# Young Minds Matter: the second Australian Child and Adolescent Survey of Mental Health and Wellbeing

Survey User's Guide



Australian Government Department of Health







Suggested citation: Telethon Kids Institute (2015) *Young Minds Matter: the second Australian Child and Adolescent Survey of Mental Health and Wellbeing, Survey User's Guide.* Centre for Child Health Research, University of Western Australia: Perth, Australia, ISBN 978-1-74052-336-3

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# **CHAPTER 1: INTRODUCTION**

### **Overview**

*Young Minds Matter*: The second Australian Child and Adolescent Survey of Mental Health and Wellbeing (YMM) was conducted in 2013-14 by the Telethon Kids Institute, The University of Western Australia in partnership with Roy Morgan Research on behalf of the Australian Government Department of Health. The survey is part of the National Survey of Mental Health and Wellbeing initiative and complements data collected in the population survey of adults and of people living with psychotic disorders conducted in 2007 and 2010 respectively. The conduct of the survey was approved by the Department of Health Departmental Ethics Committee (Project 17/2012) in accordance with the National Health and Medical Research Council (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)* and the Federal *Privacy Act 1988*. Participation in the survey was voluntary and required written consent.

Many mental health problems in adults, such as anxiety and depressive disorders, have first onset in childhood and adolescence. Emotional and behavioural problems in childhood and adolescence can have significant impacts on children's development, including engagement with school education, and can disrupt learning. Emotional and behavioural problems can be pervasive and there are often long delays in recognising problems, and providing support and referral for children and families to appropriate services. Information about these problems can help plan, and support future funding for services for children and families. YMM sought to provide information on the prevalence and nature of mental disorders in children and adolescents, impairment associated with disorders and the use of, and unmet need for, services across the health and education sectors. Information will be used by Commonwealth, State and Territory governments and mental health service providers to plan appropriate services for children and adolescents with mental health problems, to determine the need for additional services and what these might be, and to benchmark progress in achieving national and jurisdictional goals in promoting the social and emotional wellbeing of children and adolescents.

The survey comprised a random sample of more than 6,000 children and adolescents aged 4-17 years across Australia. Information was collected by computer-assisted personal interviewing within the home. Parents and carers were interviewed about one selected child in the family, and adolescents aged 11-17 years were asked to complete a questionnaire on a tablet computer. Fieldwork and data collection for the survey took place between May 2013 and April 2014.

The survey provides information on the 12-month prevalence of the following mental disorders:

- Anxiety disorders
  - Social phobia
  - Separation anxiety disorder
  - Generalised anxiety disorder
  - Obsessive-compulsive disorder
- Major depressive disorder
- Attention-deficit/hyperactivity disorder
- Conduct disorder

In addition, the impact of these disorders and the services that were used in their management as well as overall measures of emotional and behavioural difficulties and other contextual information were captured. For the first time in an Australian national survey, young people aged 11-17 years answered questions on symptoms of major depressive disorder along with their use of services, risk behaviours and other contextual information.

A summary of the findings of the survey are presented in the main Department of Health publication 'The Mental Health of Children and Adolescents: Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing.'<sup>1</sup> Further results can be accessed using the 'Survey Results Query Tool' available via the YMM website <u>http://www.youngmindsmatter.org.au</u>. For users who wish to undertake more detailed analysis of the survey data, a Confidentialised Unit Record File (CURF) has been prepared and is housed at the Australian Data Archive <u>http://ada.edu.au</u>. Please refer to the CURF Technical Guide for information on access and use of the CURF. For a full listing of data products and sources available from the survey, please see the Data Access Statement which is also available via the YMM website.

This Survey User's Guide provides a comprehensive overview of the survey design (methodology, development, data collection and data processing), survey content (parent or carer interview and youth self-report questionnaire), reliability of estimates and interpretation of results, and of YMM survey products.

# The role of population surveys in Government policies on mental health

In 1992, the Commonwealth, State and Territory Governments endorsed the first National Mental Health Strategy. This Strategy provided a framework for reform and the basis for a coordinated government approach to mental health in Australia. It consisted of the National Mental Health Policy and the First National Mental Health Plan. Since then, there has been a succession of plans with the Fourth National Mental Health Plan providing the agenda for action from 2009-2014.<sup>2</sup>

In developing the Strategy it became apparent that little information was available nationally about the prevalence of mental disorders and how people with disorders were doing. Therefore, national surveys were recommended and endorsed and fall under the banner of the 'National Survey of Mental Health and Wellbeing'. The first surveys were conducted over 1997 and 1998 and consisted of three components: adult, low prevalence disorders (psychotic illness), and child and adolescent. Each component has had a follow up survey but at different time points. The adult survey was conducted again in 2007 and the second low prevalence disorders survey was conducted in 2010. YMM is the follow up survey for the child and adolescent component, with more than 15 years having passed since the first survey.

# Overview of the first child and adolescent survey

The first child and adolescent component of the National Survey of Mental Health and Wellbeing was conducted in 1998.<sup>3</sup> The Mental Health Branch of the then Commonwealth Department of Health and Aged Care commissioned the University of Adelaide to undertake the survey. The 1998 survey was the first of its kind, both nationally and internationally, to measure prevalence and burden of mental health disorders in children and adolescents. The survey provided important data

on the prevalence of mental health disorders, the burden associated with these disorders, and the services used in their management.

The survey found that mental health problems were relatively common, with approximately 14% of children and adolescents having mental health problems based on scores obtained from the Child Behaviour Checklist (CBCL).<sup>4</sup> These problems had significant impacts on children and adolescents, particularly on their schooling and peer relationships. They also had significant impacts on parents and family activities. However, only one in four children and adolescents with mental health problems had attended professional services in the six months prior to the survey. Even among children and adolescents with the most severe problems, only 50% received professional help. General practitioners and school-based counsellors were the services most frequently used by children and young people and their families.<sup>4</sup> These data have informed the development and provision of mental health services for Australian children and adolescents up until the present time.

Since 1998 there have been substantial changes in the way mental health care is provided in Australia. There have been significant changes in people's understanding of mental health. A range of new programmes and services has been developed in the education and health sectors that provide information, support, and specialist help for young people and their families. Programmes such as *KidsMatter* and *Mind Matters* promote mental health through the school environment. While each jurisdiction has taken its own approach, schools are generally providing higher levels of support, including access to specialist counselling. Through the Australian Government's *Better Access* programme introduced in November 2006, more general practitioners have been trained in supporting the mental health needs of children and adolescents and their families, and children and families now have access to Medicare-subsidised psychological therapy. Also launched in 2006, *headspace* has rapidly expanded and provides a range of support services for young people aged 12-25 years with emotional and behavioural problems and substance use problems. Additionally, several counselling services are now available by telephone and a range of internet-based services has also been created that provide information and counselling support online.

#### **Survey development**

Development of specifications for the survey was guided by a series of meetings with technical experts convened by the Department of Health. Membership of the Technical Advisory Group is provided in Appendix 1. This process led to the establishment of aims and objectives and identified the major methodological parameters of the survey.

Meetings with the Technical Advisory Group focussed upon consideration of the various options for the specific diagnostic and behavioural measures that form the core of a national survey of mental health and wellbeing. A range of other content requirements were also raised to be determined by the organisation engaged to undertake the survey. The information gathered from the survey aimed to complement that compiled from the 2007 national survey of the adult population and the 2010 survey of people living with psychotic disorders, to provide a complete, contemporary picture of the prevalence of mental illness in Australia and the use and need for services.

Development of content for each domain was informed by a review of the scientific literature and other relevant surveys, including the two other international surveys of child and adolescent wellbeing - the British Child and Adolescent Mental Health Survey (BCAMHS) conducted in 1999 and

2004, and the National Comorbidity Survey—Adolescent Supplement (NCS-A) conducted in the United States in 2001-02.

After the contract was awarded in June 2012 to the Telethon Kids Institute, development of the survey continued with advice from a Survey Reference Group (SRG) which included over 20 experts in child health care, psychology, psychiatry, education and mental health service delivery. See Appendix 2 for membership of the SRG. Members also included representatives from relevant organisations including the Australian Government Department of Health and Department of Social Services, the Australian Bureau of Statistics (ABS), and mental health consumer and carer representatives.

#### Survey aims

The aims of the survey were to determine:

- 1. How many children and adolescents have which mental health problems and disorders.
- 2. The nature of these mental health problems and disorders.
- 3. The impact of these problems and disorders.
- 4. How many children and adolescents have used services for mental health problems and disorders.
- 5. The role of the education sector in providing services for children and adolescents with mental health problems and disorders.

In achieving the survey aims, the following principles were used to determine the essential and desirable elements of the survey:

- The study should produce population representative estimates at the national level with a sufficient degree of accuracy to be useful for policy and planning purposes.
- Where data items from the first national survey were found to produce useful indicators, these were to be retained, where possible, to facilitate comparisons over time.
- Content would not be retained from the first national survey if the data quality was poor, the frequency of occurrence was too low to produce any output or the data items were not known to be used in the generation of any output from the study.
- Where new content was added to address new or emerging policy priorities, preference was to be given to the use of internationally recognised and validated instruments.
- Within the limitations of achieving the aims of the study, it was attempted to harmonise data items with other national surveys, specifically the other components of the National Survey of Mental Health and Wellbeing.
- Additional content would only be considered where inclusion of that content would not jeopardise the achievement of the main aims of the survey.

# Timeline

The following table outlines the timeline for major stages of the survey.

Stage	Date
Commencement of project	June 2012
First meeting of the SRG	August 2012
Second meeting of the SRG	October 2012
Cognitive Testing	November- December 2012
Pilot Testing	January-February 2013
Third meeting of the SRG	February 2013
Dress Rehearsal	April-May 2013
Main wave of data collection	May 2013- April 2014
Fourth meeting of the SRG	June 2014
Completion of main report and submission to the	April 2015
Department for public release	
Completion of the CURF and submission to the	June 2015
Australian Data Archive for public use	

# **Measuring mental health**

#### **Diagnostic instrument for mental disorders**

Mental disorders were assessed using the *Diagnostic Interview Schedule for Children Version IV* (DISC-IV).<sup>5</sup> The DISC-IV implements the criteria for mental disorders set out in the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, produced by the American Psychiatric Association.<sup>6</sup> These criteria are based on clinically significant sets of symptoms that are associated with impaired functioning by young people with disorders.

The DISC was particularly suited to the survey as it was developed primarily for epidemiological research and can be administered by trained, lay interviewers. The most recent version, the DISC-IV, is able to address more than 30 psychiatric diagnoses based on DSM-IV criteria that occur in children and adolescents. Most questions are worded so that they can be answered 'yes', 'no', and 'somewhat' or 'sometimes', allowing for easy scoring and not requiring clinical assessment. Questions reference the four weeks and 12 months prior to the interview, allowing for the generation of prevalences for different periods. The 12-month prevalence is the primary measure produced by the DISC-IV modules, and this aligned with what has been produced from other National Survey of Mental Health and Wellbeing initiative surveys.

