word 'slut' for example. Does it suggest strong disapproval about the person who is called a slut? What about a word like 'gay'? Do you know anyone who has been diagnosed with a sexually transmitted infection? How did you or others react to that? Since a person can catch an infection such as Chlamydia without knowing, does it really say anything about their sex life or about their beliefs and values?

Research suggests that people might not talk to a health professional about sexually transmitted infections because they worry about stigma. Health professionals are legally bound to keep information confidential. A person should be able to trust that the health professional they see will show them respect and be non-judgemental. Advising someone about dangers to their health (such as smoking or unprotected sex) is not the same as being judgemental. See Getting a Chlamydia test for more information.



# Chlamydia and Relationships

## Intimate relationships

Intimate, or romantic, relationships often start during the teenage years. While younger teenagers often have crushes on people, by the mid to late teens, many young people become involved in direct, one-to-one relationships. These relationships do not necessarily involve sexual intercourse or any sexual contact, but the research shows that in Australia, most young people have experienced some forms of intimate contact by the age of 16. This includes kissing and light sexual touching. About one third of Australian high school students have had sexual intercourse by the age of 16 or 17, and about half by the age of 18. Many young people feel romantically and sexually attracted to people of the same sex as well and sexual contact is not necessarily just with someone of the opposite sex. It's very common for young people to wonder about their sexuality and experiment with different types of sexual behaviours and partners. This can happen throughout life but is usually more intense for young people (those under 25).

There are many reasons why romantic relationships and sexual experiences begin at this time. One of the most important reasons is that the body going through puberty is charged with high levels of what we call the 'sex hormones'. These hormones not only bring about the physical changes of puberty but also 'allow' the body to become sexually aroused. Hormones don't count for everything though. Plenty of people with adult levels of sex hormones do not want, need, or enjoy sex very often, while others do.

Experts think that there are other factors that are just as important as hormones when it comes to intimate relationships. Sometimes decisions about having sex, or using protection during sex, result from a lot of different influences, such as whether the person feels a desire to have sex, how they feel about their partner, whether they think their friends would approve, what they see and hear about in the media, and whether it fits with their beliefs and values about sex and what their family believes.

Two really important influences are family and friends. This is probably because the family you grow up in and the close friends you have during adolescence help you to work out what's important to you and who you want to be. This includes your ideas and values about relationships and sex. A person's gender, cultural background and factors such as religion can also be important influences. These factors probably also influence how a young person understands and develops opinions about health issues related to sex, such as sexually transmitted infections, including Chlamydia.

## **Friends**

Friends are important at any age, but during adolescence the 'peer group' is extremely important. Decisions that a young person makes about how to behave and what to think or do often come after discussing the issue with their peer group or from observing what their peers are doing or saying. Young people in their late teens and early twenties are more likely to make decisions on their own, or with less emphasis on what their peer group thinks. Of course, everyone is different, so this is a generalisation. Being guided by the peer group is considered a healthy and normal part of growing up. It can sometimes lead to problems if a person feels they are under 'peer pressure' to do something they don't really want to do. This can include getting involved sexually. How much do you think your friends influence your ideas about sex and sexually transmitted infections like Chlamydia?

## Partners

For a young person thinking about having sex, obviously a really important person to consider is their partner! Since sexual activity (usually) involves another person, the decision to have sex can't be made by just one person. A young person might feel pressured into having sex by their partner or feel confused about whether they are ready or not. They might already be sexually experienced but feel differently towards a new partner compared with a previous one. Research suggests that young people often worry about what their partner thinks about them sexually, whether they and their partner can please each other sexually, and how to communicate with their partner about sex and sexual practices. There might also be a difference about these concerns between young women and young men. Young women might find it difficult to ask their male partner to use a condom for example. Young men might think that they are supposed to 'know it all' when in fact they don't because they are inexperienced, and this can cause anxiety for them. These issues can come up for young people whose partners are of the same sex as well. How much do you think your partner/s influence your ideas about sex and sexually transmitted infections like Chlamydia?



## **Family**

A young person's family is usually a very strong influence on their beliefs and attitudes about many things, including sex. A family might consist of a father and a mother, adopted parents, same-sex parents, single parents, step-parents and sometimes extended family, such as aunts, uncles and grandparents. While 'rebelling' against family can be part of adolescence, and although not all young people have good relationships with everyone in their family, it's true to say that family is very important to most young people. Parents or parental figures in a young person's life might express their opinions about sex and relationships by talking about them with the young person or from the things they say or do in their day to day life. How much do you think your family has influenced your ideas about sex and sexually transmitted infections like Chlamydia?



# When Sex is Not OK

## Sexual Assault

The majority of young people in Australia feel positive about sex and get involved sexually at a time that's more or less right for them. Sadly, this isn't always the case. Sexual assault is "any unwanted sexual behaviour that makes a person feel fearful, uncomfortable or threatened. It includes any sexual activity that a person has not freely agreed to. All forms of sexual assault are criminal and the responsibility lies solely with the offender." Australian statistics show that the majority of victims of sexual assault are girls and young women. For both girls and boys, and young women and young men, the greatest number of victims of sexual assault are children, teenagers and young people under 25. Women who are sexually assaulted nearly always know the person who did it.

For more information about sexual assault statistics go to http://www.aifs.gov.au/acssa/statistics.html

For more information about where to go for help for yourself or a friend, there are a number of websites that you might find useful:

www.reachout.com.au www.kidshelp.com.au http://www.burstingthebubble.com/services.shtml

http://www.dvirc.org.au/whenlove/

http://www.aboutdaterape.nsw.gov.au/index.html

## The influence of drugs or alcohol

There can be other times when sex is not OK either. Research shows that one quarter of Australian high school students who have had sex report that they were drunk or intoxicated the last time they did it. This meant the sex was unprotected, or that they didn't really want to have sex but were too 'out of it' to know.

## When a relationship is not equal

Another, different situation, is when a young person has sex in exchange for money or some other reward. For some people this might be OK, but for others, it can obviously lead to abuse and exploitation. It is also illegal in most states and territories in Australia for someone in a position of authority over a young person to have sex with them if they are under 18 years. Teachers and sports coaches are examples of this.

For someone who has been sexually assaulted, or who has had sex under circumstances which they don't feel completely OK about, it can make it much more difficult to even think about sexually transmitted infections like Chlamydia, let alone go to a doctor to ask for a test. That's why it can be useful to involve a 'support team' that might include a trusted adult, counsellor, sexual assault professional and a doctor.



# **General Practitioners**

## Who's your GP?

The most commonly accessed health service is a general practitioner, or GP. It's possible that you have your own 'family doctor' or 'family GP' whom you have known for many years. Perhaps you have found your own GP, different from the one you saw when you were a child. Perhaps you prefer to go to a local medical centre and don't mind which doctor you see, so don't really have your 'own' GP. In Australia, young people like everyone else, can choose which GP they want to see, and can see different GPs at different times. (By the way this isn't the case in all countries). The sex of your GP might be important to you – some people prefer female, and some prefer male, GPs. The cultural background of the GP – whether it's the same or different from yours, could also be important. Hopefully you can find a GP who is 'right' for you, and whom you can trust.

## GPs in rural areas

One of the problems for young people living in rural areas is that there aren't as many GPs to choose from. In some towns there might only be one GP. If a young person doesn't feel comfortable with that GP it can be difficult to find another one, since the next closest GP could be a long way away.

## The cost of seeing a GP

When you go to a GP they can either charge you money for the consultation or they can 'bulk bill' you. Charging you money 'upfront' means that you have to pay and then you can take the receipt with you to a Medicare office and get some of that money back. Bulk billing means that you give the doctor (or their receptionist) your Medicare card (or just your number if you have it written down somewhere) and they get you to sign a Medicare form. That means that the doctor can get payment for seeing you directly from the government instead of from you.

You can ask the GP (or their receptionist) when you make an appointment whether they bulk bill. Many GPs will bulk bill young people, as well as health care card owners and pensioners.



# Other health services for young people

## Sexual health clinics

Across Australia, there are a number of free sexual health clinics available to young people. These clinics are run by health departments in all the states and territories and are staffed by expertly trained doctors, nurses and counsellors. They specialise in sexual health and sexually transmitted infections. These clinics are free, but some do require you to bring a Medicare card (or number) with you. Some require appointments and some are drop in.

You can find out if there is a sexual health clinic in your area by going to: http://www.racp.edu.au/index.cfm?objectid=1F341D23-9A87-24D0-BD2364ED00196B11

### Family planning clinics

Every state and territory in Australia has a "Family Planning Association". These associations provide clinics (as well as other programs such as sex education and research).

Most clinics provide a free, or low cost, service and most require a Medicare card (or number). Clinics are confidential.

You can find out if there is a clinic near you by going to:

#### NSW

http://www.fpahealth.org.au/services/local/

Victoria http://www.fpv.org.au/2\_14\_1.html

Queensland http://www.fpq.com.au/locations.stm

#### South Australia

http://www.shinesa.org.au/download.cfm?downloadFile=43296638-E081-51EF-A78803706137B39D

Tasmania

http://www.fpt.asn.au/?page=locations\_and\_times

Western Australia http://www.fpwa.org.au/services/clinicalservices/

Australian Capital Territory http://www.shfpact.org.au/index.php?option=com\_content&task=blogsection&id=4&Itemid=32 Northern Territory

http://www.fpwnt.com.au/

## Aboriginal medical services

Each state and territory in Australia has a number of Aboriginal Medical Services. Most of these are managed or controlled by the local Aboriginal or Torres Strait Islander community. Services are confidential and most are free (needing a Medicare card or number) or low cost.

For a list of services in your area go to: http://www.health.gov.au/internet/wcms/publishing.nsf/Content/health-oatsih-servicespage.htm



#### Youth health services

A youth health service is one that only sees young people, usually within the age range 12 - 20 or 25). Not all youth health services have doctors working in them, but many have nurses who can assist with sexual health issues and STI testing. Youth health services are confidential and free, some require a Medicare card (or number).

Although all states and territories have some services that are geared towards young people, not all have a network or listing of youth health services. Some youth health services overlap with Sexual Health Clinics, Family Planning Clinics and Aboriginal Medical Services.

Below is a list of youth health services that are listed by state and territory health departments or other youth health peak organisations.

#### NSW

http://www.naah.org.au/youth.cfm

#### South Australia

http://www.cyh.com/SubContent.aspx?p=190

#### ACT

http://health.act.gov.au/c/health?a=da&did=100466744

**Queensland** - Brisbane http://www.health.qld.gov.au/istaysafe/

#### Queensland – Cairns

http://www.youthlink.org.au/home.htm

#### Tasmania

http://www.dhhs.tas.gov.au/health\_and\_wellbeing/young\_people/related\_topics/information\_and\_education /services/ youth\_health\_services

# Confidentiality

Confidentiality is one of the main concerns that young people all over the world have when they go to see a doctor or health professional. In fact young people often say it is the main reason they won't go to seek help with a health problem. This can be especially true for personal issues such as sexual health.

That's why it might be helpful to know that doctors and health professionals are legally bound to keep patient or client confidentiality. It is actually against the law for a doctor to share information about a young person without their permission. There are some important exceptions to this rule. First is if the doctor or health professional is concerned that a young person is at risk of suicide or serious self-harm. Second is if the concern is about the young person seriously harming, or killing, another person. The third important reason is if the young person is under 16 years of age and the doctor or health professional is concerned that they are being abused. This could include physical, sexual or emotional abuse or neglect. All these exceptions would lead the doctor or health professional to take any necessary steps to keep the young person (or someone else) safe. The young person would usually know that the doctor is involving others or notifying authorities because he or she would probably tell them.

When it comes to sexual health, doctors and health professionals are interested in providing young people with information and assistance with contraception, testing and treatment for sexually transmitted infections and pregnancy testing. They often try to discuss other important issues such as relationships with partners, friends and families. All of this information is treated confidentially. Some young people worry that if they are having sex and they are under the legal age of consent then doctors and health professionals will tell their parents, or other authorities. However, as long as the doctor or health professional feels that the young person is not being abused and is having a sexual relationship that is consensual, they do not have to report it.

There is heaps more information about confidentiality at Confidentiality Fact Sheet http://www.reachout.com.au/default.asp?ti=824

When it comes to testing for Chlamydia, it's important to know that a positive result must, by law, be notified to the relevant state or territory health department. This is for the purposes of collecting statistics, to allow us to know whether the rates are going up or down or staying the same. The health department that collects these statistics does not tell your parents, families or partners.



### What a Chlamydia Test Involves

#### What the test involves

Testing for Chlamydia infection has become very simple. In fact there is no need to undress or be examined by a doctor or nurse since the test can now be done on a urine sample. There are two main ways to test for Chlamydia infection:

- 1. pass a small amount of urine into a sterile urine container
- 2. have a swab taken from the cervix (in women) or the urethra (in men) and/ or from the rectum (back passage) if you have had unprotected anal sex

Most of us would probably choose the urine test anyday! But sometimes it's just as simple to have a swab taken. For example, if you are a woman having your routine Pap smear, a swab of the cervix can be taken at the same time. If you are a man and are having an examination of your genital area as part of a check up or because you have symptoms you're worried about, it can be very straightforward to have a swab of the urethra taken at the same time.

Of course, when you visit your GP or another health service for a Chlamydia test, it's likely that they won't just send you off for a test and nothing else. Ideally, they will spend a bit of time talking to you about your health and sexual health generally, and explain what the test involves and what will happen if it is positive.

#### <u>Cost</u>

There can be two costs involved with a Chlamydia test. The first is the cost of seeing the GP or service itself. When a doctor or nurse arranges for you to have a Chlamydia test, the urine sample or swab is then sent to a laboratory for analysis. The laboratory also charges to do the test. In some clinics this is free, but in most there is a charge.

Laboratories can also bulk bill you, in the same way as GPs can. You can ask your GP to request that the laboratory bulk bills you. If you do have to pay the laboratory, you can claim most of this back from Medicare. If you do not want your home address written on the form that accompanies your urine sample or swab to the laboratory, let the doctor or nurse know.



# A Positive Chlamydia Result

#### **Treatment**

Chlamydia infection can be cured with one dose of antibiotics. It is one of the easiest infections to treat and the antibiotics are very effective. The recommended antibiotic is called 'azithromycin' (brand name Zithromax) and this is a white capsule-shaped tablet. The packet will include 2 of these tablets and you will be advised to take both at once. It is a safe antibiotic but your doctor will explain any possible side effects to you beforehand. Some of the more common side effects include nausea, indigestion and diarrhoea or constipation.

You will need a prescription from your doctor for azithromycin and this will be an additional cost when you go to the pharmacy. Sometimes doctors have free samples they can give you.

