

NATIONAL YOUNG PEOPLE AND ASTHMA SURVEY

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ISSUES AND OPPORTUNITIES IN SUPPORTING
THE HEALTH AND WELLBEING OF YOUNG
AUSTRALIANS LIVING WITH ASTHMA

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ISSUES AND OPPORTUNITIES IN THE HEALTH AND WELLBEING OF YOUNG PEOPLE WITH ASTHMA

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YOUNG AND WELL COOPERATIVE RESEARCH CENTRE

The Young and Well Cooperative Research Centre is an Australian-based, international research centre that unites young people with researchers, practitioners, innovators and policy-makers from over 70 partner organisations. Together, we explore the role of technology in young people's lives, and how it can be used to improve the mental health and wellbeing of young people aged 12 to 25. The Young and Well CRC is established under the Australian Government's Cooperative Research Centres Program.

youngandwellcrc.org.au

ASTHMA AUSTRALIA

Asthma Australia is the nation's peak asthma body. For over fifty years Asthma Foundations have been delivering high quality support for people with asthma and their carers. Combining their collective resources twenty five years ago, the Foundations created Asthma Australia. Building on a rich history, Asthma Australia and the Asthma Foundations collectively are one of Australia's largest and most respected health charities. With extensive reach and offices, staff and resources in every state and territory, Asthma Australia works in partnership with each Asthma Foundation to deliver evidence-based, consumer-focused, accessible and appropriate services to over 200,000 Australians with asthma every year. Asthma Australia also proudly takes the role of acting as the voice of people with asthma, advocating on a range of issues including air quality, tobacco legislation and the cost of medications.

asthmaaustralia.org.au

EXECUTIVE SUMMARY

PURPOSE

This report presents the findings of a national survey of young people with asthma in Australia. The survey was conducted by Young and Well CRC, in partnership with Asthma Australia and the state and territory Asthma Foundations.

The survey aimed to gather empirical data on the experiences of young people aged 12 to 25 living with asthma, in order to inform the development of the National Young People and Asthma Strategy (NYPAS). In particular, it aimed to identify and explore issues and opportunities in maximising the health and wellbeing of this group of young people. To that end, this study had two broad aims. First, to provide a snapshot of present levels of asthma control, health and wellbeing in young people with asthma in Australia. Second, to utilise this data (combined with subsequent data) to evaluate the effectiveness of NYPAS in improving asthma control, health and wellbeing in young people with asthma in Australia.

NYPAS is funded by the Australian Government under the Asthma Management Program. It is managed by Asthma Australia as part of the Asthma Child and Adolescent Program (ACAP).

The objectives of the strategy are to provide targeted action for better asthma self-management and improved service delivery to young Australians aged 12-25 years. Priority areas contributing to the objectives include appropriate treatment for asthma, continuity of care and best practice self-management. Through activities that provide increased communication and support for young people, Asthma Australia aims to improve medication use and adherence, interactions with doctors and specialists, and use of Asthma Action Plans, all contributing to improved quality of life.

Working with a reference group of young people through an online forum, Asthma Australia and the program evaluators, Young and Well CRC, will consider a range of innovative approaches to achieve the above objectives, identifying for development those that resonate with the target population. This will include an approach for all young people that addresses 'how to help a friend' when they have an asthma attack.

BACKGROUND

A large body of research shows that people with asthma have consistently lower self-assessed health status, poorer health, and lower quality of life, than people without asthma (Australian Centre for Asthma Monitoring 2005). Furthermore, people with asthma have higher risks of morbidity (Akinbami & Schoendorf 2002) and mortality (Akinbami & Schoendorf 2002; Calmes et al. 1998) than people without asthma.

Likewise, poor mental health and wellbeing can dramatically affect a young person's quality of life. Mental illness is more prevalent in the 16-24 age group than in any other demographic, with one in four young people experiencing a diagnosable mental health disorder (Slade et al. 2009). Suicide is the leading cause of death among people aged 15-24 years (ABS 2014), with only 31% of young women and 13% of young men reaching out for help in relation to their mental health (Slade et al. 2009). Put simply, young people are not receiving the assistance they need, when they need it (ABS 2008; Burns et al. 2013).

The reasons behind this lack of help-seeking behaviour are complex and varied (Burns et al. 2013; Wilson & Deane 2010; Wilson et al. 2010; Yap et al. 2011). However numerous studies assert that technology will have a significant role to play in the improvement of young people's overall mental health and wellbeing (Burns 2011; Collin et al. 2011). With 99% of Australian young people using the internet (Burns et al. 2013) and tending to "search for specific conditions, (and) search for information before an appointment with a medical practitioner" (Campbell & Robards 2013), the wider mental health sector has the opportunity to have a major presence in the online space, providing information, services and support.

The health and wellbeing impacts of chronic illnesses such as asthma are heightened by the social, psychological and developmental challenges posed by adolescence (Boice 1998; Britto et al. 2011; Bruzzese et al. 2004; Buston & Wood 2000; Cohen et al. 2003; de Benedictis & Bush 2007). As such, young people with asthma in particular face greater health and wellbeing concerns than people with asthma of other ages, and young people without asthma (Akinbami et al. 2009; Akinbami & Schoendorf 2002; Australian Centre for Asthma Monitoring 2011; Calmes et al. 1998; Sawyer et al. 2007).

Because approximately 10% of Australian young people have asthma (Asthma Australia 2014a), there is a great public health interest in improving their quality of life, health status, and health outcomes. To that end, NYPAS aims to implement targeted public health initiatives to improve asthma control, health and wellbeing in young people with asthma. This study provides useful information to inform the development and evaluation of those initiatives.

STUDY DESIGN

The study utilised an online survey of 533 young people with asthma aged 12-25, living in Australia. It comprised a combination of standard survey instruments (Asthma Control Score and Kessler 10), questions from Young and Well CRC's standard measures, and specific-to-purpose researcher-designed questions informed by a literature review. The survey collected data on asthma control and physical health, as well as social and psychological wellbeing and technology use.

Participants were recruited using a 'snowballing' strategy, taking advantage of existing networks within the asthma and youth sectors. This strategy was implemented via social media, email and websites, with the assistance of a variety of youth-serving organisations.

The data was analysed using the SPSS Statistics Package.

RESULTS

A total of 533 eligible young people responded to the survey. Respondents ranged in age from 12 to 25, with a mean and median age of 21.5 years. Of all participants, 428 (80.3%) were female, and 105 (19.7%) were male.

On the whole, the respondents in this survey appeared to have poorly controlled asthma, with a large number of young people scoring in the 'off target' group, using the Asthma Control Score as a guide. Male respondents had poorer control of their asthma, and differences in asthma control were also found between specific age groups.

The mental health and wellbeing of the young people surveyed was also poor. This was particularly the case for young people whose asthma was poorly controlled. Just over 50% of those who participated in the study had K10 scores which suggest they are likely to have a mental disorder, which is double the rate in the wider population of young people (Slade et al. 2009)

Participants cited a number of concerns which impacted their health and wellbeing, including self-consciousness, lack of confidence and poor body image. Smoking was noted as a personal concern for 12.4% of young people surveyed, and 11.6% reported that they currently smoked.

IMPLICATIONS AND RECOMMENDATIONS

While the results must be interpreted in the context of the self-selecting participant sample, this study has documented a number of key concerns regarding the health and wellbeing of young Australians living with asthma. As a result, it has informed a series of recommendations about steps that could be taken to assist young people living with asthma to lead healthy and productive lives.

Recommendation: Interventions need to be designed to educate young people, their supporters and healthcare professionals regarding the importance of preventative medications in helping manage asthma.

Recommendation: Interventions need to be designed to support young people to decrease their smoking behaviour.

Recommendation: Support for young people with asthma needs to be embedded into existing online and face-to-face service models that support young people's mental health and wellbeing.

Recommendation: Provide training and support to general practitioners and other health professionals to help them understand the needs of young people with asthma, including how to support these young people's mental health and wellbeing.

Recommendation: Conduct further research to understand the experiences of young men with asthma, with the view to designing interventions that specifically support their needs.

Recommendation: Conduct further research to understand the experiences of Aboriginal and Torres Strait Islander young people, with the view to designing interventions that specifically support their needs.

Recommendation: Take a developmental approach to designing interventions for young people living with asthma, considering the specific needs of different age groups, and supporting transitional periods.

Recommendation: Develop tailored online and mobile applications to support the wellbeing of young people with asthma, targeting asthma control, mental health, and general wellbeing.

Recommendation: Consider embedding tailored interventions for young people living with asthma in an online ecosystem of care, inclusive of promotion and prevention activities, and activities that support peers to help their friends.

'TAKE A DEVELOPMENTAL APPROACH TO DESIGNING INTERVENTIONS FOR YOUNG PEOPLE LIVING WITH ASTHMA, CONSIDERING THE SPECIFIC NEEDS OF DIFFERENT AGE GROUPS, AND SUPPORTING TRANSITIONAL PERIODS.'



GLOSSARY

ASTHMA CONTROL SCORE

This score is based on an assessment of an individual's level of clinical asthma symptom control, ranging from five (extremely poor asthma control) to 25 (excellent asthma control). The score is derived from participant responses to the five asthma control questions, each providing a five point Likert-style response scale. This score helps individuals with asthma, and their health professional, decide on a course of asthma management. It also helps to determine whether their asthma is controlled, or if there is room for improvement.

KESSLER PSYCHOLOGICAL DISTRESS SCALE (K10)

A simple survey designed to measure the level of an individual's psychological distress. The K10 scale involves 10 questions about emotional states, each with a 5-level response scale. This tool gains a brief scan of an individual's state of mind, and is often used by mental health professionals in initial consultation with their patient.

OFF TARGET

An asthma control score of 19 or under. A score within this range classifies your asthma as being partly controlled or uncontrolled.

ON TARGET

An asthma control score of 20-25. A score within this range classifies your asthma as being controlled.

INTRODUCTION

MENTAL HEALTH AND WELLBEING OF YOUNG AUSTRALIANS

Young people are the age group most likely to experience mental health challenges (Slade et al. 2009), with suicide remaining the highest cause of death of young people aged 15–24 years (ABS 2014). Before the age of 24 years, 75% of serious mental health, alcohol or substance abuse problems have emerged (Kessler et al. 2005). Australia's young men are particularly vulnerable, with 42% experiencing 'moderate' to 'very high' levels of psychological distress and one in five young men reporting they had been diagnosed with a mental health or behavioural problem (Burns et al. 2013).