A considerable investment was made by the Technical Advisory Group in examining the relative merits of two potential diagnostic instruments for use in the survey - the Development and Well Being Assessment (DAWBA) used in the British Child and Adolescent Mental Health Survey and the DISC-IV. Detailed analyses were undertaken of each instrument and through consultation with the expert advisors, a decision was made that the DISC-IV would be best to meet the needs of a child and adolescent survey in the Australian context. Whilst the DISC-IV has disadvantages, the Department was advised that these were outweighed by the benefits in relation to comparability with the first survey, production of both 1-month and 12-month prevalence estimates, flexibility around content and changes to the questionnaire, and access to the scoring algorithms and data.

#### Instrument to measure emotional and behavioural problems

The first survey supplemented the DISC-IV with the Child Behaviour Checklist (CBCL) which was an instrument used to capture a broader range of mental health problems experienced by children and adolescents.<sup>7</sup> The CBCL was administered to the parent or primary carer of children and also self-reported by young people aged 13 years and over. Because a relatively narrow range of DISC-IV diagnostic modules were used in the first survey, the CBCL was used to provide the main prevalence estimates derived from the first survey and such a behavioural measure was considered a core component of the survey.

For comparability with other national and international data collections, and after consultation with the Technical Advisory Group, the Department decided that the Strengths and Difficulties Questionnaire (SDQ)<sup>8</sup> would replace the CBCL for the second child and adolescent survey. The SDQ is a brief behavioural screening questionnaire that can be completed by parent and carers of 4-17 year-olds and self-reported by 11-17 year-olds. The questionnaire takes around five minutes to administer and covers emotional symptoms, conduct problems, hyperactivity and inattentiveness, and peer relationship problems, as well as pro-social behaviour. The SDQ correlates well with diagnoses of disorders, but cannot generate these directly. In contrast, the DISC-IV identifies presence or absence of specific mental disorders.

There were several reasons for this change. The SDQ is significantly shorter than the CBCL, has equivalent sensitivity and specificity in identifying children with emotional and behavioural problems, and has been widely adopted in other collection activities in Australia and internationally. For example, the SDQ is one of several standardised instruments widely used in routine outcome measurement across Australia's public mental health services. For these reasons, the use of the SDQ in YMM facilitates comparison of survey results with information from jurisdictional and clinical reporting systems and allows for comparison with more general health surveys, such as the Longitudinal Study of Australian Children and the New South Wales Health Survey that use the SDQ.

# **CHAPTER 2: SURVEY DESIGN**

# **Overview**

The YMM survey was designed to provide prevalence estimates on common mental disorders in children and adolescents, measure the burden associated with these disorders, and the services used in their management. The survey included two sampling components: a main survey of 4-17 year-olds and an oversample of 16-17 year-olds.

Fieldwork for the survey was originally divided into three phases commencing 31<sup>st</sup> May 2013 and due for completion on 15<sup>th</sup> December 2013. However, due to delays in fieldwork because of problems with under-identification of in-scope children, a fourth phase of interviewing was required to complete fieldwork. This included a large focus on the oversample component. Phase four began on 18<sup>th</sup> January 2014 and was completed by 10<sup>th</sup> April 2014. As Phase four occurred in a new calendar year and many children would have attended only a few weeks of school, the questionnaires were modified slightly.

This Chapter provides a complete overview of the survey methodology, its development, data collection procedures including duty of care and consent procedures, and data processing.

### Survey methodology

#### Scope and coverage

The scope of the survey was children aged 4-17 years (up to but not including the age of 18) who were usually resident in private dwellings in Australia, excluding very remote areas. Private dwellings were houses, flats, home units and any other structures used as private places of residence at the time of the survey. Usual residents were those children who usually lived in the household at least 50% of the time, including those children usually living in the household but away at the time such as at boarding school, hospital, on holiday, or staying with another parent or relative. Children who usually spent more than 50% of their time in another household and less than 50% in the selected household were not in scope.

Specific exclusions were:-

- The one percent most remote SA1s in Australia. These remote areas were excluded from the survey for practical reasons. This is considered standard practice for surveys that aim to yield estimates at a national level.
- *Children who were homeless or in institutional care*. Although this is likely to be a small proportion of children and adolescents, these sub-populations are known to have a high risk of mental health problems. A completely different approach would be required to represent this population adequately.
- Children in families where the interview could not be conducted in English. Proxy, interpreted or foreign language interviews were not conducted for a number of reasons. First, it meant that the survey could be conducted by lay interviewers using a standard format for all respondents. Second, it ensured that survey questions were asked exactly as described and responses reflected the interpretation by the respondent rather than a third party. Thirdly,

the sensitive nature of the survey questions made them unsuitable for use with proxies or interpreters. Fourth, there would be additional costs associated with translation. Therefore, conducting the survey in foreign languages was not considered viable.

A separate Indigenous sample was not included as there are important cultural issues in appropriately measuring mental health and wellbeing in Aboriginal and Torres Strait Islander children that could not be addressed within the framework of the population survey. A separate study would need to be undertaken to assess the mental health of Aboriginal and Torres Strait Islander children and young people in a culturally appropriate manner. The survey cannot produce estimates of mental disorders and service use for Indigenous peoples. Random sampling alone with the number of participants for this survey was not considered sufficient for generation of these data within acceptable levels of accuracy.

#### Sample design

The survey sample was selected in two components: a main sample and an oversample. Interviewers were allocated workloads for these components separately.

#### Main sample

The first component was a randomly selected sample of 5,500 families with children aged 4-17 years from across the country. The sample size was chosen to deliver reliable national estimates of prevalence, burden and service use by sex and for the two age groups of 4-11 and 12-17 years.

In total 46,248 households were approached to achieve a calculated final sample of 5,500 based on an in-scope rate of 21% and a target response rate of 60%.

#### Oversample

In recognition of the increased risks for a range of emotional and behavioural problems in the older teenage years, the main survey sample was supplemented by a second component of 16-17 yearolds. This comprised an additional random sample of 800 families with children aged 16-17 years. The sample size was determined to be sufficiently large for separate analyses of the data and to produce specific estimates for this age group. The oversample of 16-17 year olds was recruited through additional screening in approximately 50% of the SA1s selected in the main sample.

The oversample aimed to allow for the results for just 16 and 17 year-olds to be analysed together with that for 16 and 17 year olds from the 2007 adult survey. The combination of data from both surveys provides two perspectives on mental health problems in this age group—one based on questions specifically designed for teenagers and one based on questions designed for adults.

An additional 30,358 households were approached to achieve the required 800 interviews.

#### Sampling method

A multi-stage, area-based sample selection procedure was employed to select the areas for interviewing for both the main sample and oversample. First, Statistical Area Level 2s (SA2s), representing a community both socially and economically with an average population of 20,000, were stratified by State/Territory and by metropolitan versus rest of the state to ensure proportional

representation of geographic areas across Australia. Then from these selected SA2s, 550 Statistical Level Area 1s (SA1s) were selected. SA1s are smaller than SA2s with an average population of 400 people. It was anticipated that on average, each SA1 would achieve 10 interviews to produce the required sample size of 5,500 families. SA1s were randomly selected with probability proportional to the number of children aged 4-17 years-old from the ABS 2011 Census of Population and Housing.

A total of 225 SA1 areas were selected from those where there were at least ten families with children living at the time of the 2011 Census of Population and Housing. SA1s in very remote areas were excluded.

The SA1s used for the main sample were also used for the oversample. A target of four interviews of randomly selected households in each of the 225 SA1s was predicted to deliver the required sample of 800 families. However, selection of an additional 41 SA1s was necessary to achieve the desired 800 interviews. In total 266 SA1s were selected.

Interviewers went to a randomly selected sample of houses in each SA1 to identify households that had one or more children aged 4-17 years-old. In households where there was more than one resident child aged 4-17 years-old, the names of all children were entered into the interviewer's hand-held computer, which then selected a child at random as the study participant for the survey.

#### **Blocklisting procedures**

The first step in the field enumeration phase was to construct a list of all dwellings within each selected SA1 area. This process is referred to as blocklisting. Blocklisting is designed to create an accurate list of all dwelling addresses within a specified SA1 from which a random sample may be drawn. Each interviewer was given a map for the selected SA1 area and they travelled to the SA1 and comprehensively walked the area and checked the address listing for errors including new and removed dwellings. These corrections were entered directly on the tablet to compile the list of dwellings in that area for sample selection. SA1 areas typically contain around 200-250 households.

To facilitate this task, the best available information as to the current addresses for each specified SA1 was pre-loaded directly into the interviewer's tablet computer. The address base was drawn from the Geocoded National Address File (G-NAF) provided by the Public Sector Mapping Agency (PSMA) and provided it to the Telethon Kids Institute for the purposes of YMM as a charitable donation. PSMA have created the G-NAF as the most authoritative geocoded address index for the entire country. It lists over 14 million physical addresses, each linked to a specific latitude and longitude. G-NAF is compiled from a range of administrative data sources including jurisdictional land registries, Australia Post and the Australian Electoral Commission.

Once the corrected block list was completed by the field interviewer, the information was transmitted from the tablet computer in the field to a central server. The server then applied a random start point in the selected SA1 as well as a skip interval to select the sample of dwellings for the survey. The final selections were downloaded to the interviewer's tablet enabling the interviewer to approach and screen selected dwellings.

#### Unexpected issues with identifying in-scope families

As mentioned, the number of children aged 4-17 years-old living in each SA1 was estimated based on figures from the 2011 Census of Population and Housing conducted by the ABS. The number of

households approached in order to achieve a final sample of 5,500 was based initially on an average estimated in-scope rate of 28% and a response rate of 60%. However, approximately three months into the fieldwork after fieldwork had been completed in 143 SA1 areas, the achieved in-scope rate was substantially less, at 21%. The difference between a roughly one in four to one in five in-scope rate had a significant impact on the number of households that needed to be approached to recruit the sample. Unless changes to sample selection and fieldwork were made at the time that the problem was identified, it was anticipated that the current sample would yield 4,500 participating families instead of 5,500 families, a shortfall of 1,000 families.

Extensive investigations failed to identify any reason why this occurred. The reasons that were examined included:

- Recording errors on the Computer Assisted Parent Interview (CAPI) or RMR system;
- Errors in calculation of skip patterns;
- Incorrect figures from the ABS;
- Errors in drawing of the sample;
- Significant SA1 changes since the 2011 census;
- Blocklisting errors by interviewers;
- Interviewer/scripting error (interviewer call patterns, approach, or recording of outcomes on CAPI tablet);
- Respondent understanding of what is in-scope;
- Systematic bias in those groups where in-scope status was not identified; and
- Passive refusal.

No systematic problems were uncovered in sample selection or field procedures. The effect was likely to be a combination of a number of factors, including migration out of selected sample areas since the 2011 Census, the ABS introducing a greater degree of random error into tables released from the 2011 Census to strengthen how they protect respondent confidentiality, and the possibility that some households may have reported being out of scope as a simple and passive way to opt out of the survey.