There are other antibiotics that are just as effective as azithromycin and that are cheaper to buy. The downside is that you need to take them for 10 days instead of just once. These antibiotics include doxycycline, erythromycin and roxithromycin.

#### How would I feel?

Sometimes it's impossible to know how you would react to the news that you have Chlamydia. For some people it's not a big deal. It could be much the same as being told you have tonsillitis or the flu. You might say to yourself "fine I'll get treated and it will go away". You might be incredibly relieved that is was picked up so that you can get treatment and prevent complications. For others it could trigger lots of emotions such as anger, anxiety or fear. So much will depend on how you feel about sexually transmitted infections in general, your partner/s or relationship/s and even yourself. It's useful to think about your possible reaction before you have a test and to get as much information about Chlamydia as you can beforehand. It might help you put everything in perspective. Talking to your doctor or health professional about how you feel when you are given the result can be very helpful.

#### What should I do?

If you have a positive Chlamydia test, your doctor will recommend that you take some antibiotics to cure the infection. They will also advise you to avoid sexual intercourse for one week after you have finished taking the antibiotics. And it's likely that your doctor will also talk to you about condom use to prevent other STIs.

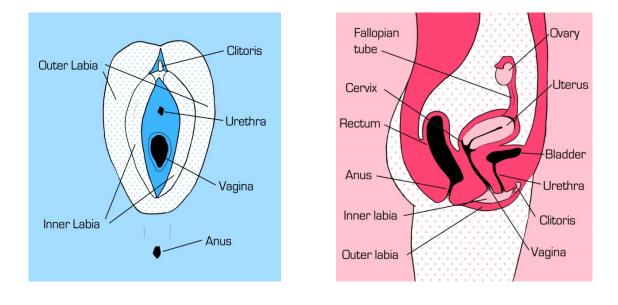
#### Who do I tell?

It is very important that you tell your sexual partner or partners. This is so that they can go and get tested and treated if they are also Chlamydia positive. It will protect their sexual health and also prevent them from reinfecting you after you've been treated.

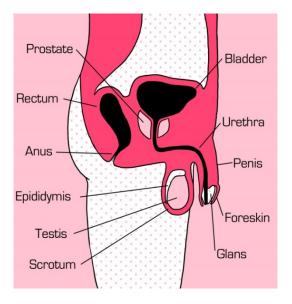
Talking to your partner about some aspects of sex and sexual health can be difficult at any time, let alone if you have to discuss something like a positive Chlamydia test. You can ask your doctor for advice about how to do this.

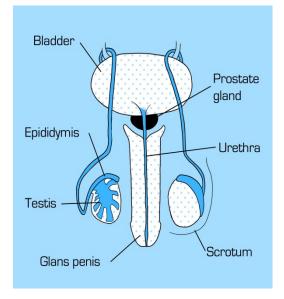
#### How will it affect my health?

Most people with a Chlamydia infection don't have symptoms and don't know they have it. From this point of view you might say that it won't affect your health at all! However the complications of Chlamydia can be very serious and it might be further down the track before you realise the effects on your health. But health isn't always just about physical symptoms or consequences. Feeling positive about yourself, your relationships and in control of your health are all part of feeling healthy for most young people. That's why it's important to understand that Chlamydia is really just another bug, is commonly transmitted, doesn't mean anything 'bad' about a person or their sexuality and best of all it can be prevented and cured. Understanding all of this can really reduce any negative effects of Chlamydia infection on your health.









#### **APPENDIX C**

# FULL PAGE PRINT ADVERTISEMENTS IN *DOLLY* MAGAZINE PROMOTING *GETCLUEDUP*

A20: Dolly magazine advertisement, April 2007

A21: Dolly magazine advertisement, May 2007

A22: Dolly magazine advertisement, June 2007

Some secrets aren't

meant to be

### Also known as 'the silent disease', Chlamydia is a sexually transmitted infection that likes to keep itself secret from you!

That's right: three quarters of young women and up to half of young men with Chlamydia do not know they have it. And they could share it with their partners through unprotected sex. Sexually active teenagers are much more susceptible than older people to being infected with Chlamydia. It is also the most common bacterial sexually transmitted infection in Australia with the numbers going up each year, mostly among young women. If it's not treated early, it can lead to serious health problems such as infertility and ectopic pregnancy. But what are you supposed to do if you don't even know you have it? Chlamydia can be detected with a simple urine test and cured with one dose of antibiotics.

OF WOMEN WITH CHLAMYDIA HAVE NO SYMPTOMS?

did yoi

Find out more at www.getcluedup.com.au

OSED BY MODELS

pageA20

A POLLY/CLUED UP PROMOTION

# Some secrets aren't meant to be

Also known as "the silent disease", chlamydia is a sexually transmitted infection that's the sort of secret no one wants to keep!

That's right: 75 per cent of young women and up to 50 per cent of young men with chlamydia don't know they have it, meaning they could inadvertently share it with their partners through uprotected sex. Sexually active teenagers are also much more susceptible to being infected with chlamydia much more susceptible to being infected with chlamydia, which is the than older people. Figures show that chlamydia, which is the most common bacterial sexually transmitted infection in Australia, is on the rise, mostly among young women. And if Australia, is on the rise, mostly among young women, and if like infertility and ectopic pregnancy. But what are you meant to like infertility and ectopic pregnancy. But what are you meant to do if you don't know you have it? It's simple, really. Chlamydia can be do if you don't know you have it? It's with one dose of antibiotics. CHLAMYDIA IS THE MOST COMMON BACTERIAL SEXUALLY

ACTERIAL SEXUAL TRANSMITTED INFECTION IN AUSTRALIA

Find out more at www.getcluedup.com.au

### Some secrets aren't meant to be

Also known as "the silent disease", chlamydia is a sexually transmitted infection that's the sort of secret no one wants to keep!

That's right: 75 per cent of young women and up to 50 per cent of young men with chlamydia don't know they have it, meaning they could inadvertently share it with their partners through unprotected sex. Sexually active teenagers are also much more susceptible to being infected with chlamydia most common bacterial sexually transmitted infection in Australia, is on the rise, mostly among young women. And if it's not treated early, it can lead to serious health problems, it's not treated early, it can lead to serious health problems, like infertility and ectopic pregnancy. But what are you meant to do if you don't know you have it? It's simple, really. Chlamydia can be do if you don't know you have it? It's simple, really. Chlamydia can be do if you don't know you have it? It's simple, really. Chlamydia can be CHLAMYDIA CAN BE CURED WITH JUST

OF ANTIBIOTICS

NE DOSE

Find out more at www.getcluedup.com.au

#### APPENDIX D

#### EXAMPLES OF EMAILS SENT AND RECEIVED DURING THE RCT

- A23: D (i) Email exchanges between young people who engaged and nurse
- A26: D (ii) Initial email sent to young person in Control group

#### D (i) Email exchanges between young people who engaged and nurse

#### Example 1

Nurse -> Young person

Helloooo!!!!! Anyone there?????

This is [research nurse] again from the University of Sydney. I still haven't heard from you...so I assume you have no questions for me??? If you ever have any queries, or just wanna talk – write to me! Hope to hear from you soon. Cheers, [research nurse].

Ps you'll find me listed as a staff member of the University by typing my name [Name] at: http://www.usyd.edu.au/staff/directories/index.shtml

-----

#### Young person -> Nurse

Hi [research nurse]

Sorry, yeah I didn't have any questions. I meant to write you back but I guess i just forgot about it, I'm sorry. Thanks for the support and I will write you if I want to know something or feel worried about something. Thanks, [young person's name]

-----

Nurse -> Young person

Thanks for your reply [young person]! Anytime you have a question, just fire away <sup>(2)</sup> Seeya for now [research nurse] Example 2

Nurse -> Young person

Dear [name of young person]

My name is [name of research nurse] and I am a nurse from the team at getcluedup.com.au. I work at the University of Sydney and have many years of experience working with young people in sexual health. Thank you very much for completing the confidential online questionnaire on our website. You have now been entered into our research study. For confidentiality purposes your information has been stored as Study No. [xx]

I'd like to chat via email with you about chlamydia and getting tested. I wonder whether you have any questions you would like to ask me, such as where you could go to get tested? Do you know what services are available in your local area? Do you have any issues about confidentiality? Please drop me an email! Hope to hear from you soon.

Cheers, [research nurse].

Ps you'll find me listed as a staff member of the University by typing my name [Name] at: http://www.usyd.edu.au/staff/directories/index.shtml

#### Young person -> nurse

G'day [research nurse], I've heard that getting tested is putting a swab down the urethra, giving it a twirl or not, and pulling it out, sounds like it hurts, so, no thanks I don't want to get tested that way. I know I can get tested at the STD clinic on [address], elsewhere eg [other service]. Thanks anyway, [young person's name].

\_\_\_\_\_

#### Nurse -> Young person

Hiya [young person]!

The testing method you described was very old-school!!! Yes, it did seem to hurt the guys when we did it, but that method was used about 8 - 10 years ago. Now (lucky you!) we just ask you to pee into a jar. You need to make sure you haven't peed for a few hours (1-3) before the testing, tho'. (The chlamydia germs are found in the cells of the urethra, not the urine, so we need to make sure you haven't just peed them down the loo before having your test). So if you have any history of unprotected sex, it would be a great idea to go along and have one done – it really won't hurt. Nice to hear you know where to go for testing. Good luck with it! [research nurse]

.../continued

Nurse -> Young person

Hi there [young person]

Have you thought further about having chlamydia testing now you know it's not so terribly painful?

Let me know how you get on!

Cheers, [research nurse]

-----

<u>Nurse -> Young person</u>

Hi again [young person]

Hope you have been keeping well. Do you have any questions for me? I have also been wondering...did you ever end up going for chlamydia testing? Truly, it won't hurt!!

Cheers, [research nurse]

\_\_\_\_\_

#### Nurse -> Young person

Dear [young person]

This is [research nurse] from the University of Sydney. Thanks again for completing the confidential online questionnaire on our website. We will be sending you monthly emails to remind you of the study. In about 3 months you will be asked to complete another similar questionnaire and then the study will be finished. At that time you will received a clued up pen and a chance to win and iPod or a CD voucher. Remember if you ever have any questions, just ask!

Cheers, [research nurse]

\_\_\_\_\_

Young person -> nurse

Thanks [research nurse]

I look forward to doing the second part of the survey.

[young person]

#### Email template: Control group: initial email

To be sent from: cluedup@med.usyd.edu.au

Subject: Hi from the GetCluedUp team!

Dear <<name if provided>> / Hi there!

Thank you very much for completing the confidential online questionnaire on our website. You have now been entered into the research study that you will have read about on the website before you completed the questionnaire.

We hope you will find the information on the website useful and relevant.

We will send you another email in one month to remind you that you are still in the study. In about 6 months (Month, Year) you will be asked to complete another similar questionnaire and then the study will be finished. At that time you will receive a getcluedup pen and a chance to win an iPod or CD voucher.

Thanks again

The Research Team from Sydney University & the Inspire Foundation at <u>www.getcluedup.com.au</u>

PS Find out about Chlamydia and where you can get advice and help from www.getcluedup.com.au

#### **APPENDIX E**

### **RCT QUESTIONNAIRES**

- A27: Baseline questionnaire
- A35: Follow-up questionnaire

#### **BASELINE QUESTIONNAIRE**

The following questions ask about you and where you come from:
How old are you?years
Are you Male? Female?
Were you born in Australia? Yes/ No
If you were not born in Australia, where were you born?
In which country was your mother born?
In which country was your father born?
Are you of Aboriginal or Torres Strait Islander origin?
No
Yes Aboriginal
Yes Torres Strait Islander
Yes both Aboriginal and Torres Strait Islander
Is English the main language spoken at home? Yes/ No
If no, please specify what the main language spoken at home

What is the postcode of the place you live \_\_\_\_\_

Which of the following best describes what you do? (please tick only one)

I am

- studying at school
- studying at university or another tertiary institution
- looking for work
- working full time
- working part time
- -working casually

-other (please specify)\_\_\_\_\_

Which of the following best describes your education?

I have

- completed a university or tertiary qualification

- -completed my Year 12 qualification
- completed a Year 10 qualification
- did not complete Year 10 at school

How many times have you changed schools (including changing from primary to secondary school) since kindergarten? (does not include university or tertiary places of education) Never

- 1 or 2 times
- 3 or 4 times
- 5 or 6 times
- 7 or more times

How many times have you changed homes since kindergarten?

Never

1 or 2 times

3 or 4 times

5 or 6 times

7 or more times

Which of the following best describes your living situation?

I am

- living at home with parent/s or guardians and family

- living away from my parent/s or guardians and family

If you live away from parent/s guardian and family do you

- live in private rental or own home (either alone, with a partner, or with friends)

- live with a friend's family

- live in a refuge or supported accommodation

- other (please specify)\_\_\_\_\_

### The following questions ask what you know about Chlamydia

#### (all yes/ no/ don't know options)

Chlamydia is a sexually transmissible infection that affects only women Chlamydia can lead to sterility among women A woman can have chlamydia without any obvious symptoms A man can have chlamydia without any obvious symptoms Chlamydia is curable Chlamydia can be prevented by using condoms when you have sex

Chlamydia can be tested for with a urine sample

#### The following questions ask about your own sexual experiences and sexual history

Have you ever had <u>sexual intercourse</u>?

(Yes/No)

If yes, how old were you when you first had <u>sexual intercourse</u>? years

If yes, how many sexual partners have you ever had (partners where you had penis-vagina or anal sex)?

(1; 2; 3-5; 6-10, 11 or more)

If yes, how many sexual partners have you had in the past 12 months? (1; 2; 3-5; 6-10, 11 or more)

If yes, how often do you use condoms when you have sexual intercourse?

(Never, Sometimes, Usually, Always)

Have you ever been diagnosed with: (all yes/ no/ don't know)

<u>Chlamydia</u>

Genital Herpes

Human papillomavirus (also called HPV or the 'wart virus')

HIV

Gonorrhoea

Other\_\_\_\_\_

#### The following questions ask about smoking, drinking and drug taking

Have you smoked cigarettes in the **past 12 months**? Never Once or twice Once in a while but not regularly Regularly, but less than everyday Almost everyday or everyday How often do you have an alcoholic drink?

Never Less than once a month About 1 day a month 2 – 3 days a month About 1 day a week 2 – 3 days a week 4 – 6 days a week Everyday

On the day that you have an alcoholic drink how many <u>standard drinks</u> do you usually have? Never drink alcohol

- 1 2 drinks
- 3 4 drinks
- 5-6 drinks
- 7 8 drinks
- 9-12 drinks
- 13 or more drinks

#### In the past 2 weeks have you had five or more alcoholic drinks in a row?

Never

Once

Twice

- 3-6 times
- 7-9 times
- 10 times or more

In the past 30 days have you used marijuana (pot, weed, grass)?