The prevalence of mental ill health is high among young people. However just 31% of young women and 13% of young men seek help in relation to mental health challenges (Slade et al. 2009). Stigma remains a hurdle to accessing help (Horgan & Sweeney 2010; Patel et al. 2007), translating to a delay in young people receiving the appropriate care they need, when they need it. In addition, help-seeking behaviour is hindered due to concerns relating to confidentiality, availability and proximity to services, and service costs (Campbell & Robards 2013).

HEALTH AND WELLBEING OF YOUNG PEOPLE WITH ASTHMA

People with asthma face a variety of challenges to their health and wellbeing. For example, people with asthma are at greater risk of morbidity (Akinbami & Schoendorf 2002) and mortality (Akinbami & Schoendorf 2002; Calmes et al. 1998) than people without asthma. They also have a lower quality of life than people without asthma (Goldney et al. 2003; Lemanek et al. 2001).

Like all people with asthma, young people with asthma face these challenges, which span both the direct physical impacts of their condition, but also its social, psychological and functional impacts. However, research shows that in young people, the health and wellbeing impacts of chronic illnesses such as asthma are heightened by the social, psychological and developmental challenges posed by adolescence (Boice 1998; Britto et al. 2011; Bruzzese et al. 2004; Buston & Wood 2000; Cohen et al. 2003; de Benedictis & Bush 2007).

As such, the health and wellbeing of young people aged 12–25 with asthma has been found to be poorer than that of both their peers without asthma, and people with asthma of other ages (Akinbami et al. 2009; Akinbami & Schoendorf 2002; Australian Centre for Asthma Monitoring 2011; Calmes et al. 1998; Sawyer et al. 2007).

Young people with chronic illness in general (Sawyer et al. 2007), and asthma in particular (de Benedictis & Bush 2007), have been found to be at increased risk for a wide variety of health and wellbeing issues that are distinct from the direct physical effects of their condition. Some examples include increased levels of anxiety (Barton et al. 2003; Boice 1998; McGrady et al. 2010), risk-taking behaviour (de Benedictis & Bush 2007; Sawyer et al. 2007; Towns & van Asperen 2009), depression (Goldney et al. 2003; Moussavi et al. 2007), absenteeism (Bruzzese et al. 2004) and social isolation (Asthma Foundation NSW 2013; Rhee et al. 2007).

NATIONAL YOUNG PEOPLE AND ASTHMA STRATEGY

Considered together, the research illustrates a great public health impetus to improve the quality of life, health status, and health outcomes of young people with asthma. Approximately 10% of the Australian population have asthma, including a large number of young people (Asthma Australia 2014b). Given this high prevalence, the benefits of improving the health of young people with asthma are potentially large and wide-ranging. Furthermore, research on the developmental stages of adolescence shows that to achieve the best results, public health programs intended to improve outcomes for young people must be specifically targeted to this demographic (Rutishauser et al. 2001).

The National Young People and Asthma Strategy (NYPAS) is funded by the Australian Government under the Asthma Management Program. It is managed by Asthma Australia as part of the Asthma Child and Adolescent Program (ACAP).

The objectives of the strategy are to provide targeted action for better asthma self-management and improved service delivery to young Australians aged 12-25 years. Priority areas include appropriate treatment for asthma, continuity of care and best practice self-management. Through increased communication and support for young people, Asthma Australia aims to improve medication use and adherence, interactions with doctors and specialists, and use of Asthma Action Plans, contributing to improved quality of life. Working with a reference group of young people through an online forum, innovative approaches will be considered to achieve the above objectives.

In order to maximise the benefits of the strategy, two key research inputs are both prudent and paramount:

- The design and implementation of the strategy should be informed by data on the health and wellbeing of young people with asthma, and their perspectives on what programs are likely to achieve the desired goals.
- The strategy should be subjected to rigorous evaluation to determine its efficacy, and make recommendations for the future.

This study is intended to support these research input goals.

THE ROLE OF THIS STUDY

An online survey, carried out from May to July 2014, collected data on the health and wellbeing of young Australians aged 12 to 25 living with asthma as part of a wider, ongoing project to evaluate the effectiveness of NYPAS.

In the first instance, the data collected will be used to inform the design and implementation of NYPAS, according to the issues, needs, desires and preferences expressed by respondents. To this end, the survey collected data on the current health and wellbeing of young people with asthma, including mental health, physical health and social concerns. When compared with similar data for young people without asthma, they give a realistic picture of the relative quality of life, health and wellbeing of young people with asthma. This will help to guide the development of NYPAS, by identifying target areas of health and wellbeing concern in this population.

Furthermore, the survey collected data on young people's health and lifestyle habits, asthma control and management, asthma knowledge, asthma information-seeking, and preferences regarding programs and initiatives to improve their health and wellbeing. These can be compared against 'golden standards' of asthma management and control.

Together, these aspects of the data assist in identifying strategies and initiatives most likely to be engaging and effective for young people, and factors to consider in the design and implementation of NYPAS.

Secondly, data collected will be used to inform the future evaluation of NYPAS and its effectiveness. The survey provides a snapshot of the health and wellbeing of young people with asthma prior to implementation of NYPAS initiatives.

Thus, it provides a point of comparison for similar data collected after NYPAS implementation. A comparison of such data sets will help to identify:

- The effectiveness of NYPAS initiatives
- The reasons why NYPAS initiatives are (or are not) effective
- Strategies to improve the effectiveness of such initiatives
- How and to what extent such initiatives improve the wellbeing of young people with asthma in Australia.

More broadly, the insights from this survey provide a snapshot of the current health and wellbeing of young people with asthma in Australia, in terms of both challenges and opportunities. They also provide useful guidance on how to best design and implement programs and initiatives to reduce the health and wellbeing burdens of asthma on young people. This can benefit young people personally, as well as have flow-on effects for the community, including decreased healthcare costs and improved productivity. Finally, the results will help to inform the more efficient and efficacious use of resources that are allocated to public health programs including, and beyond, those directly related to NYPAS.

STUDY DESIGN

LITERATURE REVIEW

At the beginning of this study, we conducted a literature review regarding methods for measuring wellbeing in young people with asthma. This literature review confirmed that young people with asthma experience unique challenges, concerns, developmental experiences, behaviours and life experiences compared to both young children with asthma, and adults with asthma (Akinbami et al. 2009; Akinbami & Schoendorf 2002; Calmes et al. 1998). As such, young people with asthma are a distinct and important research group, for whom an appropriate method of measuring wellbeing is important (Rutishauser et al. 2001). They have unique developmental characteristics and needs that need to be catered for, to ensure the integrity and value of research studies (Rutishauser et al. 2001). However, the literature review also found that – due in part to the common practice of designing asthma-related wellbeing and quality of life instruments to be exclusively ‘adult’ or ‘paediatric’ – no single instrument was ideally suited to our research sample of participants aged 12 – 25.

Furthermore, existing instruments often do not adequately differentiate between measures of clinical asthma control or functional limitations, and the actual impact of these on wellbeing and quality, as experienced by individuals with asthma (Wilson et al. 2012). That is, item scores for these factors are often indiscriminately combined, and/or instruments are based on the incorrect assumption that decreased clinical control necessarily corresponds to reduced quality of life (Wilson et al. 2012). In this sense, instruments for measuring asthma control are typically more accurately targeted to their intended purpose – measuring clinical control and functional limitations – than those intended to measure wellbeing or quality of life. For these reasons, no existing instruments for measuring quality of life and non-physical wellbeing in asthma were utilised in this survey. However, a validated instrument for measuring asthma control (the Asthma Control Score) was used (Nathan et al. 2004; Schatz et al. 2009; Schatz et al. 2006).

Findings from the literature review also identified health and wellbeing challenges for young people with asthma that have been documented in research. These included:

- Time out of work and study (average five days per year) (Bruzzese et al. 2004)
- Personal or parental anxiety obstructing activities (Asthma Foundation NSW 2013)
- Social isolation (Asthma Foundation NSW 2013; Rhee et al. 2007)
- Restricted life choices and limitations on personal potential (Asthma Foundation NSW 2013)
- Difficulty making plans for activities (Asthma Foundation NSW 2013)
- Embarrassment and shame about their condition and/or treatment (Asthma Foundation NSW 2013; Sawyer et al. 2007; Wamboldt et al. 2011)
- Depression (Goldney et al. 2003; Moussavi et al. 2007)
- Anxiety (Barton et al. 2003; Boice 1998; McGrady et al. 2010)
- Impaired social relationships (Asthma Foundation NSW 2013)
- Worry about being perceived as lazy (Asthma Foundation NSW 2013)

- Low confidence (Asthma Foundation NSW 2013)
- Frustration with their condition (Asthma Foundation NSW 2013; Cohen et al. 2003)
- A sense of missing out (Asthma Foundation NSW 2013; Rhee et al. 2007)
- Limitations on physical activity (Asthma Foundation NSW 2013; Kyngas 1999)
- Limitations on where one goes (Asthma Foundation NSW 2013; Rhee et al. 2007)
- Concerns about body image, including height, weight and acne (Boice 1998)
- Self-consciousness (Boice 1998)
- Feeling 'different' (Taylor et al. 2008; Towns & van Asperen 2009)
- Partaking in risky behaviour (e.g. smoking, drinking to excess) (de Benedictis & Bush 2007; Sawyer et al. 2007; Towns & van Asperen 2009)
- Sense of fear and looming mortal threat (Rhee et al. 2007)
- Poor self-care and self-management (Rhee et al. 2011)

These findings were used to inform the design of the survey instrument, to ensure it addressed known issues in the health and wellbeing of young people with asthma.

The literature review also identified important considerations in the interpretation of the survey results. For example, evidence supports the ability of young people to report on their own health generally (Riley 2004).

However, young people with asthma are more likely to be in denial about their condition (Buston & Wood 2000), fail to recognise and accurately attribute its symptoms (Rhee et al. 2011), be non-adherent to treatment plans (Bender 2002; de Benedictis & Bush 2007), and over-estimate the degree to which their asthma is controlled and managed (Britto et al. 2011). As such, where a self-reporting instrument is used, young people may not view themselves as 'asthmatic enough' to participate at all, or may provide answers that do not truly reflect the state of their wellbeing.

SURVEY DESIGN

The survey and research methodology were informed by a variety of information sources. These included:

- The literature review
- Consultations with the National Young People and Asthma Strategy Working Group
- Feedback from Asthma Australia's National Advisory Council
- The expertise of the investigators

Using this information, a survey instrument was developed, consisting of a self-reporting online survey (Appendix One). The survey was designed for young people aged 12-25 to complete in their own time and environment. The instrument contained a mix of three major sources of questions: pre-validated questionnaires, Young and Well CRC standard measures, and newly-devised questions. Questions consisted of a mix of both open-ended and closed questions, with this mixed methods survey combining both qualitative and quantitative measures.