In order to address the issue and to achieve the target participating sample of 5,500, it was decided to increase the number of interviews in the remaining SA1s (to 12 per SA1) by altering the skip patterns and selecting more households per SA1 to approach. The strategy was successful and the targeted sample was achieved with the extension of fieldwork into a fourth phase.

# Survey development

#### Adapting to Australian context

The primary focus of the survey was on determining the prevalence of mental disorders and their impact, and the services used by children and adolescents with mental health problems and disorders. The measurement of mental disorders and other mental health problems was based on standardised international survey instruments with restrictions on changes. With permission from the University of Columbia, some minor modifications were made to the DISC-IV instruments to make the terminology and spelling appropriate to the Australian context.

The service use module was designed specifically for the Australian context of mental health service delivery with advice from the SRG and a specialist reference group on service utilisation. The specialist reference group was mostly comprised members of the SRG. The question wording and response options were based directly on what options are currently available for young people in schools, the health system, specialist youth mental health (headspace centres), telephone and online servicing (e.g. specific reference was made to KidsHelpline, Reachout and Youth beyondblue).

Questions in the youth risk behaviours module were based on those used in the US Youth Risk Behavior Surveillance System (YRBSS) conducted by the Centers for Disease Control and Prevention<sup>9</sup> and some of the questions were modified to align with Australian standards including standard alcohol drinking levels and the use of appropriate Australian wording for drinking and drug use questions (e.g. the word cannabis is more commonly used in Australia than marijuana). Some of the response categories with respect to drug use were also modified to align with other Australian surveys.

Key sociodemographic questions were based on ABS standards to allow for the assessment of sample representativeness and comparison with other national surveys. Questions that used ABS standard wording and response categories were:

- Gross household income;
- Employment status, hours of work and job seeking;
- Household tenure and rental type;
- Marital status;
- Indigenous status;
- Country of birth;
- Main language spoken at home and proficiency in English; and
- Highest year of school completion and highest post-school qualification.

#### **Questionnaire testing**

The parent or carer interview and youth self-complete questionnaires were extensively tested to identify problems before being finalised for the main fieldwork. This testing involved three stages: cognitive testing, pilot testing and a dress rehearsal. Each stage is described in detail below.

#### Cognitive testing

The purpose of cognitive testing was to explore how respondents interpret and understand the survey content and how they formulate their responses to the questions. Cognitive testing is also an opportunity to evaluate the survey content, particularly new modules or questions, and to identify any practical or theoretical issues.

The cognitive testing was conducted during November and December 2012 in Melbourne and Perth. Both clinical and general population respondents were recruited for this process. In order to adequately test new modules that would be triggered only for children with mental health problems, such as impact on functioning and service use, clinical cases were oversampled. Clinical cases were recruited from local Child and Adolescent Mental Health Services (CAMHS) and the general population sample was recruited by RMR. As cognitive testing was primarily for identifying major practical issues, only a small sample was used. A total of 16 cognitive interviews were conducted in Perth at the Telethon Kids Institute building and 12 were undertaken at the RMR head office in Melbourne.

Each cognitive testing interview was conducted in two phases. In the first phase, the survey interview was administered as it would be administered in the main survey. The second phase involved a follow-up interview that focused on establishing if respondents understood the questions as they were intended, how they went about determining their answers to the questions, and assessing to what extent they were able to provide the information being sought. Each cognitive interview was attended by a trained survey interviewer who administered the questionnaire, and at least one additional observer who would also participate in the phase two process. The observer also noted any areas of the questionnaire where the respondent appeared to show signs of difficulty or discomfort while answering the questions and these were explored further in the second phase.

The normal procedure for cognitive testing is to test only the new components or questions in the survey. However, as there were significant modifications and additions to content since the last survey, the parent or carer interview was cognitively tested in its entirety.

A number of changes were made as result of the cognitive testing, including:

- Increasing the age limit at which some questions were asked, and increasing the age at which youth completed the service use module from 11 to 13 years;
- Some minor wording changes to facilitate interpretation and reduce burden of repetitive questioning on the respondent;
- Removal of some questions that were found to be difficult to understand or concerning for parents or carers;
- Changing text in introductory statements at the beginning of modules;
- Change in ordering of modules;
- Changes in filtering into some modules, including impact on functioning and perceived need for care;
- Additional interviewer notes and modified training.

No major changes were made to the survey content as a result of cognitive testing so that accurate timings could be obtained from the pilot testing. Minor changes to wording on the DISC-IV modules were made in collaboration the DISC custodians at Columbia University.

#### Pilot testing

The aims of the Pilot Test were to:

- Test the interviewer training and field procedures;
- Test selection and recruitment procedures and participation rates;
- Calculate average timings of individual modules in the questionnaires; and
- Identify any issues with the questionnaires in a live field test.

The pilot stage of the survey was conducted during January and February 2013, with fieldwork conducted in three metropolitan and two regional SA1s in Victoria. The Pilot Test SA1s were selected to cover a range of socio-economic areas. Five experienced RMR household interviewers were trained over a three and a half day training session for the Pilot Test. Initial response rates were

lower than expected, so to ensure sufficient parent or carer interviews were completed, an additional sample of addresses were assigned to interviewers during the Pilot Test fieldwork period. In total, 62 parent or carer interviews were completed and 32 11-17 year-olds completed a youth survey.

The Pilot Test identified a number of issues and as a result, the following changes were made:

- Reducing skip intervals within SA1s to increase capture of families in-scope;
- Change in field procedures and coding of refusals to increase known in-scope status of refusals;
- Procedural changes in administration of the Household Record Form (HRF) and Consent Module to reduce time in administration;
- Cuts to questionnaire content to reduce overall administration time, including removal of the DISC-IV Post Traumatic Stress Disorder and Dysthymic Disorder modules, and the Child Health Utility-9D (CHU-9D)<sup>10</sup> and internet modules in the parent or carer interview;
- Reduction in number of items within modules such as the McMaster Family Functioning questions<sup>11</sup>, life stress events and parent or carer drug use; and
- Modification of study brochures.

#### Dress Rehearsal

The Dress Rehearsal was the final stage of testing and the purpose was to test all procedures and operational aspects with a full roll out of the survey.

Specifically the objectives of the Dress Rehearsal were to:

- Assess field, office management and procedural issues;
- Field test the questionnaire, with particular attention to those modules and/or questions modified after the Pilot Test;
- Test the mechanical accuracy of the Computer-Assisted Personal Interview (CAPI) and Computer-Assisted Self Interview (CASI) instruments;
- Identify any remaining issues with the instruments and the showcards through interviewer debriefing;
- Undertake a full timing analysis; and
- Assess the effectiveness of interviewer training and documentation.

The Dress Rehearsal was conducted across eight SA1s in WA during April and May 2013. These included six metropolitan and two regional SA1s. Face-to-face interviews were conducted with one parent or carer in each household. In households that had a child aged 11-17 years, the youth completed a self-report questionnaire on the CASI tablet. The oversampling methodology was also tested in the Dress Rehearsal. Additional screening for 16-17 year-olds was undertaken in 50% of the SA1s selected in the main Dress Rehearsal sample.

Following the Dress Rehearsal, a few minor changes were made to question wording and response options. Modifications were also made to the interviewer training to increase efficiency and to include more content on mental health literacy and familiarity with questions. Minor modifications were made to consent forms.

#### **Interviewer training**

All interviewers were recruited and trained by RMR. Many of the interviewers had previous experience with RMR working on large household surveys. Targeted interviewer training was employed to ensure that interviewers were knowledgeable and competent prior to commencement of fieldwork. The training focused heavily on the specifics of the current study, fieldwork procedures, developing interviewer understanding of mental health problems in children and adults, and detailed training in concepts and use of the DISC-IV modules.

Training was conducted over a three-day period in each state. The training was intensive with a tightly scheduled agenda on each day combining basic instruction, theory, mental health literacy and a series of practical exercises. UWA team members were present at each session.

Overview of the training agenda:

- <u>Day 1</u>. The first day of training focused on preparation for the fieldwork, familiarisation with the CAPI and CASI tablets, approach to the household, establishing the household and completion of the HRF, and an introduction to the youth self-report questionnaire.
- <u>Day 2</u>. The second day of training focused on familiarisation with the parent or carer questionnaire, providing background, and theory for each section and exercises. A large part of the day was taken on training for administration of the DISC-IV modules with the remainder of the day on administering the consent procedures.
- <u>Day 3</u>. The third day of training covered techniques for gaining cooperation at the door and for managing sensitive situations, and the oversampling survey was introduced. Interviewers also completed a full household interview in pairs and observed the trainers role-playing a full interview.

#### **Survey content**

Once a household was found to have at least one child aged 4-17 years-old living in the household at least 50% of the time, and was willing to participate in the survey, basic demographic information was collected for each person usually resident in the household using the HRF.

Once all members of the household had been entered a member aged 4-17 years-old was randomly selected as the study child and the primary carer of the child was identified by asking which of the household members knew the most about the child. In most cases, the primary carer was a parent. The primary carer completed the interview in respect of the child or young person who had been selected as the study child. If the young person was 11 years or older they were also asked, providing parent or carer consent was given, if they would be willing to complete a self-report questionnaire on a tablet computer.

#### Parent or carer interview

A detailed overview of the parent or carer interview content is provided in Chapter 3. The modules were:

• Family structure — sex, age, marital status, country of birth, language spoken for all family members and relationships between all members of the family;

- Child health general health, chronic health conditions, disabilities and whether ever diagnosed with psychological, emotional or behavioural problems from a list provided;
- Diagnostic Interview Schedule for Children (DISC-IV) modules<sup>5</sup>;
- Level of functional impairment questions;
- Strengths and Difficulties Questionnaire (SDQ)<sup>8</sup> Parent Report Measure Baseline versions for Children (4-10 years) and for Youth (11-17 years);
- Service use in the past 12 months;
- Perceived need for services;
- Education child's year level in school, school attendance and performance in core subjects;
- Family characteristics family functioning, life stress events, impact of separation on the child or adolescent, smoking and alcohol consumption of parents and carers, mental health of parents and carers;
- Kessler Psychological Distress Scale (K10+)<sup>12</sup> for primary parent or carer; and
- Demographics education and employment of parents and carers, household income and housing tenure.