No

1 or 2 times

3 - 5 times

6 - 9 times

10 or more times

In the past 30 days have you used other illegal drugs (like speed, heroin, ecstasy, cocaine)?

No

1 or 2 times

3-5 times

6-9 times

10 or more times

# The following questions ask about your attitudes towards chlamydia testing and experiences of health services

# Please tick the box that best describes how you feel about each of the following statements

	Strongly disagree	Disagree	Maybe	Agree	Strongly agree
I think I am at risk for chlamydia	uisugree				ugree
I don't think I have chlamydia					
I don't care whether I have chlamydia or not					
I don't know how to get a <u>chlamydia test</u>					
I would be too embarrassed to see a doctor or nurse to talk about chlamydia					
I would not see a doctor or nurse about chlamydia <b>because</b> I am worried about confidentiality					
It is difficult for me to see a doctor or nurse about chlamydia because of transport					
I would prefer to see a doctor or nurse who is the same sex as me for a <u>chlamydia test</u>					
It is difficult for me to see a doctor or nurse about chlamydia because of cost					
I would feel comfortable visiting a doctor or nurse to get a <u>chlamydia test</u>					
I do not want to talk to a doctor or nurse about my sexual history					
I can't get a <u>chlamydia test</u> because I don't have a Medicare card					
I don't want a <u>chlamydia test</u> because I'm scared of what it might show					
I don't want a <u>chlamydia test</u> because my partner/s might find out					
I would have a <u>chlamydia test</u> if my partner/s wanted me to					
I would have a <u>chlamydia test</u> if my doctor recommended it					
I want to have a <u>chlamydia test</u> because I would want to prevent any long term health problems from chlamydia					
I want to have a <u>chlamydia test</u> because I don't want to give chlamydia to my partner/s if I have it					

#### Where could you go to get a test for chlamydia?

#### (please tick one box for each service listed)

	Yes	No	I don't know	I don't know what this service is	This service is not available where I live, work or study
<u>General practitioner (GP)</u>					
Sexual Health Clinic					
Family Planning Clinic					
Youth Health Centre					
Other (please specify)					

#### Where would you *prefer* to get a chlamydia test? (please tick one only)

- My usual General practitioner (GP)
- A different GP who doesn't know me
- A Sexual Health Clinic
- A Family Planning Clinic
- A Youth Health Centre
- Other (please specify)\_\_\_\_\_

#### Have you had a chlamydia test in the last 6 months?

Yes

No

#### If yes, what was the result?

Positive

Negative

Don't know – I didn't find out the result

#### If positive did you:

- receive antibiotic treatment

Yes

No (please give reason)\_\_\_\_\_

- inform your partner/s had a positive Chlamydia test

Yes

No, I wasn't advised to

No, I didn't want to

No, other reason (please specify)\_\_\_\_\_

- go back and have another test a few weeks to months later

Yes

No, I wasn't advised to

No, I didn't want to

No, other reason (please specify)\_\_\_\_\_

#### FOLLOW-UP QUESTIONNAIRE

#### First of all, we would like to ask some questions about what you know about Chlamydia

#### (all yes/ no/ don't know options)

Chlamydia is a sexually transmissible infection that affects only women

Chlamydia can lead to sterility among women

A woman can have chlamydia without any obvious symptoms

A man can have chlamydia without any obvious symptoms

Chlamydia is curable

Chlamydia can be prevented by using condoms when you have sex

Chlamydia can be tested for with a urine sample

# The following questions ask about your experiences <u>in the past 6 months</u> in relation to Chlamydia

#### In the past 6 months have you had a chlamydia test?

Yes

No

#### If yes, what was the result?

Positive

Negative

Don't know – I didn't find out the result

#### If positive did you:

- receive antibiotic treatment

Yes

No (please give reason)\_\_\_\_\_

- inform your partner/s had a positive Chlamydia test

Yes

No, I wasn't advised to

No, I didn't want to

No, other reason (please specify)\_\_\_\_\_

#### If positive did you:

- go back and have another test a few weeks to months later

Yes

No, I wasn't advised to

No, I didn't want to

No, other reason (please specify)\_\_\_\_\_

In the past 6 months have you been diagnosed with any of the following: (all yes/ no/ don't know)

Genital Herpes

Human papillomavirus (also called HPV or the 'wart virus')

HIV

Gonorrhoea

Other\_\_\_\_\_

In the past 6 months, how many sexual partners have you had (0; 1; 2; 3-5; 6-10, 11 or more)

In the past 6 months, how often have you used condoms when you have sexual intercourse (penis-vagina or penis-anus intercourse)?

(Never, Sometimes, Usually, Always, Not applicable)

The following questions ask about your attitudes towards chlamydia testing and experiences of health services.

# Please tick the box that best describes how you feel about each of the following statements

	Strongly disagree	Disagree	Maybe	Agree	Strongly agree
I think I am at risk for chlamydia	uisugice				ugree
I don't think I have chlamydia					
I don't care whether I have chlamydia or not					
I don't know how to get a <u>chlamydia test</u>					
I would be too embarrassed to see a doctor or nurse to talk about chlamydia					
I would not see a doctor or nurse about chlamydia because					
I am worried about confidentiality It is difficult for me to see a doctor or nurse about chlamydia because of transport					
I would prefer to see a doctor or nurse who is the same sex as me for a <u>chlamydia test</u>					
It is difficult for me to see a doctor or nurse about chlamydia because of cost					
I would feel comfortable visiting a doctor or nurse to get a <u>chlamydia test</u>					
I do not want to talk to a doctor or nurse about my sexual history					
I can't get a <u>chlamydia test</u> because I don't have a Medicare card					
I don't want a <u>chlamydia test</u> because I'm scared of what it might show					
I don't want a <u>chlamydia test</u> because my partner/s might find out					
I would have a <u>chlamydia test</u> if my partner/s wanted me to					
I would have a <u>chlamydia test</u> if my doctor recommended it					
I want to have a <u>chlamydia test</u> because I would want to prevent any long term health problems from chlamydia					
I want to have a <u>chlamydia test</u> because I don't want to give chlamydia to my partner/s if I have it					

#### Where could you go to get a test for chlamydia?

#### (please tick one box for each service listed)

	Yes	No	I don't know	I don't know what this service is	This service is not available where I live, work or study
General practitioner (GP)					
Sexual Health Clinic					
Family Planning Clinic					
Youth Health Centre					
Other (please specify)					

#### Where would you *prefer* to get a chlamydia test? (please tick one only)

My usual General practitioner (GP)

A different GP who doesn't know me

A Sexual Health Clinic

A Family Planning Clinic

A Youth Health Centre

Other (please specify)\_\_\_\_\_

Please feel free to add any other comments about the questionnaire or your responses:

Finally, we would like to ask whether you would like to provide a mailing address so that we can send you a Clued Up pen to thank you for your participation. This is optional. You will also be notified by email if you win one of the IPods or CD vouchers and asked to provide a current mailing address at that time.

Current mailing address:

#### APPENDIX F

#### A39: Signed statement from co-authors

A40: Kang M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Sexual behaviour, sexually transmitted infections and attitudes to chlamydia testing among a unique national sample of young Australians: baseline data from a randomised controlled trial. BMC Public Health 2014, 14:12.

#### A47-48: Signed statements from co-authors

Kang M, Rochford A, Mindel A, Skinner SR, Webb M, Hillier L, Usherwood T.
 Young people get clued up about chlamydia: an internet based randomised controlled trial [abstract]. *Sexual Health*, 2007; 4:289.

#### In relation to the published articles:

Kang M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Facilitating chlamydia testing among young people: a randomised controlled trial in cyberspace. *Sexually Transmitted Infections* 2012; 88:568-573.

Kang M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Sexual behaviour, sexually transmitted infections and attitudes to chlamydia testing among a unique national sample of young Australians: baseline data from a randomised controlled trial. *BMC Public Health* 2014, 14:12

#### We verify that:

Melissa Kang wrote the original grant application with assistance from Rachel Skinner and Adrian Mindel. She wrote the entire content of the website (*getcluedup*) and Arlie Rochford, Rachel Skinner, Adrian Mindel and Marianne Webb reviewed it. She developed the study design with assistance from Rachel Skinner, Adrian Mindel, Tim Usherwood and Marianne Webb. She and Marianne Webb recruited the Youth Consultant groups and Melissa facilitated their meetings. She and Arlie Rochford recruited study participants, delivered the intervention and collected all data. She, Arlie Rochford, Jennifer Peat and Tim Usherwood completed data analysis and all authors assisted with interpretation of findings. She prepared the first drafts of the manuscripts and completed revisions after discussion with all authors. She revised manuscripts after reviewer feedback after discussion with co-authors.

Acape 21/2/15

Arlie Rochford

24/2/15

**Rachel Skinner** 

21/2/15

**Adrian Mindel** 

Marianne Webb

Tim Usherwood

#### **RESEARCH ARTICLE**



**Open Access** 

### Sexual behaviour, sexually transmitted infections and attitudes to chlamydia testing among a unique national sample of young Australians: baseline data from a randomised controlled trial

Melissa Kang<sup>1\*</sup>, Arlie Rochford<sup>1</sup>, S Rachel Skinner<sup>2</sup>, Adrian Mindel<sup>3</sup>, Marianne Webb<sup>4</sup>, Jenny Peat<sup>5</sup> and Tim Usherwood<sup>1</sup>

#### Abstract

**Background:** Chlamydia infection is the most common notifiable sexually transmitted infection (STI) in Australia and mostly affects young people (15 – 25 years). This paper presents baseline data from a randomised controlled trial that aimed to increase chlamydia testing among sexually active young people. The objectives were to identify associations between sexual behaviour, substance use and STI history and explore attitudes to chlamydia testing.

**Methods:** This study was conducted in cyberspace. Study recruitment, allocation, delivery of interventions and baseline and follow up data collection all took place online. Participants were 16 – 25 years old and resided in Australia. Substance use correlates of sexual activity; predictors of history of STIs; barriers to and facilitators of chlamydia testing were analysed.

**Results:** Of 856 participants (79.1% female), 704 had experienced penetrative intercourse. Sexually active participants were more likely to smoke regularly or daily, to drink alcohol, or to have binge drunk or used marijuana or other illicit substances recently. Risk factors for having a history of any STI were 3 or more sexual partners ever, 6 or more partners in the past 12 months, condom non-use and being 20 years or older. Almost all sexually active participants said that they would have a chlamydia test if their doctor recommended it.

**Conclusions:** Sexually active young people are at risk of STIs and may engage in substance use risk behaviours. Where one health risk behaviour is identified, it is important to seek information about others. Chlamydia testing can be facilitated by doctors and nurses recommending it. Primary care providers have a useful role in chlamydia control.

Trial Registration: Australian and New Zealand Trials Registry ACTRN12607000582459

Keywords: Adolescents, Young people, Chlamydia, Sexually transmitted infections, Health risk behaviour

#### Background

Most people experience their first partnered sexual interactions in the second decade of life [1]. The average age of first penetrative vaginal intercourse in Australia has been 16 years for females and males for over three decades [2,3]. Despite the initiation of sexual intercourse in the teenage years being normative, the 1980s' HIV

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pandemic and changing patterns of sexual relationships among young people have contributed to worldwide concern about adolescent sexual behaviour as a public health issue. Genital chlamydia infection is more prevalent than HIV globally and affects people under 25 years more than any other age group [4]. To address the rapid rise of chlamydia notifications in Australia since 1999, the first (2005 – 2008) and second (2010 – 2013) national sexually transmissible infections (STI) strategies included chlamydia control and young people as specific priorities



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[5,6]. One of the key components of both strategies was to increase chlamydia testing among target groups.

Research into young people's sex lives in the public health context has focused on sexual risk behaviour. This has been variously defined as penetrative intercourse without consistent condom use, intercourse with casual partners, having three or more sexual partners in twelve months and/or initiation of sexual intercourse before 16 years of age [7-9]. Many studies have found that adolescent 'risk behaviours' tend to cluster, for example smoking, binge drinking and sexual risk behaviours [9,10]. The technical ease with which chlamydia infection can be tested in urine samples has added a new dimension to recent studies, with attention to young people's interaction with the health system and the barriers and facilitators to testing of prime importance.

This study was one of fifteen projects funded by the first national STI strategy [5] to evaluate chlamydia testing interventions. The aims of this study were to:

- Provide demographic, substance use and sexual history characteristics of a unique sample of young Australians (16 – 25 years).
- Identify associations between sexual behavior, substance use and STI history.
- Report on chlamydia knowledge and attitudes to chlamydia testing.

#### Methods

This paper reports on baseline data from a randomised controlled trial (RCT) [11] of 16 - 25 year-old Australians. The study was conducted in cyberspace. A website about chlamydia was launched in March 2007 and invited eligible visitors to participate in a study to promote chlamydia testing. This website was developed with input from 20 youth consultants (16-25 years) who were recruited through professional and collegiate networks. The website was promoted through paid advertising, existing youth-related websites, social networking sites and opportunistic radio interviews. Website traffic was monitored using Google Analytics.

The website invited eligible visitors to participate in the study via clickable links on the homepage and all other webpages. To be eligible, visitors had to be aged 16 - 25 years, reside in Australia, answer 'yes' to whether they had ever had penetrative (vaginal or anal) intercourse and provide an email address. Potential participants were taken to a Participant Information Statement, entered a current email address and ticked a consent box. This step took them to the baseline questionnaire housed within the website.

The sampling frame was all eligible visitors to the website, but participation rates were not measurable since the denominator was unknown. The target sample size for the RCT was 1000. A detailed description of the RCT methods has been published elsewhere [11].

One hundred and fifty-two young people who completed baseline data had not had penetrative sex and were not enrolled in the RCT. Their substantial number provided a comparison group when analysing sociodemographic correlates of health risk behaviours, as many differences achieved statistical significance.

The baseline questionnaire collected sociodemographic data, sexual and substance use history, knowledge about chlamydia, attitudes towards chlamydia testing and testing preferences. Some attitude questions explored known barriers to accessing health care for Australian young people [12], such as concerns about confidentiality and owning one's own 'Medicare card'. Australia has a universal health insurance scheme ('Medicare') and doctors and pathology providers can choose to bill a service directly to Medicare, meaning the patient has no upfront fee. Possessing one's own card (separate from a family card) is not essential, but can facilitate this direct billing process.