The pre-validated questionnaires included were the Asthma Control Score and Kessler 10. The Asthma Control Score (a variation of a similar instrument called the Asthma Control Test in the USA) is a widely-used and validated test of clinical asthma control (Nathan et al. 2004; Schatz et al. 2009; Schatz et al. 2006). The Kessler 10 is a validated tool that screens for signs and symptoms of mental illness in the general population. The Oxford Happiness Questionnaire is a validated scale for measuring psychological wellbeing in the general population. These measures are included in the Young and Well CRC standard measures.

Questions sourced from the Young and Well CRC standard measures were intended to increase the usefulness of the data, by allowing ease of comparison with data sets from other research studies. These measures covered areas including demographics, mental health and wellbeing, and technology use.

Newly-devised questions were designed to fulfill the specific requirements of this survey, by filling gaps in data collection that could not be addressed with pre-validated questionnaires or Young and Well CRC standard measures. These questions collected data on such factors as smoking status, asthma status, physical health, functional limitations, medication use and adherence, health service use, access to information about asthma, perspectives on potential NYPAS initiatives, and wellbeing issues specifically identified in research as problematic for young people with asthma (for example embarrassment about taking medication, and feelings of missing out).

The survey was prepared using the online application Gravity Forms. It was designed to limit participation to individuals who:

- Were aged 12 – 25
- Were living in Australia
- Had 'current asthma'

Potential participants who did not meet these criteria were excluded from completing the survey. As this study was intended to collect data only from those currently living with asthma, measures to include only those with 'current asthma' were put in place. For the purpose of the survey, the definition of 'current asthma' was based on widely accepted understandings drawn from the literature review. That is, a person with 'current asthma' (a) has been diagnosed with asthma by a doctor or nurse, and (b) has experienced asthma symptoms in the past 12 months and/or has used asthma medications in the past 12 months. Including screening questions for current asthma ensured that those who were once diagnosed with asthma, but are no longer affected by asthma, were excluded from the study.

ETHICS

This study was approved by the Human Research Ethics Committee at the University of Melbourne (ethics ID number 1441802) in July 2014. The diverse age range (12–25) of young people targeted by the survey meant it was vital that all recruitment and consent procedures, along with the survey questions, were appropriate and accessible to young people. The questions were sourced, developed and refined by the research team to ensure they were understandable, purposeful, relevant, inclusive, and informed by existing research.

SURVEY DISSEMINATION AND RECRUITMENT

The survey period spanned July and August 2014. The survey was designed using an online platform – Gravity Forms – that connected participants to the survey page via an active web link. This link was the basis for promoting the survey.

Recruitment was conducted using the contact networks of the national, state and territory Asthma Foundations, the Young and Well CRC, as well as a variety of non-clinical youth-serving organisations (for example, the Australian Youth Affairs Coalition). Direct emails were sent to organisations providing services to young people, asking them to forward recruitment information to their networks.

'QUESTIONS SOURCED FROM THE YOUNG AND WELL CRC STANDARD MEASURES WERE INTENDED TO INCREASE THE USEFULNESS OF THE DATA, BY ALLOWING EASE OF COMPARISON WITH DATA SETS FROM OTHER RESEARCH STUDIES.'



Posts containing recruitment information for the survey were also posted on the social media accounts of the Young and Well CRC, the Asthma Foundations and other youth-serving organisations. A link to the survey was also posted on the home page of the Asthma Australia website.

Eligible participants who completed the survey were offered the opportunity to enter a random prize draw as an incentive for participation. The prize draw included vouchers for online music purchases, as well as electronic tablets.

DATA ANALYSIS

The questionnaire data was entered into SPSS and a summary of descriptive statistics produced. A variety of analyses were conducted. A number of measures were not normally distributed, despite attempts to transform them, and in these cases non-parametric tests had to be used. Non-parametric tests are generally more conservative than parametric analyses. Specific analyses performed have been described throughout the report. As this is a cross-sectional study, the data cannot be used to infer causality. Instead, it provides an indication of the occurrence of particular attitudes and behaviours among the group surveyed.

STRENGTHS

The strengths of this survey include its use of a range of validated and accepted measures for considering the health and wellbeing of young people living with asthma.

Survey participants represented a broad range of ages within the target group. It was also reassuring to see that the proportion of Aboriginal and Torres Strait Islander individuals completing the survey (4.2%) was comparable to national averages (3.5%) (Australian Institute of Health and Welfare 2011).

WEAKNESSES

As described above (under 'Literature review'), pre-validated standard instruments for measuring quality of life do not exist for young people with asthma aged 12-25. There are two main reasons for this. First, because instruments are typically designed to be either paediatric or adult, and thus do not span the full age range of young people considered in this study (12-25). Second, existing measures that have attempted to measure quality of life are typically based on the assumption that decreased clinical control or increased physical limitations necessarily demonstrate poor quality of life. Yet this relationship is not clear.

Some more inclusive measures have been developed (for example, the AQOL-8D). However, these tend to be long and difficult to administer in a survey of this type, which seeks to establish baseline measures in a range of domains. There is a need to develop positive measures of quality of life in young people that are easy to administer, and acceptable for young people.

In relation to survey participants, both young men and younger adolescents were underrepresented. These patterns are often seen in self-selecting research samples. Whether this underrepresentation was due to the nature of the survey dissemination, or decisions by young men and younger adolescents not to respond, is unclear. This is because the type of sampling used in this survey does not allow a determination of response rate.

KEY FINDINGS

PARTICIPANT DEMOGRAPHICS

	Survey
Female	428 (80.3%)
Male	105 (19.7%)
Aboriginal and Torres Strait Islander	22 (4.2%)
Speak a language other than language at home	31 (5.8%)
Studying (school or a tertiary institution)	303 (56.9%)
Working (full time or part time)	165 (31%)
Unemployed/looking for work	13 (2.4%)
Live in an urban area (major cities)	303 (56.8%)
Live in a rural/regional area	141 (26.5%)
Tertiary educated	208 (39%)

N = 533

A total of 533 eligible young people responded to the survey. Respondents ranged in age from 12 to 25, with a mean and median age of 21.5. Of all participants, 428 (90.3%) were female, and 105 (10.7%) were male. As mentioned above, the uneven gender distribution in this survey is a notable limitation.

Respondents identified as Aboriginal or Torres Strait Islander in 4.2% of responses, in contrast to general population figures of 3.5% (Australian Institute of Health and Welfare 2011). Of the respondents, 5.8% reported speaking a language other than English at home. Those who spoke a language other than English at home represented 20 different languages.

With respect to main current activity, the majority of participants were students, with 38.5% attending school and 18.4% attending a tertiary institution. The next largest representation was young people who were working (31%), with 18.4% working full time, and 12.6% working part time. The remainder of participants were split across home duties (6.2%), unemployed/looking for work (2.4%), volunteer work (0.4%) and other (0.6%).

Regarding highest completed level of education, the largest proportion (50.3%) had completed or partially completed high school. The next largest group was those who had completed tertiary education (39%). A small number reported having completed or partially completed primary school (6.6%), with the remaining 4.1% selecting either 'I don't know' or 'no formal education'.

Postcodes were provided by 93.9% of participants. These postcodes spanned all states and territories, including New South Wales (50.7%), Victoria (20.8%), Queensland (12.4%), Western Australia (4.4%), South Australia (8%), Tasmania (1.4%), Australian Capital Territory (1.2%) and Northern Territory (1.2%). Just over half of all participants lived in major cities (56.8%), with 26.5% living in inner regional areas.

Table 1: Location of participants by Australian Standard Geographical Classification for Remoteness

Location by Australian Standard Geographical Classification for Remoteness (ASGC-RA)	
RA1 Major cities	303 (56.8%)
RA2 Inner regional	141 (26.5%)
RA3 Outer regional	51 (9.6%)
RA4 Remote	4 (0.8%)
RA5 Very remote	1 (0.2%)

The table below describes the frequency of smoking behaviour by the young people surveyed.

How often do you smoke cigarettes?	
I don't smoke	471 (88.4%)
Rarely	17 (3.2%)
A few times a month	14 (2.6%)
A few times a week	2 (0.4%)
Every day	29 (5.4%)

N = 533

Smoking was noted as a concern for 12.4% of young people surveyed, and 11.6% reported that they currently smoked. Daily smoking was reported by 5.4% of participants, and 'rarely' smoking by 3.2%, with the remainder reporting smoking a few times a month (2.6%) or a few times a week (0.4%). Given the relationship between smoking and respiratory diseases such as asthma, this is notable.

PARTICIPANT ASTHMA CONTROL

All participants with valid, completed surveys reported current asthma, and a prior professional diagnosis of asthma, because an affirmative answer to these items was one of the inclusion criteria for the survey. Additionally, all survey participants indicated that they have had some respiratory symptoms (e.g. coughing, wheezing or shortness of breath) in the last twelve months.

The items summarised in the Tables 2-6 are the individual questions which constitute the Asthma Control Scale, and collectively provide a standard measure known as the Asthma Control Score. These items were used to calculate an Asthma Control Score for each participant.

In responding to the first item of the Asthma Control Score, participants were asked to consider the role of asthma in impacting their daily lives. 34.1% of respondents reported that asthma did not impact their capacity to get things done at work, school or home.

Table 2: Impact of asthma on daily life (preventing tasks getting done)

In the past four weeks how often did your asthma prevent you from getting as much done at work, school or home?				
Not at all	A little of the time	Some of the time	Most of the time	All of the time
182 [34.1%]	155 [29.1%]	144 [27%]	44 [8.3%]	5 [0.9%]

N = 530

In responding to the second Asthma Control Score item, almost all participants (90.5%) had experienced shortness of breath at least once or twice a week in the past four weeks. 18.9% experienced shortness of breath more than once a day (n = 101).

Table 3: Impact of asthma on daily life (shortness of breath)

In the past four weeks how often have you have you had shortness of breath?				
Not at all	1 to 2 times a week	3 to 6 times a week	Once a day	More than once a day
56 [10.5%]	205 [38.5%]	119 [22.3%]	50 [9.4%]	101[18.9%]

N = 531

In relation to the third Asthma Control Score item, many of the participants reported experiencing regular symptoms which impacted on their sleep. Of all respondents, 70.9% reported waking up at night or earlier than usual in the morning due to symptoms such as wheezing, coughing, shortness of breath, chest tightness or pain (n = 376).

Table 4: Impact of asthma on daily life (symptoms)

In the past four weeks how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?				
Not at all	Once or twice	Once a week	2 to 3 nights a week	4 or more nights a week
155 [29.1%]	139 [26.1%]	56 [10.5%]	102 [19.1%]	79 [14.8%]

N = 531

Following on from the large numbers experiencing symptoms of asthma, it is not surprising that similar numbers reported needing to use their reliever medications in the fourth Asthma Control Score item. In the past four weeks, 85.6% of participants had used a reliever such as salbutamol, with 14.4% using this medication three or more times per day (n = 77)..