#### Youth self-report questionnaire (11-17 year-olds)

Young people aged 11 years and older were asked to complete a self-report questionnaire on a tablet computer in private. A detailed overview of the youth self-report questionnaire content is provided in Chapter 4. As some of the questions were considered inappropriate for younger children, some modules were asked only of young people older than a specified age. The questionnaire comprised the following modules:

- DISC-IV major depressive disorder module<sup>5</sup>;
- Level of functional impairment questions;
- Presence of symptoms of psychosis;
- Strengths and Difficulties Questionnaire (SDQ)<sup>8</sup> Youth Self Report Baseline version;
- Kessler Psychological Distress Scale (K10+)<sup>12,13</sup>, which had the basic ten questions about how the child is feeling, together with four questions on days out of role and additional questions on anger, control, concentration and feeling calm and peaceful;
- Child health utility-9D (CHU-9D)<sup>10</sup>, which is composed of nine questions designed to measure quality of life for use in economic evaluation;
- Service use in past 12 months health, school, telephone counselling and online services and informal supports (13 years and older);
- Perceived need for services (13 years and older);
- Education school attendance, performance in core subjects, and school connectedness;
- Youth risk behaviours consisted of six sections, with questions varying for different ages

   smoking (screener questions only for 11 and 12 year-olds); alcohol consumption
   (screener questions only for 11 and 12 year-olds) and use of other drugs (13 years and older); self-harm (12 years and older); suicidal behaviours (12 years and older); problem eating behaviours (11 years and older) and sexual behaviour (13 years and older);
- Use of internet and electronic games;

- Experiences of bullying, both as victim and perpetrator; and
- Level of self-esteem and protective behaviours.

#### Changes to questionnaires for phase four of survey

Phase four of the survey ran from the end of January to the beginning of April 2014. This meant that the majority of children had just started a new school year. As a result, some slight modifications of the questionnaire were required.

Minor changes were made to the education module and the impact on functioning module in the parent or carer questionnaire. In the education module parents or carers were asked to recall days missed in the previous school year rather than current school year. The survey team thought this would be a better representation of absence, as many children surveyed in phase four would have only just begun the school year. The questions regarding functioning at school within the impact on functioning modules needed to capture those students who had just finished schooling in the previous school year, e.g. 17 year-olds who had just completed year 12, not just those children currently at school.

Similar changes were required to the youth questionnaire. Small changes were made to the education module, the impact on functioning module, and the service use module to capture those young people who had recently finished school. The question about days absent from school was changed in line with the parent or carer module to ask about days missed in the previous school year. A question was also added to ensure those young people who had just finished schooling the previous year were still asked the education module questions. A filter was added to the impact on functioning module to ensure young people who answered these questions and had attended school in the previous year were asked about their functioning in this environment. Similarly filters were added to the service use questions to ask about services received in the last 12 months at school.

# **Data collection**

Data collection was conducted between May 2013 and April 2014. Selected households were approached directly and screened for eligibility by the interviewer. Interviewers were required to make up to six call-backs to make contact with the household. Face-to-face household interviews were conducted by trained RMR interviewers at selected private dwellings. Interviews with parents and carers were conducted using a CAPI which involves the use of a notebook computer to record, store, manipulate and transmit the data collected during interviews. Young people aged 11-17 completed a self-report questionnaire in private using a CASI on a tablet computer.

#### Allocation of interviewer workload

Interviewers from RMR were allocated workloads (list of dwellings) by SA1. Each YMM interviewer was assigned two paired SA1 areas that were geographically close together and easy to manage as one workload. The interviewer's role was to approach each of the addresses and complete dwelling observations prior to making contact with the household and to identify dwellings that were out of scope. The size of the workload depended on the geographical area. As the fieldwork period spanned nine months, some interviewers completed multiple workloads. Around half of the interviewer workloads also included an oversample component.

#### Strategies to encourage participation

Participation in the survey was voluntary. Due to the length of the survey and the sensitive nature of the survey content, a number of measures were taken to encourage participation including:

- Primary Approach Letter explaining the authority for the study, why it was being conducted and what its information is to be used for, the confidential nature of the information and its uses, and the voluntary basis of participation.
- Parent Information Brochure for parents and carers written in plain language explaining the study, what was involved, an assurance of confidentiality, contact details for information and a list of health and support services.
- Youth Information Brochure similar to the Parent Brochure but with the information and language targeted towards young people (11-17 year-olds).
- A letter of endorsement, which was signed by three survey ambassadors, namely Professor Fiona Stanley, founding director and patron of the Telethon Kids Institute and Australian of the Year 2003; Professor Fiona Wood, plastic surgeon specialising in burns and Australian of the Year 2005; and Jessica Watson, solo around-the world sailor and Young Australian of the Year 2011.
- An 1800 number was staffed by RMR to answer any queries or concerns participants may have had about the survey.
- Information about the survey was available to participants through the YMM website, which was listed on the brochures.
- A payment of \$40 was offered to parents and carers to compensate them for their time completing the interview and young people were offered \$20 to compensate them for their time completing the youth self-report questionnaire.

#### **Household approach**

The first stage of the approach required the interviewer to speak initially with any adult living in the household. If an adult did not answer the door, interviewers asked to speak with an adult to explain the purpose of the survey and to screen the household to see if it was eligible. Any responsible adult was able to answer the screening questions on the HRF. The principal screening question took the following form: "Are there any children that live here or usually live here who are between four years and 18 years of age." If not, then the household was ineligible, If the household was in scope, the interviewer proceeded to administer the questions on the HRF. This included basic demographic characteristics of all usual residents in the household (e.g. sex and age) and the relationship between all household members (e.g. spouse, own child, step child, not related).

Through call-backs and follow-ups at selected households, every effort was made to contact householders in order to conduct the survey. Interviewers were required to make six attempts to make contact with the household and to call back at different times of the day and on both weekends and weekdays. All initial approaches were made in the hours that were consistent with the Association of Market and Social Research Organisation restrictions. Specifically, all initial approaches were made during the hours 9am and 8pm from Monday to Friday, and between 9am and 5pm on a Saturday or Sunday.

From the information provided, the CAPI identified children in the age range 4-17 years and if there was more than one child in scope, randomly selected a child to be the survey child. Once the survey

child was identified, an interview was conducted with the primary carer of the survey child. The primary carer was the person in the household who "knows the most about" the selected survey child. This was almost always a parent (i.e. mother, step-mother, father or step-father). If it was possible, the interview was conducted at the time, otherwise the interviewer made an appointment to call back to the household. Interviews with parents and carers took on average 60 minutes to complete (excluding the HRF and consent module).

If the selected study child was aged 11-17 years, they were also eligible to complete their own selfreport questionnaire. With permission from their parent or carer, the young person was given a copy of the Youth Information Brochure, reassured that their responses would be confidential and asked if they would like to participate. Consenting youth were given the use of a CASI tablet computer and, wherever possible, completed the questionnaire in private at the same time that the parent or carer was being interviewed in person. The youth self-report questionnaire took, on average, 35 minutes to complete.

#### **Duty of care/respondent reactions**

In the conduct of the survey, it was recognised that discussing mental health and emotional and behavioural issues may raise concerns for some participants. Specific protocols were developed to manage situations where the respondent became distressed during the interview, or indicated that they would like help or assistance in dealing with their children's problems, or with their own problems. Interviewer training included specific instructions on how to manage such sensitive situations.

In cases where a respondent became upset, interviewers were given a number of ways in which to deal with the situation:

- Give the respondent time to compose themselves;
- Offer to call back another time to continue the interview;
- Provide the respondent with the survey brochure and point out the list of services available that they may wish to contact;
- If appropriate, offer to provide the number for the study psychologist: "I can provide the number of the study psychologist if you would like to talk to someone. This is also printed in the survey brochure.";
- Interviewers were trained never to confuse their role as an interviewer with that of a counsellor or social worker. Their role in these situations was to facilitate the respondent being referred to an appropriately qualified service; and
- Interviewers were instructed to remain neutral but empathetic at all times.

Parents or carers with urgent questions in relation to child or family problems were given access to an on-call registered practitioner (psychologist or psychiatrist) via a 1800 telephone number rostered 24 hour/seven days a week throughout the study fieldwork phase. In the first instance, participants were encouraged to see their general practitioner or usual health care provider but were also given crisis numbers. The role of the on-call psychologist or psychiatrist was to assist in making referrals to appropriate services as required and not to provide an in-depth consultation.

The YMM website also provided information on how to seek help for emotional or behavioural problems. The survey team advised State and Territory mental health services of the survey progress

and fieldwork stage so that services were aware of the survey should they be contacted by concerned respondents.

If the interviewer left the household and still had significant concerns for the safety of the respondent or child, they were instructed to advise the RMR 1800 Team who would make decisions about how to proceed on a case-by-case basis. In the event that an interviewer felt they were personally in immediate danger, they were instructed to remove themselves from the situation or to contact emergency services ("000") if they felt anyone else in the household was in crisis or in immediate danger.

#### Refusals

The survey was entirely voluntary and respondents were not compelled to participate. While every effort was made to maximise participation in the study, it was recognised that a time-intensive voluntary survey such as YMM would encounter a degree of non-participation. One aspect of addressing non-response in the study was to collect as much information as possible on non-respondents to assist in later analysis of non-response patterns and potential biases, and to assist in developing an appropriate weighting strategy for the survey. In all cases, location of the non-responding dwelling and reason for refusal was recorded. Additionally non-respondents were asked to provide some basic demographic information about the household including number and ages of in-scope children and family structure.

#### Withdrawals

Participants were able to withdraw from the survey and request that their data be destroyed at any time up until April 30<sup>th</sup> 2014. In total, seven parents (and youth where applicable) requested that their data be removed from the survey. Of these seven, two participants sent an email to the YMM inbox after the interviewer had left the dwelling stating that they wished to withdraw their data. Five participants refused to sign the consent form at the completion of the interview. In one instance, a partner refused while the parent who had completed the survey questionnaire was signing the consent form. In another instance the parent refused to sign due to the youth not wishing to take part and in a third instance, the respondent decided not to complete the consent form and called the 1800 number to ask for the interviewer not to return. Data from these participants was removed by Roy Morgan Research and not delivered in the output file to the survey team at the Telethon Kids Institute.

#### **Computer Assisted Personal Interview (CAPI)**

Due to the length, complexity and sensitive nature of the subject matter, studies like YMM are most effectively conducted using face to-face methodologies. Such an approach provides greater flexibility in building rapport with the participants and in laying a solid foundation for their engagement with the study. A face-to-face approach presents an opportunity to reassure survey participants who may be cautious about taking part in a government sponsored survey that asks personal and probing questions.

All parent and carer interviews were conducted face-to-face with respondents in their homes using a CAPI on a tablet computer. RMR have extensive experience in the use of CAPI technology and routinely use it for their Establishment Survey which includes over 50,000 face-to-face interviews per year, as well as for other national household surveys such as the Household Income and Labour

Dynamics Australia Survey. RMR provided dedicated software and hardware support for the survey as well as extensively trained CAPI interviewers.