Data were analysed using SPSS v19.0 (IBM, USA). Categorical variables were compared between groups using chi-square tests with Yate's correction for  $2 \times 2$  tables. Continuous variables were compared using independent samples t-tests. Logistic regression analyses were conducted on the whole sample to assess substance use behaviours that were associated with being sexually active while controlling for age and sex, and on the sexually active group to predict risk factors for STIs.

Ethical approval was obtained from The University of Sydney Human Research Ethics Committee and the trial was registered with the Australian and New Zealand Trials Registry (ACTRN12607000582459).

#### Results

Recruitment took place between March 2007 and January 2008 and 856 people aged 16 – 25 years provided complete datasets. Seven hundred and four young people reported they had ever had sexual intercourse and 152 reported they had never had sexual intercourse.

Of the 856 young people, 677 (79.1%) were female, 175 (20.4%) were male and 4 (0.5%) did not state their sex. Mean age was 19.8 years (SD = 3.0). Twenty-seven (3.2%) were either Aboriginal or Torres Strait Islander or both, compared to 3.4% of the general population aged 15 – 24 years [13]. The majority were born in Australia, spoke English at home and were studying and living at home with family. All states and territories of Australia were represented, as were all Australian Standard Geographical Classification groups (major cities, inner regional, outer regional, remote, very remote). The majority (83.3%) were fully engaged in employment and/or education (working or studying *full time* or working *and* studying). Those not fully engaged were working part time or

casually (8.3%), looking for work (5.0%), engaged in parenting or domestic duties (1.8%) or did not respond (1.8%). Sixty-three point nine percent had attained a Year 12 certificate (the highest school-based qualification in Australia) or above (27.7% were still in school and could not yet have attained this). Table 1 compares these characteristics

# Table 1 Sociodemographic characteristics of the sample (n = 856) compared to the population aged 15–24 years from the 2006 Census [15]

	Sample at baseline 2007	Australian population
	16 – 25 years	15 – 24 years in 2006
	Valid percent	Percent
Sex = female	79.1	48.7
Born in Australia	88.4	84.1
Born overseas in English speaking country	6.7	5.3
Born overseas in non-English speaking country	5.1	10.1
Aboriginal and/or Torres Strait Islander	3.2	3.4
Speak English at home	95.3	84.0
State of residence		
New South Wales	33.0	32.2
Victoria	25.7	24.9
Queensland	17.8	19.9
WA	9.2	10.2
SA	5.7	7.4
Tas	4.0	2.3
ACT	3.4	1.9
NT	1.2	1.1
Geographic location		
Major cities	71.5	68.4
Inner Regional	18.5	19.6
Outer Regional	9.1	9.1
Remote	0.7	1.4
Very remote	0.1	0.9
Occupation		
Fully engaged in education and/or employment	83.3	83.6*
Education Level (highest attained)		
Completed Year 12 or above	63.9	59.1*
Living situation		
At home with parents/guardian	57.8	
Away from home (private rental, campus based, with friends)	41.0	
Refuge or supported accommodation	0.7	
Not stated	0.5	

\*Taken from 2007 Education and Work Australia survey [16].

between our sample and the general population aged 15-24 in Australia.

### Sexually active and non-sexually active respondents compared

The mean age of young people reporting that they had ever had sex at baseline ("sexually active, SA", n = 704) was significantly higher than the mean age of those reporting never having had sex ('NSA' group, n = 152). There were higher proportions of males and of people who spoke English at home in the SA group compared to the NSA group. Logistic regression was performed to explore associations between being sexually active and substance use. Odds ratios were adjusted for age and gender. SA young people were significantly more likely than NSA young people to smoke regularly or daily, to drink alcohol at all or to drink once a week or more, to have binge drunk (5 or more drinks in a row) in the past 2 weeks, and to have used marijuana or other illicit substances in the past 30 days (Table 2).

Chlamydia knowledge was measured using seven questions, some of which were taken directly, and others adapted from, the National Secondary Students and Sexual Health Survey [14]. SA young people scored significantly higher on composite scores, and for six out of seven questions (Table 3).

#### Characteristics of the sexually active group

The SA group (n = 704) was analysed to explore sexual history (number of sexual partners, condom use, history of chlamydia or other STIs) as well as attitudes to and preferences for chlamydia testing.

The mean age of the SA group was 20.3 years (SD 2.9) and 78.0% were female. Although mean age of males was higher than females, mean age of first penetrative intercourse for females was significantly lower. Compared to

### Table 2 Substance use factors associated with beingsexually active (n = 856)

	Sexually active (n = 704)	Not sexually active (n = 152)	Odds ratio (95% CI)*	P value
Smoking regularly	29.0%	2.7%	15.1 (5.5, 41.6)	<0.0001
Drinking alcohol ever	93.8%	63.8%	6.6 (4.1, 10.7)	<0.0001
Drinking > once/week	49.0%	12.5%	4.9 (2.9, 8.3)	<0.0001
Binge drinking	58.4%	17.1%	6.2 (3.9, 9.9)	<0.0001
Marijuana in last 30 days	19.2%	5.3%	5.0 (2.3, 10.6)	<0.0001
Illicit drugs last 30 days	12.9%	1.3%	11.1 (2.6, 46.0)	0.001

\*Adjusted for age and gender.

Question	Sexually active% who answered correctly (n = 704)	Not sexually active% who answered correctly (n = 152)	p value
Chlamydia is a sexually transmissible infection that affects only women	89.4	84.7	0.05
Chlamydia can lead to sterility among women	84.7	80.5	0.11
A woman can have chlamydia without any obvious symptoms	91.3	86.0	0.03
A man can have chlamydia without any obvious symptoms	83.4	76.5	0.02
Chlamydia is curable	84.6	77.3	0.03
Chlamydia can be prevented by using condoms when you have sex	91.2	82.0	0.0003
Chlamydia can be tested for with a urine sample	77.1	70.0	0.05
Mean composite score/7	5.3	4.9	0.001

#### Table 3 Differences in chlamydia knowledge between sexually active and non-sexually active young people

females, males had greater numbers of sexual partners ever and in the past 12 months. Among the STIs, gender was significant only for gonorrhoea, where males were more likely to have had a diagnosis than females. There was no difference between males and females with respect to condom use. Table 4 shows sexual history variables by sex.

One hundred and eighteen young people (16.9%) reported a history of ever being diagnosed with chlamydia at baseline. The next most frequently reported STI was human papillomavirus (defined as 'human papillomavirus also called HPV or the wart virus') (8.3%) followed by genital herpes (3.9%), gonorrhoea (2.1%) and HIV (1.0%).

One hundred and eighty-eight young people (26.7%) reported having had a chlamydia test in the past six months, of these 70 (37.2%) reported that the test was positive. All but one who reported a positive chlamydia test stated that they had received antibiotic treatment and 65/70 had informed their partner of the result. Forty-seven (67.1%) of those who had tested positive reported that they had returned for a second test. Most who had not returned for a second test stated that insufficient time (to test for re-infection) had passed.

A logistic regression analysis was conducted to predict risk factors for ever having had an STI. Four of the independent variables (age, number of sexual partners in the past 12 months and ever, and condom use) made a statistically significant contribution to the model. Gender, being Aboriginal and/or Torres Strait Islander, speaking English at home and having first intercourse before the age of 16 years were neither significant univariate predictors nor significant when included in the model. The strongest predictor was the number of sexual partners ever. Table 5 shows the adjusted odds ratios for the risk factors for STIs.

Early initiation of sexual intercourse (< 16 years) was associated with being Aboriginal and/ or Torres Strait Islander (71.4% cf 31.6%, p <0.0001); no/low condom use (54.7% cf 42.7%; p = 0.004); 6 or more partners in

the past 12 months (17.5% cf 7.7%; p < 0.0001); smoking regularly (47.9% cf 27.2%, p < 0.0001) and using cannabis (46.0% cf 29.9%; p = 0.001) or illicit drugs (44.6% cf 31.3%, p = 0.02). There was no association between early sex and gender, alcohol use or history of chlamydia testing.

Table 4 Differences in sexual history between females and males

Variable	Females	Males	p value
	N = 547	N = 154	
Mean age (SD)	20.0 years (3.0)	21.4 years (2.6)	p <0.0001
Mean age of first intercourse (SD)	16.1 years (2.3)	16.7 years (2.3)	0.004
Mean no. of years since first intercourse (SD)	3.9 years (3.0)	4.7 years (3.0)	0.002
Number of sexual partners ever			
One	22.9%	14.4%	
Two	12.3%	11.8%	0.03
Three to five	25.8%	20.9%	
Six to ten	17.8%	22.9%	
Eleven or more	21.2%	30.0%	
Number of sexual partners in last 12 months			
One	49.9%	40.4%	
Two	19.3%	17.2%	0.02
Three to five	20.6%	23.8%	
Six to ten	5.4%	12.6%	
Eleven or more	4.8%	6.0%	
Use condoms always or mostly	51.6%	56.5%	0.32
History of chlamydia	17.6%	13.9%	0.34
History of HPV	8.1%	9.2%	0.81
History of gonorrhoea	1.3%	5.2%	0.009
History of genital herpes	3.7%	4.5%	0.79
History of HIV	1.1%	0.6%	0.35

Risk factor	Percent (%) in exposed group	Percent (%) in unexposed group	Unadjusted odds ratio	Adjusted odds ratio (95% Cl)	P value
N	164	524			
Gender (female)*	23.9%	23.5%	0.98	-	
Aboriginal and/or Torres Strait Islander*	38.1%	23.4%	2.41	-	-
English at home*	24.2%	11.5%	2.44	-	-
Age 20 years and older	29.0%	13.1%	2.72	1.95 (1.22, 3.12)	0.005
Age first intercourse < = 15 years*	26.4%	22.6%	1.23	-	
Condom use never or sometimes	28.5%	19.7%	1.61	1.48 (1.02, 2.16)	0.04
Three or more sexual partners ever	32.3%	7.0%	6.34	4.78 (2.67, 8.54)	< 0.0001
Six or more sexual partners last 12 months	45.9%	21.1%	2.01	2.25 (1.34, 3.79)	0.002

Table 5 Predictors of STI history in participants who had sexual intercourse ever

\*Not significant predictors in multivariate logistic regression.

Attitudinal questions explored barriers and facilitators to testing. The strongest facilitators of testing in the SA group were 'if my doctor recommended it' (97.4% agreed), 'because I don't want to give it to my partner if I have it' (95.4% agreed), 'to prevent long term health problems' (94.5% agreed) and 'if my partner wanted me to' (88.5% agreed). Seventy-six percent agreed that they 'would feel comfortable visiting a doctor or nurse for a chlamydia test', although 43.2% also agreed that they 'would feel too embarrassed to talk to a doctor or a nurse about chlamydia'. Less than half the sample (46.2%) agreed that they did not want to talk about their sexual history with a doctor or nurse. Barriers to testing included being scared of what the test might show (40.0% agreed), their partner/s finding out (25.1% agreed) concerns about cost (36.5% agreed) confidentiality (19.8% agreed), transport (17.3% agreed) and not having their own Medicare card (11.2% agreed). Thirty-three percent agreed that they did not know how to get a chlamydia test. Seventy-nine percent agreed that they would like to see a doctor or nurse the same sex as themselves to get a chlamydia test. Young women were significantly more likely than young men to prefer seeing a doctor of the same sex (83.2% cf 66.0%, p <0.0001) but there were no gender differences in relation to attitudes to testing.

Two hundred and ninety-six young people in the SA group (42.0%) indicated that they would prefer to have a chlamydia test done by their usual general practitioner (GP), and 144 (20.5%) preferred a different GP. One hundred and fifty-five young people (22.0%) preferred to be tested at a sexual health clinic. The remainder preferred a Youth Health Service (4.5%), Family Planning Clinic (2.8%), or did not state a preference (8.2%).

#### Discussion

This unique sample, recruited entirely in cyberspace, adds to knowledge about sexual behaviours of young Australians and their socio-demographic and substance use correlates. For those who had had sexual intercourse, the mean age of sexual debut was 16.2 years. Sexually active young people were more likely than their nonsexually active counterparts to speak English at home, to smoke regularly, drink alcohol, binge drink and use marijuana or other illicit substances. They also had greater knowledge about chlamydia infection and testing. Sexually active young people reported that they would be willing to have a chlamydia test if their doctor recommended it, or to protect their own or their sexual partner/ s' health. Barriers to testing included embarrassment, concerns about confidentiality, cost, transport and not having a Medicare card. Most preferred to see a general practitioner (GP) for chlamydia testing.

Compared to Census data from 2006 (the closest year to our study) [15], young people living in major cities, born in Australia and speaking English at home were over-represented but differences were minor. Ninety-one per cent of our sample were engaged in education or paid employment, which is higher than comparable national data from 2007 which found 83.6% of 15 - 24 year old Australians fully engaged in education or training and/ or work [16]. We found that being Aboriginal and/or Torres Strait Islander was a predictor of sexual debut < 16 years. This is entirely consistent with sexual experience reported by the first systematic survey of child health among Aboriginal children and young people in Western Australia in 2005 [17]. Reasons for earlier sexual activity are thought to reflect earlier social maturity and the cultural acceptability of earlier child bearing [17]. Rates of substance use in this sample are difficult to compare with either the 2007 national drug strategy household survey [18] or the 2008 national survey of secondary students and sexual health [14] because of different age groupings, definitions, and wording of questions, however there were no stark differences. In the national drug strategy household survey, 32.4% of 14 - 29 year olds smoked daily or weekly, compared to 24.2% of our sample of 16 -25 year olds. Patterns of alcohol use were very similar between our sample for those aged 16 and 17 and the

2008 National Secondary Schools and Sexual Health survey [14]. Rates of marijuana and other illicit substance use were reasonably congruent between our sample and the national household survey [18]. The correlation between being sexually active and substance use and the clustering of health risk behaviours are consistent with international studies; [19] this is one of very few Australian studies [20] to report explicitly on this.

The high proportion who had had a recent positive chlamydia test is not surprising. We would expect those who had reason to be concerned to be searching for relevant information and come across our website. Therefore it was pleasing that the majority had *not* had a test and that, although unanticipated, young people who had never had sex also chose to complete the baseline questionnaire. Knowledge about chlamydia was considerably higher for comparable questions than in the national survey of secondary students in 2008 but this may reflect the older age of study participants as well as the bias towards young people interested in chlamydia.

Most young people indicated that they would have a chlamydia test to protect their, or their partner/s' health. This, combined with the fact that one-third of the sample did not know how to get a chlamydia test, while a smaller proportion expressed concerns about confidentiality suggests that education about access to testing is also warranted.