Table 5: Use of reliever medication in the past four weeks

During the past 4 weeks, how often have you used your reliever medication (such as salbutamol)?				
Not at all	Once a week or less	Two or three times per week	One or two times per day	Three or more times per day
75 [14.4%]	118 [22.1%]	111 [20.8%]	147 [27.6%]	77 [14.4%]

N = 528

Despite the large numbers of young people using their reliever medications regularly, respondents tended to perceive their asthma to be controlled in the fifth and final Asthma Control Score item. Well over three quarters (79.8%) felt that their asthma was somewhat, well or completely controlled (n = 425)

Table 6: Self-perception of asthma control in the past four weeks

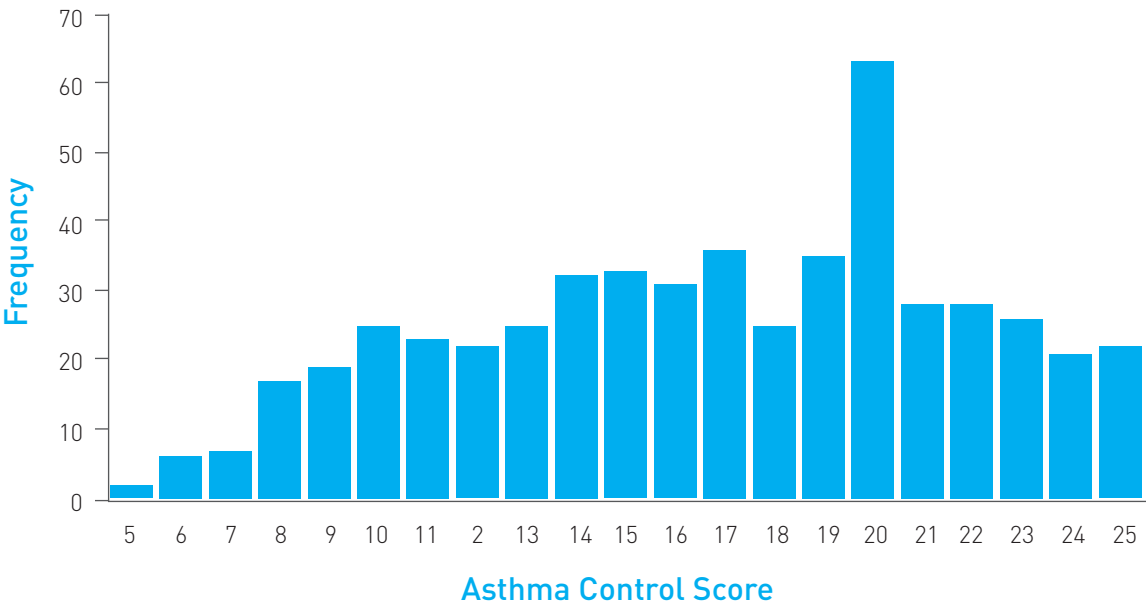
How would you rate your asthma control during the past 4 weeks?				
Not controlled	Poorly controlled	Somewhat controlled	Well controlled	Completely controlled
25 (4.7%)	80 (15%)	163 (30.6%)	187 (35.1%)	75 (14.1%)

N = 530

It is clear from participants’ responses to the Asthma Control Score items that overall, their asthma is not well controlled. 63.4% of those surveyed fell into the ‘off target’ category (n = 338) of Asthma Control Score, indicating that their asthma is not well managed. The remaining 35.7% of respondents fell into the ‘on target’ category (n = 188), suggesting good management of asthma symptoms. The minimum Asthma Control Score was five and the highest 25, with a mean of 16.68 (Standard deviation: 4.969).

The figure below shows the distribution of participants’ Asthma Control Scores.

Figure 1: Asthma Control Score distribution



The raw data suggests indigenous participants had lower Asthma Control Scores than non-indigenous participants, with 77.3% falling into the “off target” category, compared to 63.7% of non-indigenous participants. However, a Mann-Whitney U test showed no statistically significant relationship for Asthma Control Score between participants who identified as Aboriginal and Torres Strait Islander, and those who did not (p=0.151). This should be interpreted with caution due to the low sample size of indigenous participants.

The difference in median Asthma Control Score between males and females was found to be statistically significant, with males scoring higher (median = 19) than females (median = 17) (p=0.030) using a Mann-Whitney U test. This suggests that males have better controlled asthma than females.

Table 7: Asthma Control Score by gender

Are you...	Median	N	Mean
Male	19.00	103	17.61
Female	17.00	423	16.46
Total	17.00	526	16.68

A Kruskal-Wallis H test was run to determine if there were differences in Asthma Control Score between four age groupings. Distributions of Asthma Control Scores were similar for all groups, as assessed by visual inspection of a boxplot. Median Asthma Control Scores were statistically significantly different between groups, $H(3) = 7.862$, $p = .049$. Subsequently, pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. Adjusted p-values are presented. This post-hoc analysis revealed statistically significant differences in median Asthma Control Scores between the 18-21 (median = 16.5) and 12-14 year old age groups (median = 19) ($p = .044$), but not between any other group combinations.

FUNCTIONAL IMPACTS OF ASTHMA

Respondents were asked to consider how much asthma limited their usual activities and enjoyment of life. Just 30.8% reported that asthma did not limit their usual activities, while 56.1% reported that asthma hindered their enjoyment of life.

Table 8: Limitations arising due to asthma in the past four weeks

In the past 4 weeks, how much did your asthma limit					
	Not a lot	A little	Moderately	Quite a lot	Extremely
Your enjoyment of life N = 530	231 (43.6%)	154 (29.0%)	90 (17.0%)	38 (7.2%)	17 (3.2%)
Your usual activities N = 530	164 (30.8%)	194 (36.4%)	105 (19.7%)	54 (10.1%)	13 (2.4%)

For most young people surveyed, asthma did not prevent them from socialising, although some did experience limitations on their socialisation at times. Only six individual young people (1.1%) reported that their asthma always prevented them from socialising.

Table 9: Impact of asthma on socialisation

In the past 4 weeks, how often did your asthma prevent you from socialising				
Never	Rarely	Sometimes	Often	Always
289 (54.2%)	130 (24.4%)	77 (14.4%)	28 (5.3%)	6 (1.1%)

N = 530

Asthma had a measureable impact on young people’s attendance at school, University, TAFE and/or work. 41.8% had not attended these activities due to their asthma in the last twelve months. Of those who had missed school, University, TAFE and/or work due to their asthma, the median was three days, with one individual reporting have missed up to 130 days over a twelve month period.

“My boss needs to understand asthma when I am late for my part time job.”
19 year old male, Queensland.

Table 10: Impact of asthma on school, university, TAFE or work attendance

In the past 12 months, have you ever missed school, university, TAFE or work because of your asthma		
Yes	No	Don't know
223 (41.8%)	289 (54.2%)	21 (3.9%)

N = 533

MEDICATIONS, HEALTH SERVICE USE AND ADHERENCE

The survey also asked young people to indicate the types of medication that they took for their asthma, and describe the reasons for taking the medication. Almost all (96.1%) of the young people surveyed reported that they had taken medication in the last twelve months for their asthma. Just 60% of those surveyed took asthma medication every day, despite preventative medications typically requiring a daily dose.

Table 11: Use of medication to manage asthma

In the last 12 months, have you taken any medication (inhalers or tablets) for your asthma		
Yes	No	Don't know
512 (96.1)	18 (3.4%)	3 (0.6%)

N = 533

Table 12: Use of medications daily to manage asthma

Do you take asthma medication every day?	
Yes	No
320 (60%)	195 (36.6%)

N = 515

Young people were able to indicate more than one use for each medication they used. Responses revealed that many young people were taking medications for reasons other than their intended use, with many relying on reliever medications, rather than taking preventers regularly. Ventolin was by far the most common medication taken, with almost twice as many young people taking this common reliever than the most common preventative medication, Symbicort.

Table 13: Use of medications to manage asthma

Medication	% taking this medication	Reason for taking medication					
		I use it regularly to prevent asthma symptoms	I use it only when I can feel that my asthma symptoms are getting worse	I use it to relieve asthma symptoms	I use it when I have an asthma attack	Don't know	Other
Ventolin	449 (84.2%)	106 (19.9%)	202 (37.9%)	310 (58.2%)	169 (31.7%)	3 (0.6%)	11 (2.1%)
Seretide	221 (41.5%)	166 (31.1%)	47 (8.8%)	31 (5.8%)	14 (2.6%)	1 (0.2%)	3 (0.6%)
Symbicort autohaler	134 (25.1%)	101 (18.9%)	30 (5.6%)	36 (6.8%)	14 (2.6%)	1 (0.2%)	3 (0.6%)
Asmol	114 (21.4%)	38 (7.1%)	50 (9.4%)	76 (14.3%)	41 (7.7%)	1 (0.2%)	1 (0.2%)
Flixotide	82 (15.4%)	49 (9.2%)	20 (3.8%)	9 (1.7%)	4 (0.8%)	3 (0.6%)	4 (0.8%)
Flixotide	70 (13.1%)	45 (8.4%)	18 (3.4%)	6 (1.1%)	4 (0.8%)	3 (0.6%)	2 (0.4%)
Bricanyl turbuhaler	65 (12.2%)	33 (6.2%)	18 (3.4%)	26 (4.9%)	17 (3.2%)	2 (0.4%)	1 (0.2%)
APO (Salabutomol)	38 (7.1%)	14 (2.6%)	9 (1.7%)	15 (2.8%)	10 (1.9%)	1 (0.2%)	1 (0.2%)
Singulair tablets	27 (5.1%)	18 (3.4%)	5 (0.9%)	5 (0.9%)	2 (0.4%)	1 (0.2%)	2 (0.4%)
Airomir	22 (4.1%)	8 (1.5%)	8 (1.5%)	12 (2.3%)	6 (1.1%)	0	1 (0.2%)
Alvesvo	16 (3%)	12 (2.3%)	3 (0.6%)	3 (0.6%)	1 (0.2%)	1 (0.2%)	0
Pulmicort	16 (3%)	9 (1.7%)	6 (1.1%)	2 (0.4%)	1 (0.2%)	0	1 (0.2%)
Qvar	5 (0.9%)	2 (0.4%)	3 (0.6%)	0	0	0	0
Tilade puffer	4 (0.8%)	2 (0.4%)	0	2 (0.4%)	1 (0.2%)	0	1 (0.2%)
Flutiform	3 (0.6%)	3 (0.6%)	0	1 (0.2%)	1 (0.2%)	0	0
Oxis	3 (0.6%)	2 (0.4%)	0	0	0	0	0
Intal puffer	2 (0.4%)	2 (0.4%)	0	0	0	0	0
Serevent	2 (0.4%)	0	0	0	1 (0.2%)	0	0
Onbrez	1 (0.2%)	0	0	0	0	0	0

N = 533

When asked to consider the reasons for not taking their medications daily, young people gave a range of reasons including most commonly, they didn't feel they needed to because they feel well, their doctor did not prescribe the medication to be taken every day, or they forgot.