There are many advantages of a CAPI approach over a paper questionnaire, including:

- Security unlike hard copy questionnaires, using CAPI ensures that no-one can access sensitive information without the correct password.
- Accuracy Paper-based surveys require a two-stepped process to capture responses and data: original hand-written paper recording, then re-entry of data at a later stage by a different person. Using this two-stepped process, it is easy for errors to occur. With CAPI, responses and data are captured at the interviewing location in a finished state. CAPI also provides the opportunity to validate responses as they are entered, prompt respondents by allowing reference to previous answers from the current interview and reduces the need for open-ended responses. Consequently, the interview flows more efficiently and is generally recorded more accurately, thereby reducing respondent burden and non-sampling error.
- *Efficiency* —CAPI pre-fills information where possible and manages sequencing automatically – there are no time-consuming skips to perform. This served to simplify what was a complex questionnaire and was particularly advantageous with the DISC-IV instrument which is a lengthy questionnaire and utilises complex sequencing instructions. This also substantially reduces respondent burden.
- *Timeliness* Using CAPI, completed surveys were directly submitted to RMR's computer system daily and new surveys were delivered to the tablet as required. This removed the need to rely on postal and courier services.
- *Connectivity* Using the mobile communications network, the tablet communicates directly with RMR without the need for wired connections.
- Cost efficient CAPI also greatly reduces the time and costs of data entry, scanning and, to a degree, coding. There are also substantial cost savings in terms of printing and the distribution and return of field materials.
- Efficient workload administration and team management CAPI provides a better opportunity for quality control of interviewers' work, monitoring of interview achievement rates and delivers ongoing feedback and guidance to the interviewer team. The CAPI system provides a means of distributing any piece of survey documentation or sample information to any interviewer wherever they may be. A field supervisor can make any necessary adjustments to the interviewer's workload in real time simply by updating the respondent management system and instructing the interviewer to synchronise their CAPI console. It is also possible to easily correct any errors or make modifications to questionnaires in real time and have them immediately applied without the need to send new materials to interviewers. Any changes are immediate. The instant reassignment of sample and distribution of materials, and the flexibility afforded to fieldwork management, can result in substantial cost and time efficiencies.

#### **Computer Assisted Self-Interview (CASI)**

If the selected study child was aged 11-17 years-old, they were invited, with consent from their parent or carer, to complete a CASI on a tablet computer. The tablet has touch screen functionality and the young person was able to complete the interview by themselves but with the assistance of the interviewer if necessary. By providing each interviewer with two tablet computers, it was

possible to undertake the primary interview with the parent or carer at the same time as the adolescent completed their own questionnaire. The CASI has all the benefits of the CAPI over a paper questionnaire and gave young people a form of technology that most would be familiar with.

The interviewer was required to set up the CASI tablet before entering the household by including confirmation of the household ID and entering the first name, gender and age of the young person. The young person was then given instructions about how to operate the tablet and asked to complete the questionnaire somewhere in private, without other family members or friends present.

Respondents were not given an option to skip a question on the CASI (i.e. don't know, not stated or refused were not offered as possible responses). If a respondent tried to go to the next screen with one or more items missed, they were prompted to answer the missing question. However, if they attempted again, they were allowed to skip the item and a 'not stated' response was recorded. This occurred rarely.

#### **Consent procedures**

Participation in the survey was voluntary and written consent was required from all participants.

Initially, verbal consent was obtained from parents or carers to participate in the survey. If the child was 11 years or older, parents and carers were also asked for their consent to approach the young person to ask whether he or she would complete a youth self-report questionnaire. Verbal consent was also sought directly from the young person, if he or she were willing to participate.

Paper consent forms were completed by both parents or carers and young people at the completion of the household interviews. Due to the number of forms and their complexity, the written consent process was programmed on the CAPI as a separate module in order to guide the interviewers through the process. If applicable, the youth was present at the same time. There were three different consent booklets produced depending on the age of the study child (4-11 year-olds, 12-13 year-olds, and 14-17 year-olds).

Additionally, at the end of the household interview, consent was sought from parents and carers to access Medicare, Pharmaceutical Benefits Scheme (PBS) and National Assessment Program — Literacy and Numeracy (NAPLAN) information for the selected child or adolescent. Where the selected child was aged under 14 years, consent to access Medicare and PBS data was sought from the primary carer, while, with the parent's or carer's permission, consent was sought from the young person directly if they were aged 14 years or older. For NAPLAN data, consent was sought from the primary carer. NAPLAN testing covers school years 3, 5, 7, and 9. Permission to request access to Medicare and PBS data was obtained from the Department of Human Services External Request Evaluation Committee (ref 2012/C011823 & SF4040173). Permission to provide linked NAPLAN data was obtained from the custodians of NAPLAN data in each of the eight States/Territories.

Although the parent interview alone took an average of 60 minutes to complete, with the extra time needed to administer the HRF and the consent module, the average time in the household overall was about 75 minutes.

Participants were informed that they had the right to withdraw their consent for study participation or the use of their information at any time during the interview and up to 31 March 2014, at which time final validation was being completed and data would be de-identified for inclusion in the main unit record file. A decision was made to extend the period for fieldwork part way through the initial collection phase and, in turn, the cut-off for withdrawal of consent for use of information was extended to 30 April 2014 for participants in this later phase of fieldwork.

# **Data processing**

#### Data capture

Computer based systems were used to collect and process data from the survey. The survey used CAPI for data collection and the UWA team used SAS version 9 to process the data. The code for programming the DISC-IV was created using Confirmit software by RMR in collaboration with UWA. For more information see *survey development* in this chapter.

The use of CAPI ensured that respondents were correctly sequenced throughout the questionnaire. Inbuilt edits meant that some issues could be clarified with the respondent at the time of the interview. Mostly these worked well.

Using CAPI, completed surveys were encrypted and then directly submitted to RMR's computer system daily using the mobile communications network. Checks were made to ensure that the workloads were fully accounted for and that the questionnaires for each household and respondent were completed.

#### **Data editing**

Data editing was performed on the data to ensure the highest quality of data for analysis. It aimed to correct errors made in the data entry or through misunderstanding of the questionnaire items. It was assumed by the survey team that respondents did their best to answer the questions truthfully and therefore answers given by respondents are accepted as true unless logically inconsistent.

A number of measures were taken in the development and design of the YMM questionnaire to minimise data entry errors. For example, logic checks were placed on certain questions so that only certain ranges of numbers could be entered. Sequencing of the questionnaire ensured that questions could not be inadvertently skipped or answers entered to the wrong question. The number of write-in items was minimised, as current tablet technology is prone to handwriting recognition errors. However, despite these measures, a number of checks and edits were required prior to the analysis.

Editing was required on a number of items in the parent or carer questionnaire that had write-in options. For example, a question about household member's country of birth included a list of 11 countries in the response options. If a participant was born in a country not included in the list, interviewers were required to write in the country of birth. As a result, spelling and handwriting recognition errors needed to be identified and corrected on the data set.

A number of checks needed to be performed on those households with both a parent or carer and youth self-report interview. The interviewer entered the gender, age and date of birth of the young

person into the tablet prior to the youth self-complete interview. Checks were performed to ensure that this information was the same in both parent or carer questionnaire and the youth self-report questionnaire. In addition, a check was done to ensure that the age entered was consistent with the date of birth and interview date for both the parent or carer and youth. Finally, age and grade in school was checked for viability and consistency across the parent or carer and youth self-report.

A large number of checks needed to be performed on the household relationship grid. This grid listed all the individuals living in the household and recorded the relationship between every possible pair of individuals. In entering this information in the relationship grid it was easy to accidentally record the reverse relationship, that is, Person B's relationship to person A rather than Person A's relationship to person B. For example, the child is accidentally listed as the parent or carer in the relationship. These mistakes were detected by looking for cases where a parent or carer was younger than a child. Step/blended family relationships were checked to ensure they had been coded consistently with the coding practices established by the ABS.

Less common family relationships were also checked and edited where necessary, for example, where the secondary or primary carer were listed as the sibling of the study child or there were more than two parents listed in the household. Finally, all missing and not stated relationship types were checked and resolved where possible.

Due to the complexity of coding the family relationships grid data entry in Confirmit, it was not possible to build different logic checks into the process to capture errors in data entry. Future surveys could save significant resources by building more rigorous checks into the data entry system.

Family type was calculated based on assessment of all pairs of relationships in the relationship grid obtained in the HRF. Family type was derived consistent with the ABS definition for family blending in two-carer families. Although coded the same, a decision was made to replace the label of "intact" families with "original" families as it is a term that is more appropriate and sensitive to the range of families that exist in Australia who consider themselves to be intact (including sole-carer families).

#### **Coding of open-ended questions**

The survey contained only a few open-ended questions for which there were no predetermined responses. This included some open-ended responses within the DISC-IV modules that contributed to diagnosis of particular mental disorders. These responses were coded manually either by a qualified psychologist or psychiatrist on the YMM survey team. These included:

- Child health module other health problems or conditions; other psychological, emotional or behavioural problems.
- DISC-IV Obsessive-compulsive disorder module free text fields to record other obsessions and other compulsions were coded independently by two different raters with the aim of establishing whether the recorded responses represented a clinically significant obsession or compulsion. Where the two raters differed, they reached a consensus by personal discussion. These two questions were:
  - "....any other thoughts that kept coming back into [his/her] mind over and over again that [he/she] couldn't get rid of?" If yes, "Can you tell me what those thoughts were?"

- ...any other things that \_\_\_\_\_\_ did over and over again, and it seemed like [he/she] couldn't stop doing..." If yes, "Can you tell me what things like this [he/she] did?"
- Service use module pharmaceutical medications.

### Treatment of missing data

Participants had the option of answering 'don't know' to some questions and they could refuse to answer any question in the survey. These responses were treated differently depending upon the section of the survey:

- According to the international standard for scoring the DISC-IV, responses recorded as 'don't know' or 'refused' were treated as 'no' responses for all of the symptom questions within the DISC-IV diagnostic modules.
- 'Don't know' is not a valid response and refusals are not allowed in response to any questions in the SDQ. If following additional prompts no response was given, the answer was recorded as the child not having any difficulties in that area.
- Responses of 'don't know' and refusals to answer questions dealing with demographic and socio-economic measures were recorded as such.

There was a negligible amount of missing data for most data items in the parent and carer questionnaire. The main exception was in relation to household income, which had the largest proportion of missing values, with approximately 4% of families either responding 'don't know' or refusing to provide their household income. Questions in the parent and carer questionnaire where more than 1% of eligible respondents provided a non-informative answer (either refused or said 'don't know') are shown in Table A3-1 in Appendix 3.

There was a negligible amount of missing data for most items in the youth self-report questionnaire, particularly as participants were mostly not given an option to respond with 'don't know' or to refuse to answer a question. The main exceptions were in relation to the questions on self-harm and suicidal behaviours, for which participants were given the option of responding 'prefer not to say', and for height and weight. Young people who did not provide either their height or weight were excluded from analyses relating to Body Mass Index (BMI) and also low weight problem eating behaviour and binge eating or purging problem eating behaviour, both of which include BMI status as part of the definition. There was no evidence that the individual eating behaviours that form part of the definition of these problem eating behaviours occurred any more or less frequently in young people who reported their height and weight compared with those who did not. Table A3-2 in Appendix 3 shows items on the youth self-report questionnaire where the proportion of non-informative answers was greater than 1% of youth who were asked that question.

#### **Diagnostic scoring**

A set of algorithms (in SAS code) were provided to the UWA team to be used with the DISC-IV modules (Version O). These were used to determine diagnoses of mental disorders. Extensive validation of the algorithms was undertaken to ensure that any logic and/or coding errors were rectified prior to data collection, and again prior to processing.