These findings highlight the important role of GPs in chlamydia control. Over 60% of sexually active young people in this study preferred to see a GP for chlamydia testing and almost all (males as well as females) would be willing to have a test if their doctor recommended it. National general practice surveillance data has shown that the "opportunity to test" for chlamydia is the strongest predictor for being tested [21]. Yet over the same study period as ours (2007 - 2008), Medicare data showed that only 12.5% of sexually active young women and 3.7% of sexually active young men were tested for chlamydia [22]. This lower testing rate among young men is consistent with sex differences found in the United Kingdom, one of few countries with a national screening program [23] and one of few that recommends, as in Australia, that asymptomatic, sexually active young men as well as young women are routinely screened. As with our study, this research also found that young men would find screening in general practice acceptable.

Australian GPs identify lack of time and knowledge as barriers to testing, but they also report concern about 'patient embarrassment' as a factor [24,25]. Recent evidence suggests that this concern is misplaced and that most patients are willing to discuss STIs with their GPs [26].

While forty percent of our sample also nominated embarrassment as a barrier, the majority stated that they would be comfortable visiting their doctor or nurse for a chlamydia test. Our finding that less than 50% of young people did not want a sexual history taken contrasts with earlier research among young Australian women which found that having a sexual history taken was a dominant concern [27]. These apparent contradictions might reflect differences in our sample's experience with chlamydia testing compared with those of the general population. But they highlight nuances associated with, and need for sensitivity when discussing, sexuality. The onus should be on doctors or nurses to raise the issue, explore sexual histories sensitively, explain confidentiality, normalise testing as part of routine health care and recommend testing when appropriate. Promoting messages about taking care of one's health and one's partner/s' health might also be effective. We also acknowledge that our data exploring attitudes to testing are now a few years old. Awareness of chlamydia might have increased significantly due to national media campaigns. Young people's use of technology and social media might have changed considerably since we conducted this study. Whilst the impact of these changes might inform new health promotion strategies, we believe that our findings clearly support that having health professionals directly offer testing opportunistically is likely to be effective at increasing testing rates.

The main limitation of this study is the unique sampling method which brings into question the study's external validity. Although we believe this was an innovative way to deliver a behavioural intervention, it is a self-selected sample likely to be more interested in chlamydia. While the sample is not generalisable in the same way as a random sample would be, we can gain a sense of how well basic demographic groups are represented (gender, indigenous status, country of birth, region of residence). Website traffic can only infer possible reach of a website rather than provide a denominator for measuring participation rates, which is another challenge in online research. Another limitation of this study is the reliance on self-report: this may have under-estimated exposure to STIs and/or over-estimated screening. However the anonymity of the internet might have facilitated disclosure of personal information.

In summary, Australian young people begin partnered sexual activity in their mid-teen years, and many are at risk of chlamydia and other STIs. The availability of affordable testing and treatment for chlamydia, as well as young people's willingness to consult with doctors and nurses in general practice and other primary care settings and take up testing, should make it a routine part of all consultations with young people.

#### Conclusions

Where one health risk behaviour is identified, it is important to seek information about others. Chlamydia

testing can be facilitated by doctors and nurses recommending it. Primary care providers have a useful role in chlamydia control.

#### **Competing interests**

None of the authors have any financial or non-financial competing interests in the publication of this manuscript.

#### Authors' contributions

MK wrote the original grant application, designed and managed the research project, convened and facilitated the Youth Consultant team meetings, promoted the website via media interviews and advertising, assisted with delivering the intervention, conducted most of the data analysis and wrote and revised drafts of the manuscripts. AR was the main clinician involved in delivering the intervention and assisted with data collection. SRS assisted with the grant application, research design, interpretation of data analysis and review of the manuscript. AM assisted with the grant application, research design, interpretation of data analysis and review of the manuscript. MW assisted with the grant application, assisted with facilitation of Youth Consultant team meetings, provided expert advice on e-technology and the use of websites for health promotion and contributed to the interpretation of findings and manuscript review. JP performed a substantial amount of data analysis and assisted with interpretation of statistical findings. TU assisted with research design, interpretation of findings and manuscript review. All authors read and approved the final manuscript.

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## In relation to the published abstract:

Kang M, Rochford A, Mindel A, Skinner SR, Webb M, Hillier L, Usherwood T.

Young people get clued up about chlamydia: an internet based randomised controlled trial [abstract]. Sexual Health, 2007, 4, 289.

Abstracts from the Australasian Sexual Health Conference 2007 - 8-10 October 2007, Gold Coast, Australia

#### We verify that:

Melissa Kang wrote the original grant application with assistance from Rachel Skinner and Adrian Mindel. She wrote the content of the website (getcluedup) and Arlie Rochford, Rachel Skinner, Adrian Mindel and Marianne Webb reviewed it. She developed the study design with assistance from Rachel Skinner, Adrian Mindel, Tim Usherwood and Marianne Webb. She and Marianne Webb recruited and facilitated the Youth Consultant groups. She and Arlie Rochford recruited study participants, delivered the intervention and collected all data. She, Arlie Rochford and Tim Usherwood completed data analysis and all authors assisted with interpretation of findings. She prepared and submitted the abstract to the conference (Australasian Sexual Health Conference) which was reviewed by all authors. She and Arlie Rochford prepared the oral presentation.

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Arlie Rochford

**Rachel Skinner** 

Adrian Mindel

Marianne Webb

Milli

Lynne Hillier

Tim Usherwood

#### Abstracts

implementation and provides opportunities for capacity building to regionally based services. For example, poor access to sexual health services is being addressed by the participants being able to access services via telephone consultation with Melbourne Sexual Health Centre.

Approximately 1000 Victorians aged 16–25 years from the Loddon Mallee region of Victoria will be tested between June and September 2007. This paper will report on the feasibility, challenges and possible solutions in establishing a community based outreach testing and treatment program.

# 12. YOUNG PEOPLE GET CLUED UP ABOUT CHLAMYDIA: AN INTERNET BASED RANDOMISED CONTROLLED TRIAL

M. Kang<sup>1</sup>, A. Rochford<sup>1</sup>, A. Mindel<sup>2</sup>, S. R. Skinner<sup>3</sup>, M. Webbm<sup>4</sup>, L. Hillier<sup>5</sup> and T. Usherwood<sup>1</sup>

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Young people (16–25 years) are a target group for the prevention of *Chlamydia trachomatis* in the Australian national STI strategy. This study is a randomized controlled trial of an innovative internet-based intervention which aims to increase Chlamydia testing and treatment among at risk young people living in Australia. Study participation is via a website developed in consultation with young people and linked to an evaluated health promotion website. Young people in the intervention group receive personalised, confidential emails from a nurse or doctor while those in the control group receive automated emails. Follow up at 6 months will measure self-reported Chlamydia testing and other outcomes. By 5 June 2007, 359 young people of a target sample of 1000 were enrolled (83% female). Mean age is 20 years (range 16–25). Participants reside across all states and territories. Thirty percent of participants in the intervention group are in active email dialogue with the research nurse, e.g. *"The research and ... site was ... really good, ... it's kinda scared me into getting a test and just to get over the embarrassment ... will the test be able to be part of just a normal appointment?"* Zero participants in the control group have responded to the automated email. Baseline data and examples of the email interaction will be presented.

# 13. CAUGHT IN THE WEB: CYBERSEX AND ITS IMPACT ON INDIVIDUALS AND THEIR INTIMATE RELATIONSHIPS

K. C.  $Misso^{1,2}$ 

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With the current meteoric expansion in computer technology phonographic magazines and videos are fast being replaced by virtual intimacy and sex on the Internet. The affordability, accessibility and anonymity of the net offer a pseudo-intimacy less threatening and demanding than real life intimacy. The illusion of being in control, of constructing the relationship of your dreams can become quite addictive. This presentation will draw on current research and clinical data to illustrate how clients caught in the web find the compulsive behaviour patterns that emanate extremely destructive. With the passage of time such behaviour patterns can have a negative impact on an individual's psychological health, social relationships, work performance and most significantly, intimate relationships. The latter is a new factor contributing to distress in and the breakdown of couple relationships. The presentation highlights several 'warning signs' of a downward spiral and offers clinicians therapeutic strategies for working with couples caught up in this potential maelstrom. The computer hailed as a communication marvel, which was to facilitate 'connection', is fast becoming an instrument of 'disconnection' for those who are naïve enough to ignore its darker side.

#### **14. GENITAL HERPES ONLINE RISK SURVEY**

A. Mindel<sup>1</sup>, E. Christie<sup>1</sup>, C. Chung<sup>1</sup>, T. Berger<sup>2</sup> and the Australian Herpes Management Forum (AHMF)

<sup>1</sup>Sexually Transmitted Infections Research Centre (STIRC) and University of Sydney, Marian Villa, Westmead Hospital, Westmead NSW 2145, Australia.

<sup>2</sup>Australian Herpes management Forum, c/-STIRC, Marian Villa, Westmead Hospital, Westmead NSW 2145, Australia.

**Background:** Genital herpes is one of the most common sexually transmitted infections (STIs) worldwide. In Australia, a population-based survey revealed that 16% of women and 8% of men over 25 had antibodies to HSV-2. The majority of people infected with HSV-2 are asymptomatic. With increasing availability of web-based technology for use as an information and education tool, we established a web-based survey to determine risk for genital herpes and encourage people who maybe at risk to attend a health care professional for HSV testing.

Methods: A web-based genital herpes risk assessment quiz was established on the AHMF web page. The quiz was based on epidemiological data derived from a national population-based survey and other epidemiological studies and consisted of 16 questions, each with a numerical weighting.

# APPENDIX G

# DATA MEASURING ATTITUDE MEAN RANKS AT FOLLOW UP

(See Chapter 11.5.3)

- A50: G (i) Change in mean attitude scores for Intervention and Control and Engaged and Control groups
- A52: G (ii) Attitude mean ranks at follow up comparing Intervention and Control groups Attitude mean ranks at follow up comparing Engaged and Control groups

	Attitude	Intervention	Control	Independent	Ь	Engaged	Control	Independent	Ч
		Mean	Mean	samples t-	value	Mean	Mean	samples t-	value
		difference	difference	test statistic		difference	difference	test statistic	
-				(df)				(df)	
	I think I am at risk for chlamydia	-0.64	-0.40	-1.525	0.13	-0.67	-0.40	-1.463	0.15
				(293)				(261)	
	Trend towards	disagreement	disagreement			disagreement	disagreement		
	I don't think I have chlamydia	0.52	0.51	0.026	0.98	0.63	0.51	0.532	09.0
				(288)				(258)	
	Trend towards	agreement	agreement			agreement	agreement		
-	I don't care whether I have chlamydia or not	0.02	0.05	0366	0.72	0.07	0.05	0.243	0.81
				(289)				(258)	
	Trend towards	disagreement	disagreement			disagreement	disagreement		
	I don't know how to get a chlamydia test	0.52	0.41	0.740	0.46	0.67	0.41	1.421	0.16
				(291)				(259)	
	Trend towards	disagreement	disagreement			disagreement	disagreement		
	I would be too embarrassed to see a doctor or nurse	0.43	0.30	0.912	0.36	0.54	0.30	1.366	0.17
	to talk about chlamydia			(288)				(256)	
	Trend towards	disagreement	disagreement			disagreement	disagreement		
	I would not see a doctor or nurse about chlamydia	0.07	0.15	0672	0.50	0.22	0.15	0.485	0.63
	<u>because</u> I am worried about confidentiality			(293)				(261)	
	Trend towards	disagreement	disagreement			disagreement	disagreement		
<u> </u>	It is difficult for me to see a doctor or nurse about	0.05	0.02	0.198	0.84	-0.09	0.02	-0.713	0.48
-	chlamydia because of transport			(292)				(260)	
	Trend towards	disagreement	disagreement			agreement	disagreement		
	I would prefer to see a doctor or nurse who is the	09	14	0.304	0.761	-0.02	14	0.639	0.52
	same sex as me for a chlamydia test			(287)				(255)	
	Trend towards	disagreement	disagreement			disagreement	disagreement		
· - `	It is difficult for me to see a doctor or nurse about	0.13	0.12	0.026	0.98	-0.07	0.12	-0.955	0.34
-	Trend towards	disagreement	disagreement	(007)		agreement	disagreement	(1-(->)	

Change in mean attitude scores for Intervention and Control and Engaged and Control groups (Chapter 11.5.3) <u>Appendix G (i)</u>:

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	Attitude	Intervention	Control	Independent	d	Engaged	Control	Independent	ď
		Mean	Mean	samples t-	value	Mean	Mean	samples t-	value
		difference	difference	test statistic (df)		difference	difference	test statistic (df)	
10	I would feel comfortable visiting a doctor or nurse to	0.18	0.09	0.542	0.59	0.35	0.09	1.327	0.19
-	get a chlamydia test			(286)				(254)	
	Trend towards	agreement	agreement	:		agreement	agreement		
11	I do not want to talk to a doctor or nurse about my	0.17	-0.05	1.513	0.13	0.23	-0.05	1.678	0.10
	sexual history			(290)				(258)	
	Trend towards	disagreement	agreement			disagreement	agreement		
12	I can't get a chlamydia test because I don't have a	-0.03	0.09	-1.255	0.21	0.00	0.09	-0.743	0.46
	Medicare card			(286)				(255)	
	Trend towards	agreement	disagreement			no change	disagreement		
13	I don't want a chlamydia test because I'm scared of	0.37	0.20	1.180	0.24	0.48	0.20	1.768	0.08
	what it might show			(288)				(256)	
	Trend towards	disagreement	disagreement			disagreement	disagreement		
14	I don't want a chlamydia test because my partner/s	0.11	0.16	-0.289	0.77	0.19	0.16	0.204	0.84
	might find out			(286)				(256)	
	Trend towards	disagreement	disagreement			disagreement	disagreement		
15	I would have a chlamydia test if my partner/s	0.16	0.06	0.690	0.49	0.09	0.06	0.198	0.84
	wanted me to			(285)				(253)	
	Trend towards	agreement	agreement			agreement	agreement		
16	I would have a chlamydia test if my doctor	0.07	-0.02	0.873	0.384	0.11	-0.02	1.097	0.27
	recommended it			(286)				(255)	
	Trend towards	agreement	disagreement			agreement	disagreement		
17	I want to have a chlamydia test because I would	-0.08	-0.05	-0.264	0.79	0.05	-0.05	0.649	0.52
	want to prevent any long term health problems from			(287)				(256)	
	Trend towards	disagreement	disagreement			agreement	disagreement		
18	I want to have a chlamydia test because I don't want	-0.01	-0.08	0.521	0.60	0.04	-0.08	0.712	0.48
	to give chlamydia to my partner/s if I have it	1:	<u></u>	(289)				(257)	
	libid comards	mannaalsosm	mamaalarsm			agreement	aisagreement		