Table 14: Reasons for not taking asthma medications daily

Why don't you take asthma medication every day?	
I don't think I need to, because I feel well	137 (25.7%)
The doctor didn't tell me to take it every day	64 (12%)
I forget to take it	59 (11.1%)
It's too much of a hassle	20 (3.8%)
I don't have a current prescription	15 (2.8%)
I'm worried about the side-effects	13 (2.4%)
It costs too much	12 (2.3%)
I don't think the medication actually makes a difference	11 (2.1%)
I'm embarrassed to take my medication	11 (2.1%)
It makes me feel like I'm not normal	8 (1.5%)
I'm worried about getting addicted to it	6 (1.1%)
It makes me feel sick	5 (0.9%)
I don't know how to take it	0

N = 361

Other reasons why young people did not take asthma medications daily included:

- Asthma being seasonal or exercise-induced
- Not wanting to become reliant on medication
- Not feeling (or being instructed that) their asthma is not severe enough.

Most participants indicated that they had engaged with a medical professional to assist in the management of their asthma in the past twelve months, with the average number of planned visits to a GP being 1.77, and the average number of urgent visits 1.36. The range for both GP visits and hospitalisations was wide – with some young people visiting GPs up to 33 times a year, and hospitalisations ranging from zero up to seven times a year.

There were few statistically significant differences between location and the four healthcare questions. However, there appeared to be a pattern of those in regional areas visiting their GP and the hospital emergency department more than those in major cities and remote areas. The assumption of homogeneity of variances was violated, and a one-way Welch ANOVA was conducted, and found no statistically significant differences. However there does appear to be a trend, with respondents in inner regional (mean = 2.213) and outer regional (mean =2.259) areas going to the GP more than those from major cities (mean = 1.505) and remote/very remote areas (mean = 1). Going to the hospital emergency department appears to be most common for respondents in outer regional areas (mean = 1.134), compared with major cities (mean = 0.465), inner regional (mean =0.607) and remote/very remote areas (mean =0.40)

Table 15: Engagement with medical professionals to assist in the management of asthma

In the past twelve months how many times have you?				
	Gone for a routine visit to your GP to talk about managing your asthma? This means planned visits - not an urgent visit because your asthma suddenly got worse (n =533)	Gone to a hospital emergency department for your asthma? (n =532)	Been admitted to hospital because of your asthma? (n =533)	Made an urgent visit to a GP for your asthma (for example because your asthma got worse) (n =532)
Range	33	30	7	0 25
Average	1.77	0.8	0.27	1.36
Median	1	0	0	0

Just under half of all participants have a written Asthma Action Plan, with 37.7% having used this plan.

Table 16: Use of Asthma Action Plans

Do you have a written Asthma Action Plan? That is, written instructions for what to do if your asthma is worse or out of control?			
Yes, and I have used it	Yes, but I have not used it	No	Don't know
201 (37.7%)	70 (13.1%)	233 (43.7%)	29 (5.4%)

N = 533

PARTICIPANT HEALTH AND WELLBEING

Participants were asked a range of questions about their general health and wellbeing, including their management of asthma and their experience of any mental health difficulties. In particular, respondents were asked to consider the impact of asthma on their mental wellbeing in the past four weeks, by responding to items which asked them to consider how their asthma made them feel. Participants were more likely to report that their asthma made them feel frustrated or fed up, rather than sad, lonely or misunderstood.

When asked to rate their overall health, the majority of young people rated their health good to excellent. This is in line with other studies that have demonstrated that young people tend to rate their health positively, despite other indicators such as levels of psychiatric distress showing that there may be reason for concern.

Table 17: Participants' overall health rating

How would you rate your overall health in the past four weeks?				
Poor	Fair	Good	Very good	Excellent
86 (16.1%)	137 (25.7%)	150 (28.1%)	113 (21.2%)	47 (8.8%)

N = 533

The standardised Kessler Psychological Distress Scale (K10) was used to measure potential mental health concerns in the survey respondents. Responses revealed that, based on the standardised K10 measure, over 50% of the young people surveyed were likely to have a mental disorder. This was more than double the 24% figure recorded for the general population of young people [Slade et al. 2009]. In this sample, 19.5% of those surveyed were likely to have a severe mental disorder, based on their K10 scores.

Based on participants' responses to the K10 (using a score of 20 as a cut off for probability of at least a mild mental disorder), 48.1% of respondents were likely to be well, 18.9% were likely to have a mild mental disorder, 13.2% were likely to have a moderate disorder, and 19.8% were likely to have a severe mental disorder (N = 524).

The K10 data was not distributed normally, and the non-parametric Kruskal-Wallis H test was used to assess for differences in K10 scores between age groups. The mean ranks of K10 scores between age groups were found to be different at a statistically significant level, $H(3) = 18.874$, $p = 0.000$. Based on median K10 scores 12-14 year olds were less distressed (median =17) than 15-17 year olds (median =23) ($p = .000$) and 22-25 year olds (median =19) ($p=0.024$).

This demonstrates that there were differences between the mental health and wellbeing of these respondents, varying across developmental stages, and that transitional points in these young people's lives were important, with the highest levels of distress presenting in the 15-17 year old age bracket.

Table 18: Psychiatric distress (K10) by age

Age Range	Mean	N	Std. deviation	Median
12-14	18.91	98	8.738	17.00
15-17	24.85	127	9.875	23.00
18-21	21.58	128	8.262	20.00
22-25	21.12	171	8.577	19.00
Total	21.72	524	9.062	20.00

A Mann-Whitney U test showed that female participants (N = 423) were significantly more likely to be experiencing higher levels of psychological distress, as measured by the K10, than males (n =101) ($p<0.000$).

No significant difference in psychological distress, as measured using the K10, were found between participants who identified as Aboriginal or Torres Strait Islander (n = 21) and those who did not (n = 501) ($p=0.106$). This result was achieved using a Mann-Whitney U test. However, it should be interpreted with caution due to the small sample of indigenous young people who completed these questions.

Differences in K10 score between 'on target' and 'off target' Asthma Control Score groups were assessed using a Mann-Whitney U test. Median K10 scores for the 'on target' group (mediaN = 17) were statistically significantly lower than for the 'off target' (mediaN = 22) ($p = 0.000$). This means that young people whose asthma was well controlled were more likely to score lower on the K10 measure of psychiatric distress, and thus, be more likely to be mentally well.

The table below summarises the results of young people's responses to individual items within the K10 measure of psychiatric distress. Items relating to fatigue, restlessness and that everything is an effort were more commonly reported than feelings like sadness or hopelessness.

Table 19: Participants' experience of psychiatric distress, by item of the K10

In the last four weeks I have felt:					
	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Tired for no good reason	57 (10.7%)	111 (20.8%)	200 (37.5%)	119 (22.3%)	46 (8.6%)
Nervous	101 (18.9%)	163 (30.6%)	167 (31.3%)	77 (14.4%)	21 (3.9%)
So nervous that nothing could calm you down	315 (59.1%)	117 (22%)	62 (11.6%)	26 (4.9%)	13% (2.4%)
Hopeless	230 (43.2%)	145 (27.2%)	93 (17.4%)	40 (7.5%)	22 (4.1%)
Restless or fidgety	80 (15%)	151 (28.3%)	170 (31.9%)	89 (16.7%)	42 (7.9%)
So restless that you could not sit still	235 (44.1%)	131 (24.6%)	93 (17.4%)	62 (11.6%)	12 (2.3%)
Depressed	242 (45.4%)	122 (22.9%)	86 (16.1%)	56 (10.5%)	27 (5.1%)
That everything was an effort	146 (27.4%)	133 (25%)	130 (24.4%)	86 (16.1%)	37 (6.9%)
So sad that nothing could cheer you up	291 (54.6%)	114 (21.4%)	75 (14.1%)	39 (7.3%)	14 (2.6%)
Worthless	296 (55.5%)	110 (20.6%)	64 (12%)	39 (7.3%)	24 (4.5%)

N = 533

When asked to respond to items regarding positive dimensions of emotion or happiness, most participants reported that they agreed with positive statements about their mental state. These items included questions about mental alertness, life feeling rewarding, life satisfaction and being able to fit everything in, sourced from the Oxford Happiness Questionnaire.

Table 20: Participants' responses to four items from the Oxford Happiness Questionnaire

In the last four weeks						
	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
I feel that life is very rewarding N = 533	17 (3.2%)	37 (6.9%)	48 (9%)	131 (24.6%)	148 (27.8%)	152 (28.5%)
I feel fully mentally alert N = 533	21 (3.9%)	38 (7.1%)	55 (10.3%)	110 (20.6%)	166 (31.1%)	143 (26.8%)
I am well satisfied about everything in my life N = 530	34 (6.4%)	51 (9.6%)	80 (15%)	127 (23.8%)	160 (30%)	78 (14.6%)
I can fit in everything I want to N = 533	72 (13.5%)	62 (11.6%)	104 (19.5%)	126 (23.6%)	114 (21.4%)	55 (10.3%)

Table 21: Participants' health and wellbeing concerns

Participants were asked to indicate how much of a problem a variety of health and wellbeing issues were for them. Participants appeared to be least concerned about drugs, smoking, alcohol and self-harm; and more concerned about body image, coping with stress, feeling self-conscious, anxiety, poor physical health, feelings of missing out, low confidence and physical health limiting what they do. The table below provides a detailed breakdown of the results.