The DSM-IV specifies that to meet criteria for a mental disorder there must be clear evidence of clinically significant impairment in social, academic, or occupational functioning (i.e. functional

domains). The DISC-IV offers four different algorithms for assessing DSM-IV clinically significant impairment or distress. In line with other national surveys that have used the DISC-IV, such as the United States National Health and Nutrition Examination Survey<sup>14</sup>, algorithm D has been used in the present survey. This algorithm requires either severe impairment in one or more functional domains or at least moderate impairment in two or more domains. The DISC-IV provides indicators of 12-month prevalence and 30-day prevalence.

Derived variables based on diagnostic algorithms are described in detail in the CURF Technical Manual.

# **CHAPTER 3: PARENT OR CARER INTERVIEW**

# Overview

This chapter provides information on the source and nature of the content of the parent or carer interview together with relevant coding information. The parent interview modules were administered in the following order (although described in a different order):

- Education;
- Child health;
- Strengths and Difficulties Questionnaire (SDQ)<sup>8</sup>;
- DISC-IV Intro and DISC-IV Diagnostic Modules<sup>5</sup> Social phobia, separation anxiety disorder, generalised anxiety disorder, obsessive-compulsive disorder, major depressive disorder, attention-deficit/hyperactivity disorder, oppositional defiant disorder, conduct disorder;
- Impact on Functioning (administered up to 3 times see section below);
- Principal condition;
- Service use;
- Demographics;
- Family information;
- Bullying; and
- Consent (see Chapter 2).

The content areas of each of the modules are described in more detail below, including any modifications that occurred following testing and specific coding procedures. Copies of questionnaires are available on the YMM website and when accessing the CURF.

# **Mental disorders**

The survey was designed to produce diagnoses of mental disorders as assessed against the Diagnostic and Statistical Manual of Mental Disorders Version IV (DISC-IV) criteria and thus comprised the main content in the parent interview.

Although the questions were specific to the disorder, the DISC-IV modules mostly had a generic structure that first assessed a set of symptoms in the past year (stem questions), and if the symptoms were present, assessed the frequency, duration and severity of the symptoms (contingent questions). If enough symptoms were endorsed at a certain frequency, duration or severity that varied by module (i.e. a sub-threshold level was reached) then further questions were asked that assessed impact. Meeting the minimum threshold did not mean that the child had a mental health problem but just formed a trigger for the second section of the module.

#### **DISC-IV** introduction

The DISC-IV includes a standard introductory module to provide background information to pre-fill text for wording of questions and program filters for questions within the diagnostic modules. This includes identifying caregivers, age of the child, whether they lived with siblings and their educational status. Many of the questions had already been captured in the education module in the parent interview, and thus were automatically filled.

#### DISC-IV timeline

Part of the standard DISC-IV introduction module involves creating a personal timeline in order to provide a point of reference for respondents when answering questions. The timeline asks respondents to recall an event for three time periods – the last 12 months, six months, and four weeks. As questions in each of the diagnostic modules relate to different time periods, the purpose of establishing a timeline is so the respondent could put the question and response in context. For example "In the last 6 months – that is since you won the lotto....." Questions using the different timeline events are used several times within each specific module.

The DISC-IV timeline was found to be one of the most time-consuming and problematic components of the parent interview during the cognitive testing. Establishing the timeline proved difficult for the respondents with many of them not being able to think of an event that occurred within the specified time periods. Cognitive testing also suggested that the timeline approach did not particularly help respondents in remembering when their child had specific problems or behaviours, and thus had little impact on the answers to subsequent questions. The events they did remember often were negative which they were then reminded of throughout each of the modules. Also the repetitive nature of using the timeline events when asking questions in each module became annoying to the respondents. The decision was made to remove the timeline from the DISC-IV modules.

#### **Anxiety disorders**

'Anxiety disorders' refers to a group of conditions rather than a single disorder. The four most prevalent and burdensome anxiety conditions were chosen for administration in the survey. The common characteristic of the conditions that make up this category is that affected individuals experience persistent, excessive worry or fears that typically interfere with their ability to carry out their daily tasks or take pleasure in day-to-day life. It is common for young people to be fearful and anxious in some situations, but some may be more anxious than other children of their age and developmental level, and this may stop them participating in activities at school or socially, or interfere with their ability to do what other children and adolescents of their age do.

#### Social phobia

This disorder is characterised by a marked and persistent fear or avoidance of social or performance situations in which embarrassment may occur. To meet DSM-IV criteria, the fear or avoidance must interfere significantly with the child or adolescent's normal routine, academic functioning, or social activities or relationships, or the person must experience marked distress about the phobia.

#### Separation anxiety disorder

This disorder is characterised by excessive anxiety concerning separation from the home or from those to whom the child is attached. To meet DSM-IV criteria, the anxiety must be beyond that which is expected for the child or adolescent's developmental level, and cause significant distress in social, academic or other important areas of functioning. While separation anxiety disorder may be more common in younger children it can cause significant impairment in older children.

#### Generalised anxiety disorder

This disorder is characterised by excessive anxiety, worry or apprehension about a number of different events or activities, occurring more days than not for a period of at least six months.

DSM-IV criteria specify that for children the anxiety must be associated with at least one of the following symptoms: restlessness or feeling keyed up or on edge, being easily fatigued, difficulty concentrating or mind going blank, irritability, muscle tension or sleep disturbance. The constant worry causes distress to the individual. The child or adolescent has difficulty controlling the worry, and experiences impairment in social, academic or other important areas of functioning.

#### *Obsessive-compulsive disorder*

Key features of this disorder are recurrent obsessions and/or compulsions that are severe enough to be time consuming and cause marked distress or significant impairment.

Obsessions are persistent ideas, thoughts, impulses or images that are intrusive and difficult to control and that cause anxiety or distress. Common obsessions include worrying about things being dirty or having germs, or that the person might do something bad in public.

Compulsions are repetitive behaviours, such as washing hands or changing clothes over and over, repetitively checking things, or counting or ordering things over and over.

To meet DSM-IV criteria the obsessions or compulsions must cause marked distress, be time consuming or significantly interfere with the child or adolescent's normal routine, academic functioning, usual social activities or relationships.

#### Major depressive disorder

The key feature of major depressive disorder is the presence of either depressed mood, loss of interest or pleasure or being grouchy, irritable and in a bad mood. If none of the three essential features was present, then the respondent was not asked further questions in the module.

The DSM-IV criteria specify that at least five symptoms of depression must be present for a minimum of a two-week period, that these symptoms cause clinically significant distress to the child or adolescent and that they must interfere with the child or adolescent's normal functioning at school, at home or in social settings.

Symptoms of major depressive disorder may include significant weight loss or weight gain, loss of appetite, insomnia or hypersomnia, restlessness, fatigue and loss of energy, feelings of worthlessness and inability to concentrate.

#### Attention-deficit/hyperactivity disorder (ADHD)

ADHD is a persistent pattern of inattention and/or hyperactivity-impulsivity more frequent and severe than in other individuals at a similar developmental stage. Children and adolescents may find it difficult to pay attention and see tasks or activities through to the end or make careless mistakes with schoolwork or other tasks. Children and adolescents with problems in the area of hyperactivity may talk excessively, have trouble staying still when it is appropriate or expected and act like they are always "on the go".

There are three subtypes of ADHD based on the most common symptoms. Those with mostly inattentive symptoms are diagnosed with ADHD, predominantly inattentive type and individuals with primarily hyperactivity-impulsivity symptoms are diagnosed with ADHD, predominantly hyperactive-impulsive type. Those children and adolescents with symptoms of both inattentiveness and hyperactivity are diagnosed with ADHD, combined type.

The DSM-IV criteria require at least six symptoms of either inattention or hyperactivity-impulsivity to have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level. Symptoms must be present in at least two settings (e.g. at school and at home), and some symptoms causing impairment must have been present before the age of seven years.

#### **Conduct disorder**

Conduct disorder is defined as repetitive and persistent behaviour to a degree that violates the basic rights of others, major societal norms or rules in the following areas: aggression towards people or animals, destruction of property, deceitfulness or theft and serious violation of rules.

Young people with conduct disorder exhibit a range of behaviours often including bullying, frequent physical fights, deliberately destroying other's property, breaking into properties or cars, staying out late at night without permission, running away from home, or frequent truancy from school. DSM-IV criteria require at least three of these behaviours to have been present in the past 12 months, and for the disturbance in behaviour to cause clinically significant impairment in social, academic or occupational functioning.

#### Modifications to the conduct disorder module following testing

Cognitive and pilot testing revealed some practical issues in the conduct disorder module. One of the issues was that several respondents triggered sub-diagnostic threshold for behaviours that were of trivial significance. Some of the questions were not worded in a way that gave the parent an indication of the severity of the behaviours being asked about. For instance, one of the questions about stealing was interpreted by some respondents to include taking toys from other children during child's play. To resolve this issue, the UWA survey team revised the introductory statement and some questions, in consultation with the DISC custodians at Columbia University, to indicate that questions were asking about when the child was in serious trouble with authority figures, not including the parents, and stealing items of value as opposed to just stealing.

The main feedback from the cognitive testing for the module was that several of the questions were not age appropriate. For example, "Has the child ever stayed out at night more than two hours past the time they were supposed to be home?" The UWA survey team conducted an analysis of the data from the first survey in 1998 and identified ages where no positive responses were recorded for several of the questions. As a result age restrictions were put on those specific conduct disorder items.

Within YMM, if a young person met diagnostic criteria for conduct disorder, they were excluded from completing the oppositional problem behaviours module consistent with the DSM-IV hierarchy of these disorders.

#### **Comorbidity and principal condition**

Comorbidity refers to the occurrence of more than one mental disorder within the same period. For the purposes of the survey this was defined as more than one of the disorder groups (an anxiety disorder, major depressive disorder, ADHD and conduct disorder) in the 12 months prior to interview.

If a child or adolescent had symptoms of multiple mental disorders, the primary carer was asked which condition bothered or upset the child or adolescent the most and this information was used to identify a principal condition for each child or adolescent. Where the parent or carer nominated as principal condition a condition for which the child or adolescent did not meet the full diagnostic criteria, three approaches were taken to assigning a principal condition:

- 1. use the condition nominated by the parent or carer if the child or adolescent met diagnostic criteria for that condition, otherwise treat it as not stated;
- 2. use the condition nominated by the parent or carer, regardless of whether the child or adolescent met diagnostic criteria for that condition or not;
- 3. use the condition nominated by the parent or carer if the child or adolescent met diagnostic criteria for that condition, otherwise choose a condition for which the child or adolescent met full diagnostic criteria using an algorithm based on severity of each condition. More detail about how the algorithm was applied is provided in the CURF Technical Manual. This method was used in the production of the final report to determine principal condition.

#### Impact on functioning and severity of disorders

#### Impact on functioning

In the first Child and Adolescent Mental Health Survey in 1998, the DISC-IV was used to assess diagnostic status for three mental disorders — major depressive disorder, ADHD and conduct disorder. Although the first survey administered the DISC-IV impact on functioning questions, when producing the original Departmental report, the impact on functioning algorithms were not applied.