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# Appendix G (ii):

Attitude no.	Intervention (All)	Control	Mann-Whitney U	p value
	Mean Rank	Mean Rank	test z-value	-
1	148.83	153.43	-0.439	0.66
2	146.90	151.36	-0.458	0.65
3	152.54	151.03	-0.199	0.84
4	137.88	157.66	-2.098	0.04
5	140.18	155.14	-1.479	0.14
6	150.68	152.60	-0.203	0.84
7	148.78	153.45	489	0.63
8	147.25	151.22	-0.376	0.71
9	145.60	151.99	-0.621	0.54
10	158.21	146.98	-1.089	0.28
11	144.42	154.65	-0.979	0.33
12	148.26	150.79	-0.285	0.78
13	145.72	154.11	-0.829	0.41
14	143.76	152.10	-0.868	0.39
15	152.87	147.97	-0.503	0.62
16	147.87	150.95	-0.333	0.74
17	150.76	150.38	-0.038	0.97
18	151.61	151.45	-0.017	0.99

# Attitude mean ranks at follow up comparing Intervention and Control groups

# Attitude mean ranks at follow up comparing Engaged and Control groups

Attitude no.	Engaged	Control	Mann-Whitney U	p value
	Mean Rank	Mean Rank	Test z-value	-
1	135.14	134.32	-0.074	0.94
2	126.40	135.48	-0.884	0.38
3	137.46	133.02	-0.551	0.58
4	121.28	137.61	-1.636	0.10
5	118.83	136.97	-1.705	0.09
6	128.47	136.20	-0.784	0.43
7	131.11	135.46	-0.432	0.67
8	130.56	133.03	-0.222	0.82
9	134.39	132.60	-0.166	0.87
10	140.78	130.77	-0.926	0.35
11	124.86	136.54	-1.064	0.29
12	130.68	133.67	-0.321	0.75
13	126.70	136.07	-0.881	0.38
14	123.78	135.01	-1.117	0.26
15	130.27	132.49	-0.217	0.83
16	129.18	134.07	-0.503	0.62
17	137.73	132.29	-0.522	0.60
18	133.54	134.13	-0.057	0.96

# APPENDIX H

## A53: Signed statement from co-authors

**A54: Kang** M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Facilitating chlamydia testing among young people: a randomised controlled trial in cyberspace. *Sexually Transmitted Infections* 2012; 88:568-573.

# A61: Signed statement from co-authors

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Kang M, Rochford A, Skinner SR, Mindel A, Webb M, Peat J, Usherwood T. Sexual behaviour, sexually transmitted infections and attitudes to chlamydia testing among a unique national sample of young Australians: baseline data from a randomised controlled trial. *BMC Public Health* 2014, 14:12

#### We verify that:

Melissa Kang wrote the original grant application with assistance from Rachel Skinner and Adrian Mindel. She wrote the entire content of the website (*getcluedup*) and Arlie Rochford, Rachel Skinner, Adrian Mindel and Marianne Webb reviewed it. She developed the study design with assistance from Rachel Skinner, Adrian Mindel, Tim Usherwood and Marianne Webb. She and Marianne Webb recruited the Youth Consultant groups and Melissa facilitated their meetings. She and Arlie Rochford recruited study participants, delivered the intervention and collected all data. She, Arlie Rochford, Jennifer Peat and Tim Usherwood completed data analysis and all authors assisted with interpretation of findings. She prepared the first drafts of the manuscripts and completed revisions after discussion with all authors. She revised manuscripts after reviewer feedback after discussion with co-authors.

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## ORIGINAL ARTICLE

# Facilitating chlamydia testing among young people: a randomised controlled trial in cyberspace

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#### ABSTRACT

**Objectives** Chlamydia notifications have been rising in Australia for over a decade and are highest in young people. This study aimed to evaluate the impact of an internet-based intervention on chlamydia testing among young people 16–25 years.

**Methods** In this randomised controlled trial, recruitment, data collection, study interventions and follow-up occurred entirely in cyberspace, facilitated by a website. Eligible participants were aged 16—25 years and resided in Australia. The intervention group received personalised emails inviting interaction about chlamydia testing, while the control group received regular impersonal emails. Primary outcome was self-reported chlamydia testing at 6-month follow-up; secondary outcomes were condom use and changes in knowledge and attitudes.

**Results** 704 young people completed baseline information, 40 were excluded and five withdrew prior to follow-up. The follow-up rate was 47.3% overall. In the intervention group, 40.6% (95% Cl 30.7% to 51.1%) reported having had a chlamydia test at follow-up compared with 31.0% (95% Cl 24.8% to 37.2%) in the control group (p=0.07). A per-protocol analysis found that those who engaged in email interaction were more likely to report chlamydia test uptake compared with those in the control group (52.5%, 95% Cl 39.3 to 65.4% cf 31.0%, 95% Cl 24.8% to 37.2%, p=0.002). There were no differences in secondary outcomes between groups.

**Conclusions** This is the first randomised controlled trial undertaken in cyberspace to promote chlamydia testing. E-technology may be useful in promoting chlamydia testing and healthcare seeking behaviour in young people.

#### INTRODUCTION

Among the sexually transmissible infections (STIs) other than HIV, chlamydia causes the greatest burden of disease globally.<sup>1</sup> In Australia, notification rates for genital chlamydia infection have steadily increased over the past decade and are highest in women and men aged 15–24 years.<sup>2</sup> In 2011, notification rates were 1443.3 per 100 000 among 15–19-year-olds and 1801.4 per 100 000 among 20–24-year-olds.<sup>2</sup> Australia's first National STI strategy 2005–2008 identified young people aged 16–25 years as a target group for chlamydia control and prevention.<sup>3</sup> This study was one of several pilot projects to inform a national screening programme<sup>4</sup> and aimed to evaluate an internet-based intervention to increase chlamydia testing.

Australian young people experience several barriers to care, including lack of knowledge about services available and how to access them, concerns about confidentiality, embarrassment, cost and transport.<sup>5</sup> However, most young people are familiar with and access general practice.<sup>6</sup> An analysis of general practice encounters across Australia from 2000 to 2007 found that the rate of chlamydia testing among 15-24-year-old patients was only 13.2 per 1000 encounters.<sup>7</sup> Chlamydia testing rates among young people are higher in sexual health and family planning clinics,<sup>8</sup> but unlike general practices, these are not located in many rural and some urban areas. Thus, the majority of the youth population who might be at risk are unlikely to be tested for chlamydia.

Over 85% of Australian young people access the internet each year<sup>9</sup> and young people find it useful for seeking help around sensitive issues. Furthermore, men are as likely as women to use the internet to seek help.<sup>9–11</sup> A study in Switzerland suggested that the internet can facilitate access to healthcare through the use of tailored information provided to individuals in response to questions asked via a website.<sup>12</sup>

This study used the internet to engage sexually active young people aged 16-25 years residing in Australia, in confidential personalised email interactions with a clinician, with the goal of facilitating their access to primary health services for chlamydia testing. The primary aim of this study was to evaluate the impact of this intervention on chlamydia testing when compared with a control intervention (monthly impersonal emails for 6 months).

#### METHODS

#### Study location and population

This was a randomised controlled trial (RCT) with 1:2 randomisation. Eligible participants were aged 16-25 years residing in Australia who had had penetrative sexual intercourse and who provided a valid email address. Eligibility was determined by self-report of these criteria.

The study setting was cyberspace. A website (http://www.getcluedup.com.au) was the vehicle for accessing the intervention and was developed in consultation with 20 youth consultants (16–25 years) who were recruited through professional and collegiate networks. Website content included information about chlamydia and testing but also addressed known gaps in knowledge<sup>13</sup> and barriers to seeking help<sup>5</sup> and provided service

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Accepted 4 June 2012 Published Online First 4 July 2012 directories and links (see web appendix 1). The website went live in March 2007 with recruitment into the study commencing simultaneously. Recruitment ceased in January 2008, but the website remains live. The website was promoted via paid advertising, existing youth websites, social networking sites and opportunistic media interviews. Google Analytics was used to monitor website traffic.

The website invited eligible visitors to participate in the study via a homepage banner and clickable tiles on the other webpages. These links took visitors to the participant information statement. Potential participants then entered a current email address and ticked a consent box. This third step took them to the baseline questionnaire housed within the website. The baseline questionnaire collected data on demographics, education/occupation, substance use, sexual history, previous STIs, knowledge about chlamydia and attitudes to chlamydia testing. Participants could go into a draw for an iPod® or a music store voucher if they completed all elements of the study.

#### Interventions

The intervention group received *personalised* emails from a clinician (sexual health nurse or doctor). A 'personalised email' was sent from the clinician's mailbox, included the clinician's name and position, and contained a link to their staff profile on the University of Sydney's website. The email thanked the young person for their participation and said that the clinician would like to 'chat about chlamydia and getting tested'. The participant was invited to ask questions and prompted with questions about testing knowledge. Young people who responded were then engaged appropriately: advice depended on the questions asked. Non-responders were sent weekly emails for 3 months and then monthly emails for another 3 months. All email communication to non-responders in this group remained *personalised*, as described above.

Participants assigned to the control group received an email sent from the project mailbox ('Clued Up'), was signed 'The Clued Up Research Team' and did not mention a clinician by name. These emails thanked the young person for participation and stated that they would be sent a reminder email about their participation in the study every month for 5 months and a final questionnaire in 6 months. These emails were intended to enhance retention and completion of the final questionnaire but were *not personalised*. There was no interaction and no clinical advice provided.

Web appendix 2 gives examples of email interactions.

#### Outcomes

Follow-up took place 6 months after enrolment. Data were collected via an online questionnaire using similar questions to baseline on knowledge, attitudes, sexual history and chlamydia testing in the past 6 months. This questionnaire was accessed via a link sent by email from the clinician. Weekly email reminders were sent for 3 months to non-responders.

The primary outcome was self-report of having had a chlamydia test within the past 6 months. Secondary outcomes were changes in knowledge about chlamydia, attitudes towards chlamydia testing and frequency of condom use.

#### Sample size

A minimum of 320 participants in each group was required to detect at least an 8% positive difference in testing rates in the intervention versus control group with a power of 90% and significance taken at 0.05. A loss to follow-up of 10% in the intervention group and 50% in the control group was antici-

pated, giving a target sample size of 1000 (360 intervention and 640 control).

#### Randomisation

Allocation to intervention or control groups was done on a 1:2 ratio based on the anticipated loss to follow-up described above. For allocation, a computer-generated random number (1, 2 or 3) was obtained by the same clinicians who sent emails to study participants. The number '1' allocated the young person to the intervention group and '2' or '3' to the control group. Allocation took place each time a young person was deemed eligible (downloaded data showed email address, eligible age, an Australian postcode and ticked 'Yes' to having had intercourse) without any other information about the participant being known.

#### Analysis and statistical methods

Both intention-to-treat (ITT) and per-protocol (PP) analyses were performed. Only a proportion of young people in the intervention group interacted with the clinician as per the study protocol, that is, *engaged*. Engagement was defined as having had a minimum of one response of any type from the young person within 3 months from enrolment. The intervention was only deliverable when engagement occurred, where it did not occur, there was a 'failure to start the intervention'.<sup>14</sup> Thus, comparisons between the engaged group and the control group constituted the PP analysis. We propose that the PP analysis provides an 'explanatory investigation of efficacy'<sup>14</sup> and provides useful information.

Statistical analysis was performed with SPSS V.16 with the individual as the unit of analysis. Proportions are presented with 95% CIs. To assess differences at baseline between the intervention (all), engaged and control groups, independent samples' t tests for the continuous variables and  $\chi^2$  tests for the categorical variables were performed.  $\chi^2$  Analysis was used to assess the statistical significance of differences in the primary outcome and in condom use between groups at follow-up. To adjust follow-up values for baseline values, analysis of covariance was used for knowledge questions and logistic regression for binary outcome measures.

The study was approved by the University of Sydney Human Research Ethics Committee and enrolled in the Australian New Zealand Clinical Trials Registry (ACTRN12607000582459).

## RESULTS

#### Website traffic

Reliable data on website traffic for the first 3 months (March to May 2007) were unavailable due to technical problems. Traffic between June 2007 and January 2008 ranged from 2030 to 3584 unique visitors per month (see web appendix 3).

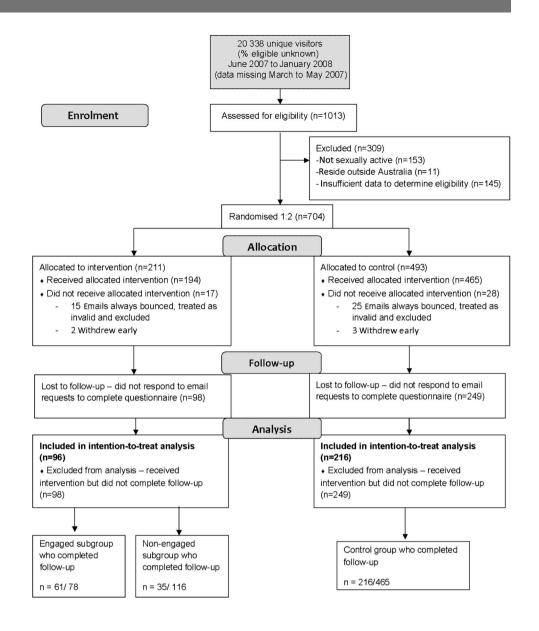
#### Sample

Seven hundred and four young people completed baseline information between March 2007 and January 2008 and were randomised. Recruitment was then stopped because of project timelines and budget constraints. Forty young people were subsequently excluded because their email addresses were invalid (all sent emails bounced). Five withdrew prior to follow-up. Three hundred and forty-seven participants did not respond to the 6-month follow-up request. Thus, 312 were included in the ITT analysis (see figure 1).

We compared baseline information between intervention (all), engaged and control groups. Of the baseline sample of 664

#### **Behaviour**

#### Figure 1 Participant flowchart.



young people, 78.2% were were. The mean age of female participants (20.0 years) was significantly lower than the mean age of male participants (21.5 years), p<0.0001. There was a small significant difference between the engaged and whole intervention groups with respect to being born overseas. Those who engaged were more likely to have been born in Australia. However, of those born overseas in both groups, most were born in English-speaking countries. Table 1 describes their demographic and sexual history characteristics. At baseline, 111/664 (16.7%, 95% CI 13.9% to 19.6%) reported having ever had chlamydia.