How much do you think the following issues are a problem for you personally?					
	Not at all	A little	Moderately	Quite a lot	Extremely
Feeling self-conscious N = 530	125 (23.5%)	125 (23.5%)	100 (18.8)	98 (18.4%)	82 (15.4%)
Difficulty coping with stress N = 531	99 (18.6%)	137 (25.7%)	138 (25.9%)	85 (15.9%)	72 (13.5%)
Body Image N = 528	84 (15.8%)	149 (28%)	115 (21.6%)	116 (21.8%)	64 (12%)
Anxiety N = 530	173 (32.5%)	141 (26.5%)	82 (15.4%)	71 (13.3%)	63 (11.8%)
Low confidence N = 530	168 (31.5%)	133 (25%)	105 (19.7%)	62 (11.6%)	62 (11.6%)
My physical health limiting what I do N = 530	176 (33%)	130 (24.4%)	101 (18.9%)	63 (11.8%)	60 (11.3%)
Depression N = 531	244 (45.8%)	123 (23.1)	75 (14.1%)	44 (8.3%)	45 (8.4%)
Feelings of missing out N = 531	181 (34%)	152 (28.5%)	87 (16.3%)	66 (12.4%)	45 (8.4%)
Poor physical health N = 531	180 (33.8%)	151 (28.3%)	96 (18%)	61 (11.4%)	43 (8.1%)
Feeling like I don't fit in N = 530	220 (41.3%)	122 (22.9%)	87 (16.3%)	58 (10.9%)	43 (8.1%)
My physical health limiting where I go N = 528	279 (52.3%)	107 (20.1%)	56 (10.5%)	45 (8.4%)	41 (7.7%)
Loneliness or isolation N = 531	263 (49.3%)	135 (25.3%)	64 (12%)	42 (7.9%)	27 (5.1%)
Bullying or emotional abuse N = 531	305 (57.2%)	116 (21.8%)	62 (11.6%)	31 (5.8%)	17 (3.2%)
Thoughts of suicide N = 531	424 (79.5%)	59 (11.1%)	20 (3.8%)	12 (2.3%)	16 (3%)
Self-harm N = 530	447 (83.9%)	44 (8.3%)	16 (3%)	10 (1.9%)	13 (2.4%)
Smoking N = 529	467 (87.6%)	28 (5.3%)	9 (1.7%)	13 (2.4%)	12 (2.3%)
Drugs N = 531	500 (93.8%)	18 (3.4%)	4 (0.8%)	4 (0.8%)	5 (0.9%)
Alcohol N = 530	444 (83.3%)	55 (10.3%)	25 (4.7%)	5 (0.9%)	1 (0.2%)

Additional analyses were run using Mann-Whitney U tests to determine if health and wellbeing concerns differed between participants in the 'on target' and 'off target' groups, as derived from their Asthma Control Scores.

With the exception of alcohol, bullying and emotional abuse, drugs and self-harm, the median score for all other items listed above was less in the 'on target' group than the 'off target' group, at a statistical significant level of $p < 0.05$. This indicates that participants in the 'on target' group experienced less concern than participants in the 'off target' group, when it came to almost all health and wellbeing areas assessed.

TECHNOLOGY USE BY YOUNG PEOPLE LIVING WITH ASTHMA

As Asthma Australia is interested in understanding the role of technologies in scaling interventions designed to improve the mental health and wellbeing of young people living with asthma, participants were asked about their use of the internet and related technologies.

Young people reported high levels of internet use, as summarised in Table 22.

Table 22: Internet use by young people living with asthma

Approximately how much time would you spend online or using the internet on a normal weekday?					
Less than half an hour	Between half an hour and 1 hour	1-2 hours	2-3 hours	3-4 hours	More than 4 hours
14 (2.6%)	25 (4.7%)	49 (9.2%)	93 (17.4%)	79 (14.8%)	273 (51.2%)

N = 533

Most young people (83.3%) used a smart phone every day or almost every day. This was more than those who used a television (73%), those who used a laptop (66.4%), or desktop computer (31.5%). Only one individual reported that they did not use any of these devices every day, or almost every day.

Table 23: Technology use by device

Which of the following technologies do you use every day, or almost every day?	
A smart phone	444 (83.3%)
A television	389 (73%)
A laptop	354 (66.4%)
A tablet (e.g. iPad)	209 (39.2%)
A desktop computer	168 (31.5%)
A games console or portable gaming device (e.g. Playstation, Xbox, Wii, PSP, DS, Gameboy)	95 (17.8%)
A mobile phone other than a smart phone	40 (7.5%)
Other (e.g. eReader and Kindle)	2 (0.4%)
None of the above	1 (0.2%)

Young people reported that they participated in a range of online activities.

Table 24: Technology use by activity

Please choose from the following list all the things you have done online in the past month?		
	Survey N = 533	Young and Well National Survey 2012* N = 1386
Checked email	472 (88.6%)	93.9%
Accessed social network websites (e.g. Facebook)	468 (87.8%)	92.7%
Listened to, downloaded or uploaded music (e.g. iTunes, Spotify, Songle)	424 (79.5%)	78.8%
Used the internet for school, study or work	408 (76.5%)	83%
Watched, downloaded or uploaded video clips, cartoons, movies, etc.	337 (63.2%)	86.4%
Accessed health information	319 (59.8%)	43.9%
Posted or viewed photos (e.g. Flickr, DropShots, Pinterest, Instagram)	310 (58.2%)	54%
Read or watched the news	300 (56.3%)	69.3%
Used eBay, auction sites, internet shopping facilities	284 (53.3%)	60.3%
Played games alone	228 (42.8%)	37.4%
Read a blog entry	206 (38.6%)	51.1%
Made or received Voice Over Internet Protocol (VOIP) phone calls (e.g. Skype)	126 (23.6%)	38.2%
Used Twitter	107 (20.1%)	15.7%
Played games with others over the internet	95 (17.8%)	32.8%
Used an instant messenger (e.g. MSN or Gmail messenger)	93 (17.4%)	41.6%
Used forums, bulletin boards, or discussion groups	87 (16.3%)	34.6%
Accessed chatrooms	84 (15.8%)	16.5%
Used a webcam	73 (13.7%)	25.4%
Searched for new friends	67 (12.6%)	21.9%
Accessed pornography	65 (12.2%)	No data collected
Written a blog or online diary	50 (9.4%)	14.6%
Accessed online virtual worlds (e.g. Second Life)	36 (6.8%)	7.9%
Sexted (sent or received nude or semi-nude photos of yourself or others)	27 (5.1%)	No data collected
Used online or email counselling	16 (3%)	4.2%
Something else (school, work, job search, etc.)	16 (3%)	3.9%
Gambled	6 (1.1%)	4%

*The age group for this data set were young people aged 16-25 years.

The online activities of young people living with asthma are broad and varied. The most common activities undertaken by participants including accessing social networking websites, checking email, listening to, downloading or uploading music, and using the internet for study. Over half of those who completed the survey indicated that they searched for health information online.

Young people were surveyed on their current and preferred information sources regarding asthma. 56.1% of respondents reported that they would like to get more information about asthma, or get information about asthma from a different source.

SOURCES OF ASTHMA INFORMATION

Table 25: Current and preferred information source on asthma

Information source	Current source	Would like to get more information from this source
Doctor	430 (80.7%)	134 (25.1%)
Family	210 (39.4%)	37 (6.9%)
Websites/online forums	197 (37%)	97 (18.2%)
Pharmacist	193 (36.2%)	84 (15.8%)
Asthma Foundation	163 (30.6%)	119 (22.3%)
Nurse	89 (16.7%)	45 (8.4%)
Friends	75 (14.1%)	19 (3.6%)
School	54 (10.1%)	48 (9%)
Social Media (for example Facebook or Twitter)	54 (10.1%)	100 (18.8%)
Newspapers or health magazines/articles	53 (9.9%)	63 (11.8%)
Nowhere (I don't look for information on asthma)	51 (9.6%)	NA
Television	44 (8.3%)	70 (13.1%)
Other health professional, for example chiropractor or physiotherapist	28 (5.3%)	40 (7.5%)
Apps (on smart phones, tablets, etc.)	26 (4.9%)	108 (20.3%)
Workshops or information sessions	9 (1.7%)	43 (8.1%)
Other	6 (1.1%)	5 (0.9%)
Face-to-face support groups	3 (0.6%)	35 (6.6%)

Use of a pharmacist for information-seeking is greater in outer regional areas than major cities ($p=0.032$). There were no other statistically significant differences in information source based on location. Interestingly, in each geographical area, 75%-100% of participants get information about asthma from their doctor.

Of those who did not want further information about asthma, over a quarter reported that this is because they already had all the information they needed.

Table 26: Reasons for not wanting more information about asthma

Why do you not want more information about asthma?	
I have all the information I need	144 (27%)
If I need information, I can find it myself	109 (20.5%)
I don't need to know, because my parents or carers deal with my asthma for me	35 (6.6%)
I'm not interested	30 (5.6%)
Information about asthma is not relevant to my life	7 (1.3%)
Other	6 (1.1%)

N = 331

Other reasons included: parents passing on information due to the young age of the respondent, and asthma being mild and not impacting their day-to-day life.

In order to assess the potential acceptability and uptake of potential NYPAS initiatives, survey respondents were asked to rate their likelihood of engaging with various initiatives. A detailed outline of responses is provided in Table 27. However, there was a clear preference for technology-based initiatives such as apps, websites and online forums, as well as initiatives that could be online, such as factsheets, stories about young people living with asthma, and films.

Table 27: Likelihood of engaging with initiatives to help young people live better with asthma

If the following things were available to help you live better with asthma, how likely would you be to engage with them?					
	Very unlikely	Unlikely	Neutral	Likely	Very likely
Apps N = 525	66 [12.4%]	53 [9.9%]	94 [17.6%]	175 [32.8%]	137 [25.7%]
A website especially for young people with asthma N = 525	76 [14.3%]	73 [13.7%]	100 [18.8%]	160 [30%]	116 [21.8%]
Support for your friends to understand asthma N = 517	119 [22.3%]	66 [12.4%]	117 [22%]	133 [25%]	82 [15.4%]
Stories about real people living with asthma N = 525	92 [17.3%]	96 [18%]	120 [22.5%]	155 [29.1%]	62 [11.6%]
Factsheets N = 521	93 [17.4%]	73 [13.7%]	127 [23.8%]	168 [31.5%]	60 [11.3%]
Music N = 507	171 [32.1%]	96 [18%]	114 [21.4%]	77 [14.4%]	49 [9.2%]
Online support networks or forums N = 520	136 [25.5%]	106 [19.9%]	135 [25.3%]	101 [18.9%]	42 [7.9%]
Film N = 511	155 [29.1%]	90 [16.9%]	129 [24.2%]	98 [18.4%]	39 [7.3%]
Computer and/or online games N = 515	195 [36.6%]	87 [16.3%]	121 [22.7%]	75 [14.1%]	37 [6.9%]
Art N = 511	180 [33.8%]	105 [19.7%]	129 [24.2%]	60 [11.3%]	37 [6.9%]
Dance N = 509	201 [37.7%]	110 [20.6%]	114 [21.4%]	48 [9%]	36 [6.8%]
Comics (online and hardcopy) N = 514	205 [38.5%]	107 [20.1%]	100 [18.8%]	67 [12.6%]	35 [6.6%]
Volunteering N = 510	169 [31.7%]	112 [21%]	131 [24.6%]	67 [12.6%]	31 [5.8%]
Face-to-face support groups N = 518	198 [37.1%]	137 [25.7%]	110 [20.6%]	52 [9.8%]	21 [3.9%]

IMPLICATIONS & RECOMMENDATIONS

This study has documented a number of key concerns regarding the health and wellbeing of young Australians living with asthma.