In addition, the first survey did not comprehensively assess impact on functioning across different life domains and lacked the capacity to classify children using diagnostic criteria into mild, moderate and severe cases. Instead a global health-related quality of life instrument was adopted that measured the level of disability associated with mental health problems independent of the diagnostic criteria, the Child Health Questionnaire (CHQ).<sup>15</sup>

The original DISC-IV included six questions about impairment that used the presence of specific symptoms to assess the level of impairment associated with them. In needing to assess level of severity, *as independent from diagnosis*, the YMM team needed to develop new items to expand the range of domains of possible impairment. This was undertaken by reviewing existing mental health assessment methods and developing new items to reflect the range of practice used to assess severity. In particular, content for the new items was drawn from the Brief Impairment Scale.<sup>16</sup>

The new impact on functioning module comprised 17 items including the original six DISC-IV items that assessed impact in four functional domains:

- at school or work;
- on friendships and social activities;
- on family relationships, family activities and other members of the family; and
- on self (i.e. level of distress).

Not all survey respondents needed to respond to the impact items. The impact items were part of the diagnostic assessment for mental disorders and were administered only when children reached at least the diagnostic sub-threshold for the disorder. This means that any survey child or young person whose interview reached *at least* the sub-threshold for diagnosis on one or more of the DISC-IV modules was subsequently administered the impact questions. This included any child who went on to score at or above the diagnostic threshold to be classified with the given disorder.

For some respondents where the child had substantial co-morbidity, the impact items could potentially be administered several times. To prevent over-burdening the respondent the impact items were administered for each of the following diagnostic groupings:

- 1. Attention-deficit/hyperactivity disorder
- 2. Conduct disorder and/or oppositional defiant disorder
- 3. Any anxiety disorder and/or major depressive disorder

This meant that a parent or carer whose child was comorbid across these three groupings, would receive the set of 17 impact items three times. Whereas, a respondent whose child was co-morbid with social phobia (e.g. anxiety) and major depressive disorder would receive the impact items only once.

On being filtered into the impact on functioning module, respondents were prompted with a summary of the symptoms that had been endorsed (i.e. the parent or carer had said "yes") in the preceding diagnostic module to help them focus on the specific problems when responding to the questions. The list of symptoms appeared as pre-filled text on the CAPI for the interviewer to read out. In consultation with the DISC custodians at Columbia University, the list of symptoms was summarised beyond the item level and made more concise for the purposes of YMM.

# Severity of disorders

The DISC-IV assesses whether a child or adolescent has a particular mental disorder, but does not routinely measure the severity of the impact due to that disorder. The YMM team was required to develop a measure of severity to be used for policy and planning purposes. The 17-item impact on functioning module formed the basis of the severity measure, the development of which is described in detail in a separate technical report. <sup>17</sup>This report is included in the CURF documentation and also on the survey website.

In brief, a graded response model was used to create a composite impact on function score. This score was standardised with a range from -3.0 to +3.0 where higher scores represent increasing severity of impact on functioning. Children and adolescents were classified into three levels of impact on functioning by applying the national mental health service planning standard ratio of

severity for mental disorders to the standardised score (1:2:4 for severe, moderate and mild cases). In addition suicide plans or attempts in the past 12 months were considered. The three levels are:

- Severe: A positive diagnosis plus an impact score greater than or equal to 1.75 and/or a history of suicide attempt in the 12 months prior to interview;
- *Moderate:* A positive diagnosis plus an impact score greater than or equal to 0.95 or a history of suicide plans in the 12 months prior to interview; and
- *Mild:* All other cases with a positive diagnosis.

# Other scales and measures of mental health and wellbeing

### **Oppositional problem behaviours**

Oppositional problem behaviours are negativistic, hostile and defiant behaviours lasting at least six months characterised by behaviour such as often losing temper, arguing with adults, actively defying adults' requests and rules, being angry, resentful, spiteful or vindictive.

The DISC-IV module for oppositional defiant disorder was included in the survey. However, unlike other disorders, the diagnosis for oppositional defiant disorder includes an element of clinical judgement that could not be implemented within the DISC-IV questions. In particular, for each symptom assessed in oppositional defiant disorder the DSM-IV specifies that the symptom criterion is met only if the behaviour occurs more frequently than is typically observed in individuals of comparable age and developmental level. A clinician is required to make this judgement. The data collection for YMM was undertaken by lay professional interviewers who were not specifically trained in psychology or psychiatry and expert clinical review of each child or adolescent in the survey was not undertaken. As such it was not possible to identify all criteria for assigning the diagnosis of oppositional defiant disorder. Instead these behaviours are referred to as 'oppositional problem behaviours' to distinguish them from the diagnostic condition of oppositional defiant disorder.

In this survey, an exclusion criterion was defined so that children or adolescents who met the diagnostic criteria for conduct disorder were not considered to have oppositional problem behaviours.

#### Emotional and behavioural problems (Strengths and Difficulties Questionnaire/SDQ)

The SDQ<sup>8</sup> provides a measure of emotional and behavioural problems as well as positive aspects of child behaviour in the last six months and was included in the questionnaires for parents and carers and for young people. This measure is routinely used as a tool to assess young people receiving State/Territory-administered specialised child and adolescent mental health services. With approval from Robert Goodman, the SDQ was programmed for computer-based administration exactly as per the hard copies provided under copyright.

The SDQ provides a brief behavioural screening questionnaire comprised of five scales of five items each. Items in four of these scales, that is emotional problems, conduct problems, hyperactivity and peer problems, are added together to generate a total difficulties score.

Standard scoring procedures for the SDQ do not allow for missing responses and so interviewers were trained to record a response for all questions. In particular, if a respondent refused or did not know the answer to a question, the interviewer was trained to record the most positive response (i.e. the one that indicated that the child had no problem with the particular behaviour).

The SDQ was designed so that approximately 10% of children and adolescents fall into the 'abnormal' range on the total difficulties score, which indicates that they are at substantial risk of clinically significant problems. The SDQ also includes an impact scale that measures interference in life due to emotional and behavioural problems in the domains of home life, friendships, classroom learning and leisure activities.

### Child health and disability

The CHQ<sup>15</sup> was used to investigate children's physical health in the first survey but as the questionnaire was no longer in the public domain, it could not be used in YMM. Therefore the section on child health and disability needed to be completely reviewed. Following review of the questions asked in the first survey, several questions were identified for inclusion. These were:

- Overall rating of health A single standard question providing an overall rating of health on a five-point Likert scale from excellent to poor;
- Any health problems or conditions Whether the child had any health problems or conditions from a pre-programmed list that was also presented as a showcard to the respondent (such as asthma, eczema or diabetes) with the option to state other problems or conditions. This question was developed by the survey team;
- *Head injury* Whether the child had ever sustained a blow to the head that had resulted in a concussion or blackout or any other head injury.
- Diagnosed emotional or behavioural problems Whether they had ever been told by a doctor or other health professional that their child had a psychological, emotional or behavioural problem. This included autism, intellectual disability and Down Syndrome. The list of conditions was presented on a showcard as a prompt for respondents. This question was developed by the survey team.
- Disability questions adapted from the ABS Census questions – In order to identify whether the survey child had a severe disability with a high need for carer assistance and to identify if the sample was underrepresenting children with such a disability, three questions were adapted from the Census. A set of four questions are used to identify if people have a need for assistance in one of three areas of activity (self-care, mobility, and communication) because of a long-term health condition or disability lasting more than six months. The fourth question determines the need for assistance or supervision if indicated in any of the three activity areas. If the reason given is not due to a long-term health condition or disability lasting six months or more, or the reason is due to old age or young age, then the person is coded as not having a need for assistance with core activities. Unfortunately an error was made in adapting these questions for the YMM and the fourth question was not included and although the wording did ask if the child needed help 'because of an illness or disability' it was not possible to tell if the need for assistance was long-term or short-term. Therefore, survey and Census distributions on these disability questions could not be compared.

# Service use and perceived need for help

One of the main aims of the survey was to determine the use of services by children and adolescents to assist them with any mental health problems they may have. The service use module was developed specifically for the survey, and tailored both for use with young people and to the current Australian health care environment.

The term 'for emotional or behavioural problems' was used to capture service use for a broader range of mental health problems, not just by those with a mental disorder. The term was defined as meaning 'a number of things, for example, being anxious or stressed, feeling depressed, having problems concentrating, or being aggressive or hyperactive'. The focus of the survey was on service use for emotional or behavioural problems in the past 12 months to be consistent with the time period referenced in the DISC-IV modules and the SDQ.

Information was collected for the previous 12 months about the following:

- health services any service provided by a qualified health professional regardless of where that service was provided (community, hospital inpatient and emergency, and private rooms);
- school services any service provided by the school or other educational institution that a young person was attending, including individual or group counselling, a special class or school, or service provided by a school nurse;
- telephone counselling services; and
- other online services used for emotional and behavioural problems.

If the child had seen a health professional in the previous 12 months, they were asked further contingent questions about where they had seen the professional (using a showcard as a prompt), whether the school had recommended or advised that the child see the professional, waiting times to the first appointment, and number of times the child had seen the professional for emotional or behavioural problems in the past 12 months.

Further information was collected on treatment delay, sources of informal help or support and whether the child had ever been in a juvenile detention centre or spoken to a counsellor or attended a drug or alcohol treatment unit or clinic.

#### **Medication use**

Within the service use module, parents and carers were asked whether their child had ever used any prescribed medication for emotional or behavioural problems, and how old they were when they first took these medications. They were also asked whether their child had taken any prescribed medication in the two weeks prior to the interview and if they had, the interviewer asked to be shown the prescribed medications. The interviewer was required to enter the number of medications, and the name of each medication onto the CAPI tablet. The interviewer was instructed to find the name of the medication (in order of preference): prescription sticker, product box, prescription form and then from the product itself (puffers, sheets of tablets, sprays etc..). Prescribed medications were classified according to the Anatomical Therapeutic Chemical (ATC) classification index.

There were two additional questions asking if in the past two weeks, the child had taken any herbal or natural treatments or remedies from a naturopath or another alternative therapist, or taken any vitamins or mineral supplements obtained over the counter for emotional or behavioural problems.

## Perceived need for help

While the focus of the service use questions was on services from specific health providers and locations, the perceived need section focused on types of help that parents and carers felt that their child needed for emotional or behavioural problems. This was measured in the survey by a separate module that determined whether the child or adolescent had any need for help with emotional or behavioural problems and whether that need was met. The module was adapted from the Graham Meadows instrument used in the 2007 adult survey.<sup>18</sup>

Perceived need for help based on parent and carer report was assessed in two ways as follows:

- Parents and carers were asked if they felt that their children needed any help with emotional or behavioural problems. If so, they were then asked whether their needs had been fully or partially met by the services they received, or were not met. When needs were not fully met, information was collected on the barriers to seeking help or receiving more of the help they felt their children needed.
- Parents and carers were also asked about the services they had received and their need for help for themselves and/or other family members to deal with the emotional and behavioural problems affecting their children.