The follow-up rate was 47.3% (312/659) overall. There were no differences in demographic (mean age, sex) or baseline sexual history characteristics (number of sexual partners ever, condom use) between those who completed follow-up questionnaires and those who did not (data not shown). There was no difference in follow-up rate between the intervention (49.5%; 96/194) and control (46.5%; 216/465) groups; however, follow-up rate for the 'engaged' group (78.2%; 61/78) was significantly higher than for the 'non-engaged' group (30.7%; 35/114), p<0.0001, and for the control group (46.6%, 216/464), p<0.0001.

Table 2 presents the primary outcome measurement in the intervention and control groups (ITT) and in the engaged and

control groups (PP analysis). Given the loss to follow-up at 6 months is a problem for ITT analysis, we also conducted a sensitivity analysis to examine the possible effects. A higher proportion of young people in the intervention group reported a chlamydia test compared with the control group (40.6% vs 31.0%) but this was not significant. However, the difference between the *engaged* intervention and control groups was significant (52.5% and 31.0%, respectively, p=0.002).

Of those who reported having had a chlamydia test at followup, a total of 14/99 (14.1%, 95% CI 7.95% to 22.6%) young people reported their tests were positive for chlamydia. Three were from the engaged group and 11 from the control group.

The proportion of young people who reported using condoms every time they had sex increased in the engaged and the control groups; however, this increase was not significant. At baseline, 12/61 (19.7%) in the engaged group and 27/216 (12.5%) in the control group reported using condoms always, at follow-up these proportions were 20/61 (32.8%) and 59/216 (27.3%), respectively (p=0.30).

There was no change in knowledge between baseline and follow-up; however, baseline knowledge was high. The proportion of young people in total (n=312) who answered each of the seven questions correctly ranged from 77.6% to 95.8% at

#### Table 1 Baseline demographic information, sexual history and substance use

	Intervention (all), n=196	Intervention (engaged), n=79	Control, n = 468	Intervention (all) versus engaged, p value	Intervention all versus control, p Value,
Mean age (years)	20.5	20.7	20.3	0.50	0.42
Female (%)	154 (78.6)	65 (82.3)	365 (78.0)	0.46	0.97
Not born in Australia (%)	21 (10.7)	4 (5.1)	60 (12.8)	0.06	0.53
Aboriginal/Torres Strait Islander (%)	4 (2.0)	2 (2.5)	14 (3.0)	1.00	0.70
Region of residence				0.29	0.21
Major city (%)	147 (75.0)	54 (68.4)	317 (67.7)		
Inner regional (%)	33 (16.8)	17 (21.5)	88 (18.8)		
Outer regional (%)	12 (6.1)	5 (6.3)	43 (9.2)		
Remote (%)	0 (0.0)	0 (0.0)	4 (0.9)		
Very remote (%)	0 (0.0)	0 (0.0)	0 (0.0)		
Occupation				0.70	0.42
School (%)	35 (17.9)	11 (13.9)	98 (20.9)		
University/tertiary (%)	60 (30.6)	26 (32.9)	128 (27.4)		
Full time work (%)	62 (31.6)	27 (34.2)	149 (31.8)		
Part time or casual work (%)	23 (11.7)	7 (8.8)	37 (7.9)		
Looking for work (%)	8 (40.8)	3 (3.8)	31 (6.6)		
Work + study (%)	4 (2.0)	3 (3.8)	4 (0.9)		
Parenting/domestic (%)	2 (1.0)	1 (1.3)	12 (2.6)		
Other (%)	2 (1.0)	1 (1.3)	7 (1.5)		
Sexual history					
Mean age of first intercourse (years)	16.2	16.5	16.3	0.15	0.42
Mean no. of sexual partners ever	3.1	3.2	3.1	0.83	0.57
Mean no. of sexual partners last 12 months	2.0	1.9	2.0	0.31	0.88
Use condoms always (%)	41 (20.9)	20 (25.3)	100 (21.4)	0.62	0.95
Had chlamydia test in past 6 months (%)	60 (30.6)	26 (32.9)	127 (27.1)	0.49	0.57
Had a previous diagnosis of chlamydia (%)	26 (13.3)	13 (16.5)	85 (18.2)	0.56	0.21
Substance use history					
Daily smoker past 12 months (%)	37 (18.9)	17 (21.5)	102 (21.8)	0.80	0.44
Drink 5 or more standard drinks at a time (%) past 2 weeks	93 (47.4)	47 (59.5)	201 (42.9)	0.67	0.95
Marijuana use (any) past month (%)	30 (15.3)	10 (13.9)	81 (17.3)	0.45	0.66
Other illicit drug use (any) past month (%)	23 (11.7)	10 (13.9)	52 (11.1)	0.60	0.83

baseline and 80.8 to 97.4% at follow-up. There was no difference between change in knowledge in the intervention and control groups or in the engaged and control groups. There were no attitude differences between the intervention and control or engaged and control groups at follow-up. The list of knowledge questions and attitude statements are shown in web appendix 4.

Table 2	Self-reported chlamydia test in the past 6 months by group
allocation	(including sensitivity analysis)

	%; 95% CI	p Value
Test uptake in those randomised and followed up (intention-to-treat population)		0.07
Intervention	39/96 (40.6; 30.7-51.1)	
Control	67/216 (31.0; 24.8-37.2)	
Test uptake in those randomised who 'engaged' per-protocol		0.002
Engaged	32/61 (52.5; 39.3-65.4)	
Control	67/216 (31.0; 24.8-37.2)	
Test uptake in all randomised, assuming all those lost to follow-up did not have a test		0.09
Intervention	39/194 (20.1; 14.7-26.4)	
Control	67/465 (14.4; 11.3—17.9)	
Test uptake in all randomised, assuming those lost to follow-up all had a test		0.34
Intervention	137/194 (70.6; 63.7-76.9)	
Control	316/465 (68.0; 63.5-72.2)	

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The amount of clinician time required to respond to emails for participants who engaged in interaction was low (a few minutes per email). Responses usually provided information about what testing involved, confidentiality and services available. Some young people asked about other screening tests such as Pap smears, and some were interested in other STIs.

#### DISCUSSION

To our knowledge, this is the first RCT of an intervention to increase chlamydia testing implemented entirely in cyberspace. Young people who engaged in email interaction with a clinician were more likely to report having a chlamydia test after 6 months than young people who were not offered such contact. Knowledge, attitudes and condom use did not change.

Strengths of this study include originality, youth consultant advice and experimental rigour despite the uncontrollable study environment. Clinicians provided clear information about testing, treatment and relevant services rather than messages about 'risk' that could provoke fear. They answered young people's questions regardless of topic, thus feeling listened-to might have generated confidence in seeking healthcare.

There were several limitations. Website reach was modest and target sample size was not achieved due to project constraints. This combined with loss to follow-up reduced the power of the study. The main outcome measure was based on self-report of testing that could not be verified. Overall followup rate was just under 50%; however, of those who engaged, 61/78 (78.2%) completed follow-up. Of the intervention group,

#### **Behaviour**

59.4% did not engage. Although there were no measurable differences in attitudes between these subgroups, it is possible that those who engaged were more concerned about chlamydia, more engaged with the health system or wanted to please the clinician or avoid embarrassment. Internet-based trials have high attrition rates, especially when there is no clinician contact at the outset.<sup>15</sup> Attrition can occur either at uptake of an intervention or with failure to complete followup. This introduces dilemmas with analysing ITT populations in exactly the way we found. To improve validity, it has been suggested that individuals who do not take up an intervention be removed and that the remaining participants in the intervention group undergo a second randomisation process.<sup>16</sup> Given our time frame, this was not feasible. Most internetbased RCTs have evaluated therapeutic interventions, such as pain management, chronic illness or mental health treatments.<sup>15-18</sup> It is possible that participants who are symptomatic are more likely to take up an intervention but also to dropout if no benefit is perceived. Our trial involved an intervention that was not therapeutic and targeted a behaviour change for an asymptomatic condition. We might therefore expect a higher dropout rate compared with therapeutic interventions but this was not the case. Nevertheless, we must be cautious about how to interpret our findings.

Other studies have used e-technology to increase chlamydia testing among young people. A RCT using SMS and email delivered sexual health messages to 994 young people who were recruited from a music festival. The study found that at 12 month follow-up, young women in the intervention group were significantly more likely to report Chlamydia testing than those in the control group. Follow-up rates were substantially lower than ours (34%).<sup>19</sup>

Strategies combining the internet with home-based chlamydia testing have been evaluated. In Sweden, 62.5% of kits requested over the internet were returned for testing,<sup>20</sup> in the USA 32.4% of women<sup>21</sup> and 31% of men<sup>22</sup> returned samples and in the Netherlands, 20% of the invitees requested testing kits and 16% returned samples.<sup>23</sup> Although our sample size was small, the fact that over 50% of young people who engaged in email interaction reported chlamydia testing at follow-up without the convenience of a home testing kit suggests that email interaction could help facilitate access to health services more broadly.

We found no significant changes in knowledge, attitudes or condom use. However, baseline knowledge was high and might have been positively impacted simply from navigating the website. That reported condom use was low and did not increase significantly highlights the complexities of this behaviour and relationship dynamics at the point of sexual encounter.<sup>24</sup> Furthermore, heterosexual couples using other contraceptive methods are less likely to use condoms<sup>25</sup> or pregnancy might be desired.

Cyberspace research presents methodological challenges. Participation rates are not measurable with unknown denominators, and external validity is difficult to ascertain.<sup>26</sup> Website traffic data do not provide demographic information that would help determine eligibility or generalisability. Technology also changes rapidly. Members of our Youth Advisory Committee developed a MySpace page to promote our website and Facebook had not reached Australia. Between 2009 and 2011, Facebook overtook MySpace in number of unique visitors, and email has been overtaken or replaced by Facebook chatting, immediate messaging and texting.<sup>27</sup>

Advantages include the potential to 'scale up' to achieve greater reach for minimal additional cost: our greatest cost was

#### Key messages

- Young people who engaged with clinicians online were more likely to access chlamydia testing than those who did not engage.
- Conducting studies in cyberspace is novel and presents challenges to the conventional frameworks for evaluating and interpreting scientific data.
- The internet can be a useful vehicle for sexual health promotion and an adjunct to screening strategies.

website development. Social networking may provide cheaper alternatives to paid advertising. The study clinicians could easily have managed a greater volume of emails at no additional cost. The internet has the potential to reach hard-to-reach populations, and the intervention itself could be transferable to other health issues.

Potential ethical issues include email security, the misuse of online communication and ownership of personal information posted on the world wide web.<sup>28</sup> While all data entered by participants in our study were secure and we were not aware of any ethical concerns, it is possible that concerns about privacy and security influenced young people's decisions to participate in the study or to disclose personal information.

Our study has implications for further research. Cost—benefit analyses of a range of screening strategies would be useful for informing a broader screening programme. Qualitative research would help us understand more about why some young people engaged and others did not and their experiences of internetbased clinical interaction. A qualitative study with volunteers from our study has been undertaken.

Chlamydia is a common curable sexually transmitted infection that can have potentially serious consequences if undetected and untreated. E-technology has the potential to be a useful adjunct to a population-based screening programme.

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**Contributors** MK prepared the first draft of the manuscript and completed revisions after discussion with the entire research team. MK, RS, AM, MW and TU participated in study design. MK wrote the content of the website. AR, RS, AM and MW reviewed website content. MK and MW recruited and facilitated the Youth Advisory Committee. AR and MK recruited study participants, delivered the intervention and collected all data. MK, AR, JP and TU completed data analysis. All authors assisted with interpretation of findings.

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#### Competing interests None.

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# Facilitating chlamydia testing among young people: a randomised controlled trial in cyberspace

Melissa Kang, Arlie Rochford, Rachel Skinner, et al.

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#### In relation to the published abstract:

Kang M, Rochford A, Skinner SR, Mindel A, Webb M, Usherwood T. Getting Clued Up in cyberspace about chlamydia: a randomized controlled trial of an internet-based intervention [abstract]. *Journal of Adolescent Health* 2009; 44(2) Supplement:S22.

#### We verify that:

Melissa Kang wrote the original grant application with assistance from Rachel Skinner and Adrian Mindel. She wrote the content of the website (getcluedup) and Arlie Rochford, Rachel Skinner, Adrian Mindel and Marianne Webb reviewed it. She developed the study design with assistance from Rachel Skinner, Adrian Mindel, Tim Usherwood and Marianne Webb. She and Marianne Webb recruited and facilitated the Youth Consultant groups. She and Arlie Rochford recruited study participants, delivered the intervention and collected all data. She, Arlie Rochford and Tim Usherwood completed data analysis and all authors assisted with interpretation of findings. She prepared and submitted the abstract to the conference (Society for Adolescent Health and Medicine, Los Angeles, March 2009), prepared all text and content for the poster and attended the poster presentation at the conference.

Cheeper 21/2/15

Arlie Rochford

24/2/15

21/2/15

Adrian Mindel

11.2.15 Marianne Webb

L 2/2

Tim Usherwood

were more likely to display sexually symbolic icons such as cherries or Playboy bunnies (p = 0.003).

**Conclusion:** Adolescents' displayed sexual references on MySpace profiles contain few references to risky sex and rare references to safe sex. The majority of sexual references for both genders describe personal attributes and experiences, suggesting that teens may use SNS to attract partners and discuss personal experiences. Given the potential potency of sexual messages displayed by adolescent peers on SNS, interventions to modulate teens' sexual displays may be warranted.

#### 20.

#### THE EFFECT OF DAILY TEXT MESSAGE REMINDERS ON ADOLESCENT ORAL CONTRACEPTIVE PILL CONTINUATION

Paula M. Castaño, MD, MPH, Carolyn Westhoff, MD, MSc, Raquel Andrés Martínez, PhD, MSc, and Marcos Lara, MBA. Dept. of Obstetrics and Gynecology, Columbia University Medical Center, New York, NY; Planned Parenthood of New York City, New York, NY

**Purpose:** Most adolescent pregnancies are unintended. Half of adolescents use oral contraceptives (OC) for birth control but often misuse or discontinue them. Up to half of teen OC users discontinue their pills at 3 months. Adolescents are at the forefront of technological innovation and frequently use their cell phones for text messaging. Our primary objective was to assess whether OC continuation rates improve after 3 months of daily text message reminders. We hypothesized that they would be higher than continuation rates after routine care.

**Methods:** In this IRB-approved pilot study, we enrolled 26 adolescents obtaining OCs at an urban family planning clinic. Adolescents agreed to receive 6 months of daily text message reminders. The reminders contained educational content adapted from standard clinic handouts. We completed a baseline interview and contacted participants 30 days, 3 months, and 6 months after enrollment to assess satisfaction with messages and OC continuation. We present descriptive statistics through 3 months.