First, the young people who responded to this online survey appear to have poorly-controlled asthma, with a large number of young people scoring in the 'off target' group, using the Asthma Control Score as a standard. Having poorly-controlled asthma appeared to impact on these young people's lives in a number of ways, including limiting their participation in education, training or employment, and constraining how they spent their time. Unplanned visits to the GP, and visits to the hospital emergency department, were also common for many of these young people.

Additionally, few of the participants appeared to be taking their asthma medications as would normally be clinically recommended, with many relying heavily on reliever medications such as Ventolin, rather than taking daily preventative medications. These young people's reasons for not taking medications regularly included feeling well (and therefore feeling that the medications are not warranted), and their perception that the doctor did not tell them to take it every day.

Recommendation: Interventions need to be designed to educate young people and their supporters regarding the importance of preventative medications in helping them manage asthma. Health professionals need to be aware of fully explaining to young people the importance of taking preventative medication daily, where appropriate, to achieve asthma control.

Little more than one in ten of this sample of young people reported that they currently smoked. Given the relationship between respiratory diseases such as asthma and smoking, this is of critical concern. It is however unsurprising, given that other studies have shown that young people living with a chronic illness, including asthma, tend to engage in more risk-taking behaviours. It is important that NYPAS interventions focus on long-term behaviour change, rather than simply on increasing young people's awareness of the potential dangers of smoking.

Recommendation: Interventions need to be designed to support young people to decrease their smoking behaviour.

Also of significant concern is the potentially poor mental health and wellbeing evident in this sample of young people living with asthma. Over 50% of those surveyed were rated as likely to be experiencing a mental disorder – much higher than the general population of young people. In this sample, mental health and wellbeing was particularly poor for those young people whose asthma was poorly controlled.

Improving the experiences of those who live with asthma requires attending to opportunities to improve their mental health and wellbeing. Untreated mental illness in young people can have enormous social and economic impacts for young people individually, as well as for the community.

In thinking about how to improve asthma control in young people, as well as addressing potentially related mental health issues, it is important to consider existing face-to-face and online services serving young people.

For example, around Australia, various models of youth-specific primary care services are used by young people. Staffed by general practitioners, nurses, psychologists and other professionals, these service include, for example, community young people's clinics and headspace centres. It may be possible to work with such services to ensure that young people's respiratory health is being managed as well as their emotional health. Similarly, websites like Youthbeyondblue and ReachOut.com by Inspire Foundation are widely utilised by young people, and could be excellent avenues to reach young people outside of an asthma-specific context.

Care for the mental health of young people with asthma could also be integrated into other emerging service models, such as the eMental Health Clinic being developed by the Young and Well CRC and the Brain and Mind Research Institute at the University of Sydney.

Recommendation: Embed support for young people with asthma into existing online and face-to-face service models which support young people's mental health and wellbeing, and trial and test technology-based strategies for enhancing their uptake by young people living with asthma.

It is also important that healthcare professionals engaging with young people with asthma are mindful of their mental health and wellbeing, and work to support young people to manage these issues. Additionally, many young people in this survey appeared to be acting on the advice of their GP when relying on reliever medications. As such, it appears more work needs to be done to educate GPs about the needs of young people living with asthma, and ways to effectively communicate health information with them.

Recommendation: Provide training and support to general practitioners and other health professionals to help them understand the needs of young people with asthma, including how to support young people's mental health and wellbeing.

Unfortunately very few young men participated in this study. However, we did find gender-based differences in some key measures. Further research is needed to understand the experiences of young men in order to support the co-design of interventions that improve their wellbeing and asthma control.

Recommendation: Conduct further research to understand the experiences of young men, with the view to designing interventions that specifically support their needs.

Similarly, there is a need to better understand the experiences of Aboriginal and Torres Strait Islander young people, who also report relatively poorer asthma control in this sample. Again, a co-design process is critical, which allows initiatives to be designed which take into account the cultural and other specific needs of Aboriginal and Torres Strait Islander young people.

Recommendation: Conduct further research to understand the experiences of Aboriginal and Torres Strait Islander young people living with asthma, with the view to designing initiatives that specifically support their needs.

Differences in asthma control and wellbeing for young people across age groups in this survey suggest the importance of taking a developmental approach to designing wellbeing initiatives. This includes considering the needs of young people living with asthma, and the possible importance of targeting interventions to specific age groups, and at key transition points in young people's lives. These transitions include the transition to high school, to further study or employment, or leaving home.

Recommendation: Take a developmental approach to designing interventions for young people living with asthma, considering the specific needs of different age groups, and supporting young people during transition periods.

With the self-selected sample in mind, this study has provided insights into the types of interventions that might be acceptable for young people living with asthma. These include:

- Mobile tools and applications
- Websites tailored to the experiences of young people living with asthma
- Real stories of young people living with asthma
- Factsheets (either stand alone, or integrated into websites or social media).

“I think that as we rely on the internet and technology, it would be clever to have more ads or apps or programs where you can find information on asthma. This may be an app with personal asthma recording, one-on-one messenger chats with an expert, advice, breathing exercises etc.”

18 year old female, Tasmania.

“Create an APP! A reminder to take medication, helpful hints to keep symptoms at bay, cleaning or exercise tips specific to asthma sufferers.”

21 year old female, NSW.

“(I’d like) a way (maybe an app) to monitor control of asthma, so evaluating asthma plan is easier, it would be a way to easily keep track of attacks and symptoms and medication use and dosage would make doctors’ appointments easier.”

23 year old female, Queensland.

The young people surveyed also indicated that interventions which assist their peers to support young people living with asthma are desirable.

There is now a strong body of evidence regarding the potential of online and mobile-tools and applications to improve young people’s wellbeing. Much of the knowledge arising from that research could be adapted and applied to meet the needs of young people living with asthma. A notable relationship between young people’s asthma control and their mental health and general wellbeing is suggested by this survey. Given this finding, there is potential to develop tailored services for young people living with asthma, which form part of a broader online ecosystem of care for young people across a range of physical and mental health concerns. This could include promotion and prevention activities.

Recommendation: Develop tailored online and mobile applications to support the wellbeing of young people with asthma, targeting asthma control, mental health and general wellbeing side-by-side.

Recommendation: Consider embedding tailored interventions for young people living with asthma in an online ecosystem of care, inclusive of promotion and prevention activities, and activities that support peers to help their friends.

CONCLUSION

This study has provided important insights into the experiences of a self-selected sample of Australian young people with asthma, who volunteered to complete an online survey regarding their health and wellbeing. Overall, this sample was characterised by poorly controlled asthma, associated with relatively poor mental health and wellbeing. Indeed, over 50% of the respondents were likely to have a mental disorder and 11.6% currently smoked.

These findings would suggest that investment should be made in initiatives that aim to improve the mental health and wellbeing of young people with asthma, taking a holistic approach to ensure they flourish.

Responses to this survey also suggest that more needs to be done to support young people with asthma to reduce their smoking – a particularly risky behaviour for young people with a respiratory disease, and one that is likely to contribute to poor asthma control.

Despite the considerable challenges faced by young people living with asthma, there is reason for optimism. Young people reported that they were likely to engage in novel initiatives to support their wellbeing, with new and emerging technologies providing a possible setting through which to provide these.

There are also opportunities to embed support for young people with asthma into existing, trusted online and face-to-face services for young people. There is also an opportunity to ensure that asthma-specific supports take into account the mental health needs of young people living with asthma. In the words of one participant:

“Make sure people know that you don’t have to live limited by asthma, anything is possible.”

**16 year old female,
South Australia.**

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APPENDIX ONE: SURVEY INSTRUMENT

DEMOGRAPHICS

1. How old are you:
 - a. (specify) [if answer \leftarrow 12 or \rightarrow 25, survey terminates]
2. Are you...
 - a. Male
 - b. Female
 - c. Other (specify)
3. What is your postcode?
 - a. (specify)
 - b. Don't know
4. Is English the only language you speak at home?
 - a. No [GO TO 5]
 - b. Yes [GO TO 6]
5. Which other language(s) do you speak?
 - a. (specify)
6. Are you of Aboriginal or Torres Strait Islander origin?
 - a. No
 - b. Yes, Aboriginal
 - c. Yes, Torres Strait Islander
 - d. Yes, both Aboriginal and Torres Strait Islander
 - e. Don't know
7. What is your highest level of education?
 - a. No formal education
 - b. Completed or partially completed primary school
 - c. Completed or partially completed junior high school
 - d. Completed or partially completed senior high school
 - e. Certificate or diploma
 - f. Post Graduate Diploma, Masters or PhD
 - g. Degree
 - h. Don't know

8. Which of these best describes your main activities?
 - a. Full-time work greater than or equal to 30 hours paid employment per week
 - b. Part-time work less than 30 hours paid employment per week
 - c. Unemployed/looking for work
 - d. Home duties
 - e. Have a job but not at work due to illness
 - f. Not working and currently receiving sickness allowance/disability support pension
 - g. Volunteer work
 - h. Student attending school
 - i. Student attending university or TAFE
 - j. None of the above
9. How often do you smoke cigarettes?
 - a. I don't smoke
 - b. Rarely
 - c. A few times a month
 - d. A few times a week
 - e. Every day

ASTHMA SCREENING QUESTIONS

10. Have you ever been told by a doctor or nurse that you have asthma?
 - a. Yes
 - b. No [survey terminates]
 - c. Don't know [survey terminates]
11. Have you experienced asthma symptoms (for example coughing, wheezing, shortness of breath, tightness or pain in the chest), or taken treatment for asthma, in the past 12 months?
 - a. Yes
 - b. No [survey terminates]
 - c. Don't know [survey terminates]

MENTAL HEALTH AND WELLBEING - KESSLER 10 (STANDARD SURVEY INSTRUMENT)

12. In the past four weeks, about how often did you feel...

STATEMENTS

- a. Tired out for no good reason?
- b. Nervous?
- c. So nervous that nothing could calm you down?
- d. Hopeless?
- e. Restless or fidgety?
- f. So restless you could not sit still?
- g. Depressed?
- h. That everything was an effort?
- i. So sad that nothing could cheer you up?
- j. Worthless?