Results: The mean age was 18 and 46% of participants identified as African American, 42% as Hispanic, 8% as White, and 4% as Asian. All participants had heterosexual intercourse in the past 6 months, 77% in the past week. Two thirds previously used the pill; most forgot to take 2 or more pills per month. Over 80% of participants used some form of birth control at last intercourse and 81% of them planned to use the pill for more than 6 months. Two thirds had been pregnant but none had given birth. All planned to have children in the future. Participants reported the same cell phone number for 23 months and only one had her service interrupted in the past 6 months. These participants sent and received a mean of over 25 text messages per day; 85% never worried about the associated costs. We reached 22 teens (85%) for the 30-day follow-up and 19 teens (69%) for the 3-month follow-up. Continuation was 86% (19/22) at 30 days and 83% (15/18) at 3 months. Only 1 teen missed more than 1 pill the first month and only 4 missed more than 1 pill the third month. All OC continuers reported that the text messages helped them remember to take their pills and 68% of teens wanted to continue receiving daily text reminders after 3 months.

**Conclusions:** This is the first study evaluating the effect of daily text message reminders on OC continuation in teens. These preliminary results suggest that daily text message reminders have the potential to improve OC continuation compared to previously-observed OC continuation rates at 3 months. We are collecting 6-month follow-up data and evaluating a control group.

**Sources of Support:** Affinity Health Plan Making a World of Difference Program.

#### 21.

#### GETTING CLUED UP IN CYBERSPACE ABOUT CHLAMYDIA: A RANDOMISED CONTROLLED TRIAL OF AN INTERNET-BASED INTERVENTION

Melissa Kang, MBBS, MCH, Arlie Rochford, CNS, Rachel Skinner, MBBS, FRACP, PhD, Adrian Mindel, MD, FRCP, FRACP, Marianne Webb, BA, and Tim Usherwood, MD, BS, FRCGP. Dept. of General Practice, University of Sydney, Sydney, NSW, Australia

**Purpose:** Notifications for chlamydia infection in Australia are highest among 15 – 24-year-olds although chlamydia testing rates are low. Young people use the internet for sexual health information. The purpose of this study was to evaluate the impact of an anonymous internet-based intervention on chlamydia testing among sexually active young people.

**Methods:** A website about chlamydia was developed in consultation with 20 young people and housed an online questionnaire. Email address, demographic information, sexual history, drug and alcohol history, and responses to chlamydia knowledge and attitudes questions were collected. Those eligible (aged 16 - 25, residing in Australia, sexually active) were randomised into Intervention and Control groups on a 1:2 ratio. Those in the Intervention group received personalized emails from a nurse or doctor, inviting email-based discussion about chlamydia testing; controls received impersonal monthly email reminders. After 6 months, participants were asked to complete a second questionnaire. The principal outcome measure was self-reported chlamydia testing during the 6-month trial period. Data were analyzed using  $\chi^2$ .

Results: A total of 705 young people (79.0% female) across Australia were enrolled over 9 months. Most were Australian-born (88.2%) and spoke English at home (94.9%); 3.2% identified as Indigenous. At baseline, 188 (26.7%) reported a chlamydia test in the previous 6 months. There were no significant differences in demographic characteristics or previous chlamydia testing between Intervention (n = 211) and Control (n = 494) groups at baseline. Emails repeatedly bounced for 15/211 Intervention participants and 26/494 Control participants. A further 4 Interventions and 3 Controls withdrew early. Of the remaining 192 Intervention participants, 78 (40.6%) became engaged in email interactions. The remainder (59.4%) of the Interventions and 100% of the Controls did not email once during the trial period. A total of 311 participants (44.1%) completed the follow-up questionnaire. At follow-up, 39/95 (41.1%) of the Intervention group and 67/ 216 (31.0%) of the Control group reported having had a chlamydia test in the preceding 6 months (p = 0.112). At follow-up, 32/60 (53.3%) of "engaged" Intervention participants compared with 7/35 (20.0%) of "non-engaged" Intervention participants and 67/216 Controls (31.0%) reported chlamydia testing in the past 6 months (p = 0.001). Conclusions: Engagement with a health professional via the internet leads to a greater likelihood of seeking chlamydia testing from a health service compared with no engagement. Anonymous, brief email interactions can deliver relevant information to facilitate access to testing. Sources of Support: This study was funded by the Commonwealth Dept. of Health and Ageing.

#### 22.

#### DO PORNOGRAPHIC WEBSITES INFLUENCE BOYS' SEXUAL BEHAVIOR?

Isabelle Pittet, MD, André Berchtold, PhD, Christina Akre, MA, Pierre-André Michaud, MD, and J.C. Surís, MD, PhD. Research Group on Adolescent Health, Institute of Social and Preventive Medicine, University of Lausanne, Switzerland

**Purpose:** To compare the sexual behavior of adolescent males who do and do not watch pornographic websites.

# APPENDIX I

# A63-64: INTERVIEW PROMPTS

participate in RCT he	o begin with your involvement in the Get Clued Up project, could you tell me why and ow you got involved? rompts
- Pi	rompts
-	
	how did you find out about it
	- what prompted you to participate
	- how did you find being in the study
	- what information if any did you find useful, interesting or important to you at
	that time
<b>Experience of</b> Fo	or 6 months at the beginning of the study, you received emails fromwhat it was like for
intervention / ye	ou to get those emails every week/ month?
control Pr	rompts:
	- Did you open/ read the emails?
	- Were the personalised emails helpful?
	- Were the monthly reminders about the study helpful/ annoying?
	- Thinking about the Clued Up website - is there anything you would do
	differently/ have done differently now as a result of the website?
	- Is there anything you would do differently/ have done differently as a result of
	your participation in the project?
Decisions about A	t the end of your involvement in the Get Clued Up project, you mentioned that you had/
chlamydia testing ha	ad not had a Chlamydia test.
C	ould we talk about what sorts of things that influenced your decision about getting
te	sted?
Pr	rompts
	- what sorts of things stopped you from going to get a test in the past 6 months?/
	what things helped you decide to get a test in the past 6 months?
	- can you describe how you felt at the time?
	- do you feel that the Clued Up emails or website influenced your decision in any
	way? If so, how?
	- what are the things that stop you from going to a health service for a Chlamydia
	test or other sexual health check?
	- were/ are you worried about confidentiality?
	- were/ are you worried about cost?
	- is it difficult for you to get to a health service because of transport?
	- were/ are you unsure about the services available to you where you could get a
	test?
	- were/ are you worried about feeling embarrassed?

	- would/ did you find it difficult to talk to a doctor or nurse about your sexual			
	health and STIs? Bring in "meanings" questions (below) here			
	- were/ are you worried about knowing the results and what that could mean for			
	you or your relationship/s? Bring in "meanings" questions (below) here			
	- what sorts of things would make it easier for you to get a test?			
Meanings of STIs	I'd like to talk about Chlamydia and STIs more generally now. What do STIs mean to you?			
	Prompts			
	- where have you heard about STIs			
	- what have you learned about STIs?			
	- where did you learn it?			
	- does the information you hear about change depending on where you are or			
	where you hear it – for example at home, at school/ Uni/ work, among friend			
	with a partner, among family?			
	- under what circumstances do you think or talk about STIs?			
	- how relevant are STIs to you in your life?			
	- what do you think your chances are of contracting an STI?			
	- can you imagine how you would feel and what you would do if you did catch an			
	STI?			
	- do you know of anyone who has an STI?			
	- are STIs a concern for young people in general?			

# APPENDIX J

# A65: Signed statement from co-author

A66: Kang M, Hillier L. Medieval wenches and other icky connotations: how young people's constructions of sexually transmitted infections deepen our understanding of their sexual health [abstract]. *Journal of Adolescent Health* 2014; 54(2) Supplement:S65.

## In relation to the published abstract:

**Kang** M, Hillier L. Medieval wenches and other icky connotations: how young people's constructions of sexually transmitted infections deepen our understanding of their sexual health [abstract]. *Journal of Adolescent Health* 2014; 54(2) Supplement:S65.

## I verify that:

Melissa Kang recruited and conducted in-depth interviews with young people under my supervision. She read all interview transcripts. I read four transcripts and supervised and assisted Melissa with analysis. Melissa prepared the first draft of the abstract for the Society for Adolescent Health and Medicine conference and as well as the content of the poster. I provided feedback on first drafts. Melissa prepared the final poster and attended the conference to present it in March 2014.

Lynne Hillier (Associate Supervisor)

Mulle

advocate for and tailor post-incarceration STI/HIV prevention efforts, which are currently lacking for this high-risk population. **Sources of Support:** Support provided by the National Institutes of

Allergies and Infectious Diseases, to author: Crosby, R. # 5 R01 AI068119.

#### 123.

MEDIEVAL WENCHES AND OTHER ICKY CONNOTATIONS: HOW YOUNG PEOPLE'S CONSTRUCTIONS OF SEXUALLY TRANSMITTED INFECTIONS DEEPEN OUR UNDERSTANDING OF THEIR SEXUAL HEALTH

Melissa Kang, MD, MPH<sup>1</sup>, Lynne Hillier, PhD<sup>2</sup>.

<sup>1</sup>University of Sydney; <sup>2</sup>La Trobe University.

**Purpose:** Genital chlamydia infection mainly affects young people and can have long term health consequences. Despite Australian guidelines recommending chlamydia screening for all sexually active young people, testing rates remain low and the epidemic continues to grow. This qualitative study involved interviews with participants from a randomized controlled trial and employed Foucauldian discourse analysis to explore in depth how young people understand sexually transmitted infections (STIs) and the subject positions they take in relation to testing, diagnosis and communication with partners.

**Methods:** Young people (16 - 25 years) who completed a randomised controlled trial about a chlamydia testing intervention were invited to take part in a subsequent, qualitative study using indepth interviews. The interviews were unstructured but guided by topic prompts and explored participants' views on chlamydia testing and the meanings attributed to STIs. The interviews were audio-recorded and transcribed. Two researchers read and analysed the transcripts in order to describe the discursive fields and subject positions taken by participants when discussing their understandings and experiences of STIs. The study was approved by the relevant ethics committee.

Results: Seven young people (5 female, 2 male) participated in indepth interviews. Sources of knowledge, information seeking and interpersonal communications about STIs were constructed as proximal or distant and these constructs played different roles when coming to terms with STIs. Participants were more comfortable discussing STIs with close friends than with sexual partners and took up a position of caring for others in doing so. The medical consulting room was seen as the most appropriate place to get personal advice but even here proximity and distance played out. STIs were unanimously constructed as negative entities in participants' lives. However as their proximity to STIs increased, the struggle to resist these negative beliefs led to taking up a new subject position of caring for self. Participants unanimously attributed their negative beliefs about STIs to sexual activity itself. Sexual activity among young people, especially females, was taboo. Within the discourse of shame, participants found ways to resist being positioned in negative ways by carefully choosing others with whom they could discuss STIs, by taking up roles as informal peer educators or by gradually rejecting notions of guilt, shame or immorality. Participants produced subject positions for individual STIs. Not all STIs were equally negative. Different STIs had different meanings including 'gross' 'disgusting', 'serious', 'scary', a 'medieval wench' and 'having icky connotations'. Conclusions: By emphasising 'risks' associated with sexual activity, health and education professionals could be reinforcing negative discourses about shame. Instead, approaches to STIs could acknowledge the struggle young people face in resisting negative discourses about their own sexual activity. By focusing on positive concepts such as caring for self and caring for others, young people might find safer spaces to seek help and discuss STIs with their partner/s and health care providers.

**Sources of Support:** The study was supported by a grant from the Australian Commonwealth Department of Health and Ageing.

#### **HEALTH DISPARITIES**

#### 124.

SOCIODEMOGRAPHIC DISPARITIES IN PATIENT EXPERIENCE AMONG YOUNG AND OLDER US ADULTS

Dougal S. Hargreaves, MD<sup>1</sup>, Jane H. Roberts, MD, PhD<sup>2</sup>. <sup>1</sup>Boston Children's Hospital; <sup>2</sup>University of Sunderland.

**Purpose:** Experience of healthcare in early adulthood may influence lifelong attitudes to health and health-seeking behaviour. Poor healthcare experience may be a key contributing factor to health disparities. This study investigates disparities in patient experience by household income and race/ethnicity among younger and older American adults.

Methods: We used logistic regression to compare the proportion of young/older adults among different sociodemographic groups who reported positive healthcare experience in the Consumer Assessment of Healthcare Providers and Systems survey (CAHPS). Participants: Adults in the Medical Expenditure Panel Survey 2008 (1333 aged 18-24, 11986 aged over 25). Principal variables: Age, household income quintile (derived from ranking the percentage of poverty level for family composition), and race/ethnicity (Hispanic, Black, Asian, Other (including non-Hispanic White)). Covariates: Sex, number of care episodes. Outcomes: A dichotomous outcome was created for overall care rating (0-8 vs. 9-10 on a scale of 0-10). Additionally, participants reported whether, over the previous year, healthcare providers had always: listened, explained clearly, respected them, and spent enough time. Models: Within each age group, unadjusted models compared patient experience by income and race. Adjusted models used all covariates and investigated interactions between age and income/race.

Results: Young adults reported poorer patient experience than older adults on all outcomes (Overall rating 40.6 vs. 49.6% (Odds ratio = 0.69 (95% CI 0.62-0.78), p < .001); Listening 54.8 vs. 59.7% (p = .001); Explaining 52.6 vs. 59.9% (p < .001); Respect 59.3 vs. 62.7% (p = .02); Time 44.3 vs. 49.7% (p < .001)). For each outcome, younger age remained significantly associated with poorer care (p < .05) after adjusting for all covariates. Among young adults, the second poorest quintile reported the worst experience of care, with significantly lower proportions reporting each outcome than the richest quintile (Overall Rating 35.9 vs. 46.7% (p = .02); Listening 48.9 vs. 62.4% (p = .003); Explaining 47.3 vs. 62.0% (p = .001); Respect 55.8 vs. 65.8% (p = .02); Time 39.0 vs. 55.8% (p < .001)). These remained significant (p < .001) .02) in the adjusted model. For all outcomes, there was a significant interaction between age and income, with greater disparity in patient experience between income groups among young adults (p < .05). Compared to the 'Other' group, young Asian-Americans reported poorer experience on all measures except for Explaining, and these differences remained significant in the adjusted model (p < = .03). Differences were also seen between Hispanics and Others but the effect disappeared or was of marginal significance in the adjusted model. For Overall Rating and Respect, the difference between Asians