ANSWER KEY

- a. None of the time
- b. A little of the time
- c. Some of the time
- d. Most of the time
- e. All of the time

PHYSICAL HEALTH (GENERAL)

13. How would you rate your overall health in the past four weeks?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

MENTAL HEALTH AND WELLBEING - OXFORD HAPPINESS QUESTIONNAIRE (STANDARD SURVEY INSTRUMENT)

14. Below are a number of statements about happiness. Would you please indicate how much you agree or disagree with each?

STATEMENTS

- a. I feel fully mentally alert
- b. I feel that life is very rewarding
- c. I am well satisfied about everything in my life
- d. I can fit in everything I want to

ANSWER KEY

- a. Strongly Disagree
- b. Moderately Disagree
- c. Slightly Disagree
- d. Slightly Agree
- e. Moderately Agree
- f. Strongly Agree

WELLBEING

15. How much do you think the following issues are a problem for you personally?

STATEMENTS

- a. Alcohol
- b. Smoking
- c. Body image
- d. Bullying or emotional abuse
- e. Difficulty coping with stress
- f. Depression
- g. Anxiety
- h. Drugs
- i. Self-harm
- j. Loneliness or isolation
- k. Poor physical health
- l. Feelings of missing out

- m. Feeling like I don't fit in
- n. Low confidence
- o. My physical health limiting what I do
- p. My physical health limiting where I go
- q. Feeling self-conscious
- r. Thoughts of suicide

ANSWER KEY

- a. Not at all
- b. A little
- c. Moderately
- d. Quite a lot
- e. Extremely

PHYSICAL HEALTH (ASTHMA SYMPTOMS) - ASTHMA CONTROL SCORE (STANDARD SURVEY INSTRUMENT)

16. In the past 4 weeks, how often did your asthma prevent you from getting as much done at work, school or home?

- a. All of the time
- b. Most of the time
- c. Some of the time
- d. A little of the time
- e. Not at all

17. During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?

- a. 4 or more night a week
- b. 2 to 3 nights a week
- c. Once a week
- d. Once or twice
- e. Not at all

18. During the past 4 weeks, how often have you used your blue reliever puffer (such as Ventolin, Asmol, Airomir, Bricanyl)?

- a. 3 or more times a day
- b. 1 or 2 times per day
- c. 2 or 3 times per week
- d. Once a week or less
- e. Not at all

19. How would you rate your asthma control during the past 4 weeks?

- a. Not controlled
- b. Poorly controlled
- c. Somewhat controlled
- d. Well controlled
- e. Completely controlled

ASTHMA AND EMOTIONS

20. In the past 4 weeks, how often did your asthma make you feel...

STATEMENTS

- a. Frustrated or fed up
- b. Anxious
- c. Sad
- d. Lonely
- e. Misunderstood
- f. Angry

ANSWER KEY

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Always
- f. Functional limitations

21. In the past 4 weeks, how much did your asthma limit your usual activities?

- a. Not at all
- b. A little
- c. Moderately
- d. Quite a lot
- e. Extremely

22. In the past 4 weeks, how much did your asthma limit your enjoyment of everyday life?

- a. Not at all
- b. A little
- c. Moderately
- d. Quite a lot
- e. Extremely

23. In the past 4 weeks, how often did your asthma prevent you from socialising?

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Always

24. In the past 12 months, have you ever missed school, university, TAFE or work because of your asthma?

- a. Yes
- b. No [GO TO 27]
- c. Don't know [GO TO 27]

25. In the past 12 months, approximately how many days of school, university, TAFE or work have you missed because of your asthma?

- a. (specify)
- b. Don't know

MEDICATION USE AND ADHERENCE

26. In the last 12 months, have you taken any medication (inhalers or tablets) for your asthma?

- a. Yes [GO TO 28]
- b. No [GO TO 29]
- c. Don't know

27. Which of these medications (if any) have you used most commonly in the last 12 months? [Show images of medications]. [Include box to tick 'don't know']

Cluster 1: (relievers):
Ventolin, Airomir, Asmol,
APO(salbutamol), Bricanyl

Cluster 2: (Preventers and Combination Medications):
Alvesco, Flixotide, Qvar,
Pulmicort, Intal, Singulair,
Tilade, Flutiform, Seretide,
Symbicort

Cluster 3: (Symptom Controllers): Serevent, Oxis,
Flixotide, Onbre

For each medication that is ticked, ask two questions:

1. Which of the following best describes the reason you use this medication?
 - d. I use it regularly to prevent asthma symptoms
 - e. I use it only when I can feel that my asthma symptoms are getting worse
 - f. I use it to relieve asthma symptoms
 - g. I use it when I have an asthma attack
 - h. Don't know
 - i. Other, please specify

2. How often do you use this medication?

- a. Every day
- b. 5 or 6 days per week
- c. 3 or 4 days per week
- d. 1 or 2 days per week
- e. Less than 1 day per week, but more than 1 day per month
- f. Less than 1 day per month
- g. Only when I exercise

28. Do you take asthma medication every day?

- a. Yes [GO TO 31]
- b. No [Go TO 30]

29. What is the reason(s) you don't take asthma medication every day? Please select all that apply.

- a. I don't think I need to, because I feel well
- b. I don't think the medication actually makes a difference
- c. I'm worried about the side-effects
- d. I'm worried about getting addicted to it
- e. It costs too much
- f. I forget to take it
- g. I don't know how to take it
- h. I don't have a current prescription
- i. The doctor didn't tell me to take it every day
- j. It's too much of a hassle
- k. I'm embarrassed to take my medication
- l. It makes me feel sick
- m. It makes me feel like I'm not normal
- n. Other (please specify – open answer)

HEALTH SERVICE USE

30. In the past 12 months, how often have you gone for a routine visit to your GP to talk about managing your asthma? This means planned visits - not an urgent visit because your asthma suddenly got worse.

- a. (specify)
- b. Don't know

31. In the past 12 months, how many times did you go to a hospital emergency department for your asthma? Please enter '0' if none.

- a. (specify) [accept numerical answers 0 and above]
- b. Don't know

33. In the past 12 months, how many times were you admitted to hospital because of your asthma? Please enter '0' if none.

- a. (specify) [accept numerical answers 0 and above]
- b. Don't know

33. In the past 12 months, how many times did you make an urgent visit to a GP for your asthma (for example because your symptoms got worse)?

- a. (specify) [accept numerical answers 0 and above]
- b. Don't know

34. Do you have a written asthma Action Plan. That is, written instructions for what to do if your asthma is worse or out of control?

- a. Yes and I have used it
- b. Yes, and I have not used it
- c. No
- d. Don't know

INTERNET AND TECHNOLOGY USE

35. Approximately how much time would you spend online or using the internet on a normal weekday?

- a. More than 4 hours
- b. 3-4 hours
- c. 2-3 hours
- d. 1-2 hours
- e. Between half an hour and 1 hour
- f. Less than half an hour

36. Which of the following technologies do you use every day, or almost every day? (Please choose as many as apply to you).

- a. A smart phone
- b. A mobile phone other than a smart phone
- c. A tablet (eg. iPad)
- d. A laptop
- e. A desktop computer
- f. A games console or portable gaming device (eg. Playstation, Xbox, Wii, PSP, DS, Gameboy)
- g. Other handheld portable devices (eg. MP3 player, iPod Touch)
- h. A television
- i. Other
- j. None of the above

37. Please choose from the following list all the things you have done online in the past month?

- a. Accessed chatrooms
- b. Accessed health information
- c. Accessed online virtual worlds (e.g. Second Life)
- d. Accessed social network websites (e.g. Facebook)
- e. Checked email
- f. Gambled
- g. Listened to, downloaded or uploaded music (e.g. iTunes, Spotify, Sungle)
- h. Made or received Voice Over Internet Protocol (VOIP) phone calls (e.g. Skype)
- i. Used online or email counselling
- j. Played games alone
- k. Played games with others over the internet
- l. Posted or viewed photos (e.g. Flickr, DropShots, Pinterest, Instagram)
- m. Read a blog entry
- n. Read or watched the news
- o. Searched for new friends
- p. Used a webcam
- q. Used an instant messenger (e.g. MSN or Gmail messenger)

- r. Used eBay, auction sites, internet shopping facilities
- s. Used forums, bulletin boards, or discussion groups
- t. Used the internet for school, study or work
- u. Used Twitter
- v. Watched, downloaded or uploaded video clips, cartoons, movies, etc
- w. Written a blog or online diary
- x. Accessed pornography
- y. Sexted (sent or received nude or semi-nude photos of yourself or others)
- z. Something else (specify_____)

INFORMATION ACCESS

38. Where do you get information about asthma at the moment? Please select all that apply.

- a. Doctor
- b. Nurse
- c. Pharmacist
- d. Other health professional (for example chiropractor or physiotherapist)
- e. Social media (for example Facebook or Twitter)
- f. Websites / online forums
- g. Newspapers or health magazines / articles
- h. TV
- i. Apps (on smart phones, tablets etc)
- j. Family
- k. Friends
- l. School
- m. Workshops or information sessions
- n. Face-to-face support groups
- o. Asthma Foundation
- p. Other (specify)
- q. Nowhere – I don't look for information on asthma

39. Would you like to get more information about asthma, or get asthma information from a different source?

- a. Yes [GO TO 40]
- b. No [GO TO 41]

40. Where would you like to get more information about asthma? Please select all that apply

- a. Doctor
- b. Nurse
- c. Pharmacist
- d. Other health professional (for example chiropractor or physiotherapist)
- e. Social media (for example Facebook or Twitter)
- f. Websites / online forums
- g. Newspapers or health magazines / articles
- h. TV
- i. Apps (on smart phones, tablets etc)
- j. Family
- k. Friends
- l. School
- m. Workshops or information sessions
- n. Face-to-face support group
- o. Asthma Foundation
- p. Other (specify)

41. Why do you not want more information about asthma? Please select all that apply.

- a. I have all the information I need
- b. I'm not interested
- c. Information about asthma is not relevant to my life
- d. I don't need to know, because my parents or carers deal with my asthma for me
- e. If I need information, I can find it myself
- f. Other (specify)

42. If the following things were available to help you live better with asthma, how likely would you be to engage with them?

STATEMENTS

- a. Fact sheets
- b. Stories about real people living with asthma
- c. Online support networks or forums
- d. Face-to-face support groups
- e. Apps
- f. A website especially for young people with asthma
- g. Comics (online and hardcopy)
- h. Computer and/or online games
- i. Music
- j. Volunteering
- k. Art
- l. Dance
- m. Film
- n. Support for your friends to understand asthma

ANSWER KEY

- a. Very unlikely
- b. Unlikely
- c. Neutral
- d. Likely
- e. Very likely

43. Is there something else (like a program, event or resource) that you would like to suggest that would help you or other young people live better with asthma?

[Optional, free answer]



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