The need for care for the child was assessed across four types of help:

- Information about emotional or behavioural problems, treatment and available services;
- Prescribed medication for emotional or behavioural problems;
- Counselling or a talking therapy about problems or difficulties (either one-on-one, as a family or in a group); and
- Courses or other counselling for life skills, self-esteem or motivation.

For each of the four types of help, the level of perceived need was classified as being either fully met, partially met, unmet or not needed. For those reporting a need for more than one type of help, perceived need for any type of help was based on a composite of the individual ratings for each type of help needed. Need for any type of help was rated as being fully met if for each type of help needed, that need was assessed as being fully met. Need for any type of help was partially met if any of the types of help were partially met or if there were combined ratings of fully met and unmet need. Need for any type of help was unmet if the level of need for all types of help needed was unmet.

To ease respondent burden in the parent or carer interview, not all participants were filtered into the perceived need section. They were filtered into the section by two main ways:

 If the parent or carer had acknowledged a problem with the child by reporting that the child had received services for emotional or behavioural problems, or feeling that their child needed help; 2. If the child had not acknowledged a problem with the child but there were indicators from the DISC-IV modules or other sections in the questionnaire that the child may have problems (i.e. met diagnostic or sub-diagnostic criteria identified in the DISC-IV modules, met borderline or abnormal criteria on the SDQ, or had a condition identified by a doctor or other health professional). If the respondent was filtered into the section without acknowledging a problem with their child, the interviewer was given a more general introductory script so that parents/carers were not given the impression that the interviewer thought there was a problem with their child.

*Barriers to help-seeking* – If respondents identified that their child needed help or more help, they were asked about the reasons that kept them from seeking or receiving more help.

Showcards were used by the interviewers in this section to assist the respondent in answering questions about types of help needed and barriers to help-seeking.

# **Child education**

The education environment and school experiences play a major role in shaping the development and wellbeing of children and adolescents. A disruptive school experience, such as poor attendance and changing of schools, are contributing factors to the development of problems such as social exclusion, poor academic performance and low self-esteem. The YMM design parameters specified the inclusion of a module on education-related information.

# **Education and work status**

Questions about the child's education and work status were adapted from those used in the DISC-IV introduction module. Wording of questions about attendance at school was adapted to be relevant across States/Jurisdictions where different terms have been used to mean the same thing (e.g. prep, pre-primary or reception refers to any full-time schooling below Year 1). Additional questions developed by the survey team were asked about the type of school, number of schools attended, absences, suspensions and how much the child liked school.

The calculation of days absent from school was reviewed. The date of each interview was recorded, allowing calculation of the number of possible days of attendance at school so far during the year by reference to school calendars in each jurisdiction. This allowed the calculation of a consistent attendance ratio measure based on possible days of attendance and reported absences. This is consistent with the methodology described in the recently released standard for reporting attendance in school issued by the Australian Curriculum, Assessment and Reporting Authority (ACARA).<sup>19</sup>

# **School performance**

The survey team developed a set of items capturing performance compared with other children in the same year on the following core subject areas for children aged six or over:

- Maths;
- English, reading or writing;
- Science (only if child age >=11);

- Art or drawing; and
- Sports or physical education.

The survey team also considered the potential of asking the parent or the young person to report on their grades at school. After a review of the practicalities in each jurisdiction, it was decided that this was too difficult to operationalise as there is no consistent standard for the reporting of school performance to parents across jurisdictions and year levels. A more subjective assessment of performance would be obtained from linkage with the NAPLAN data.

# **Demographic characteristics**

The demographic module included questions about the primary carer's (and secondary carer's if relevant) education and employment as well as household income, health care card status, financial stress and home ownership. Questions were based on ABS standard wording and response options. Other demographic questions including age, sex, marital status, language spoken at home and country of birth were collected in the HRF.

#### Parent or carer education

Two questions were included in the parent interview to measure educational status of the child's primary and secondary (where relevant) caregiver. Question wording was taken from the ABS 2011 Census questions so that these variables could be compared as a means of determining sample representativeness and for weighting if necessary. The first question asked about the highest year of primary or secondary school that the caregiver had completed and the response categories were specified exactly as with the ABS questions. These were read out by the interviewer. The second education question asked about the level of the highest post-school qualification that the caregiver had completed. For the second question, respondents were given a showcard to prompt their response based on the standard categories that are produced in ABS tables based on the ABS Classification of Qualifications (ABSCQ). The ABS Census form provides a write-in response option with some examples given as prompts and then these responses are coded into the ABSCQ categories by the ABS.

A single measure of the level of highest educational attainment was derived according to ABS standards (HEAP variable) and was coded for both primary and secondary carers, and the highest level attained by either carer in two-carer families. Derivation of the HEAP involves a decision table to allocate levels where it is unclear which is higher, for example, completing Year 11 is of higher attainment than having a Certificate I or II but is a lower level than Certificate III or IV.

Primary carers were also asked if they enjoyed school and to provide a subjective rating of their overall academic performance. Due to their subjective nature, the same questions were not asked about secondary carers.

#### Parent or carer employment

Employment questions comprised employment status, hours of work in all jobs, and if they did not have a job whether they were actively seeking work and how long it was since they last had a job. Questions were asked about primary carers who also reported about employment on behalf of the secondary carer if applicable. Parent or carer labour force status was derived using the ABS standard

which requires at least one hour of paid work or unpaid work in a family business or to be currently on leave to be classed as employed.

#### Household income and shortage of money

The primary carer was asked about the household's gross income in the past financial year and whether they had experienced any difficulties in the household due to a shortage of money.

#### Housing tenure and number of dwellings

Standard ABS Census questions were used to ask about housing tenure and type of rental if appropriate.

Parents and carers were also asked about the number of dwellings that the child had lived in since they were born.

#### **Benefits**

Parents and carers were asked if the child was listed on a health carer card or whether anyone in the household received a carer benefit or pension in relation to the child.

# **Family information**

The questions in the family information module were aimed at understanding the child's living circumstances and included questions on parent or carer mental health, stressful life events, family functioning and separation, and parental substance use.

#### Parental or carer mental health (K10+)

The impact of having a parent with mental health problems on a child has been well documented in the research literature. This information was not captured in the first survey. Level of psychological distress of the primary caregivers was assessed using the 10-item Kessler Psychological Distress Scale<sup>12</sup> including questions on days out of role and questions on positive mental health (K10+).

Two further questions were included for the primary and secondary caregiver. These questions asked if the parent's problems interfered with daily activities and if they have ever been told by a professional that they have a mental disorder. The Kessler items focus on current mental state so the additional items allowed some measure of lifetime mental health and of identifying low prevalence mental disorders that are not well covered by the Kessler items.

The K10+ was scored from 0 to 40, with higher scores indicating higher levels of distress. Scores are categorised as follows:

- 0-5 Low levels of psychological distress;
- 6-11 Moderate levels of psychological distress;
- 12-19 High levels of psychological distress; and
- 20-40 Very high levels of psychological distress.

To save interview time, the pilot study and dress rehearsal used the 6-item Kessler Psychological Distress Scale (K6) instead of the K10+ but the team were advised to reinstate the K10+.

Unfortunately, a programming error was made when reintroducing the K10+ so that question seven, "About how often did you feel depressed?", was not included. This made it impossible to derive a K10+ score from the parent responses but possible to still obtain a K6 score as an indicator of current parental mental health. As this error was discovered relatively early on during fieldwork it was possible to rectify in time for the final phase of fieldwork (January to April 2014) and ensure the remaining parent questionnaires included the full K10+. With around 1,000 parent interviews having a complete K10+ it was possible to impute the missing value for those incomplete parent questionnaires. Using the data from the phase four interviews a model was created to predict question seven based on responses to other items within the K10+.

### Stressful life events in past 12 months

Questions about stressful life events were not included in the first survey. Many of the existing scales are lengthy so as to adequately explore the impact of events on the respondent. A favoured approach in other Australian studies, such as the Longitudinal Study of Australian Children (LSAC), the 1993 WA Child Health Study and the WA Aboriginal Child Health Study (WAACHS), was the use of smaller lists of life-stress events occurring in the last 12 months. Given that the LSAC is a national study conducted in partnership with several government departments it was decided that for comparability it would be better to use the same life-stress events questions.

Following pilot testing, the list of life-stress events was further reduced to a set of 12 items in the final instrument. They were whether they, or their partner, had in the last year:

- Suffered a serious illness, injury or assault;
- A serious illness, injury or assault happened to a close relative;
- A parent, partner or child who had died;
- A close family friend or another relative (aunt, cousin, grandparent) who had died;
- Separated from a spouse or partner;
- Started living with a new partner;
- Had someone new (other than a new baby or partner) move into the household (e.g. new stepchild, foster child, other relative, friend or boarder);
- Had a major financial crisis;
- Lost their job, but not from choice (e.g. contract ended, made redundant, sacked);
- Had problems with the police or a court appearance;
- Someone in their household who had an alcohol or drug problem;
- Had themselves or their family been affected by a bushfire, flood, cyclone, or a severe storm.

# Family functioning and effects of family separation

Family functioning was assessed in the first survey using four items from the Child Health Questionnaire.<sup>15</sup> These items specifically assessed the impact of the child's health and behaviour problems on family activities. In review of appropriate instruments it was decided that, as poor family functioning can be a precursor to development of problems in children, the survey measure should also incorporate associated aspects and not only the impact of the child's problems.

Several alternative measures were reviewed and the McMaster Family Assessment Device (FAD) was selected.<sup>11</sup> The FAD has a 12-item sub-scale that measures general functioning and has high correlation with the long version of the FAD. This instrument is in the public domain and easy to administer and has also been used in several Australian based studies, such as the 2001 NSW Child Health Survey and the 1993 WA Child Health Survey.

Analysis of responses on the 12-item sub-scale from the Dress Rehearsal resulted in a shortening of the FAD instrument to 6 items.<sup>20</sup> Responses were used to classify families into four levels of functioning ranging from very good through to poor, with poor indicating unhealthy family functioning likely to require clinical intervention.

Questions in the life-stress events section included events such as relationship breakdowns or a new addition to the household. Events such as this can not only impact the child but also the parents or carers and how the family functions. In consideration of these issues, the survey team decided that further items should be included to assess how changes to the family situation, particularly where there has been a family breakup, have impacted on the child. Questions were developed by the team to capture changes in the family structure, if this caused distress to the child at the time, and also if the child was still distressed as a consequence to these changes.

### Parent substance abuse

A review of existing surveys such as the National Drug Strategy Household Survey revealed measures that were long and detailed with the intent to capture comprehensive information for each specific substance used. The limited time constraints of this survey restricted the use of such items. As the interest in substance use for this survey was in how it relates to children's mental health and wellbeing, it was decided that the survey would not attempt to replicate prevalence estimates of use of individual substances that are available from other collections. Instead, a small number of questions about smoking and alcohol use were included and asked of primary and secondary caregivers (if relevant).

# **Bullying**

Parents and carers were asked a few questions about whether their child had been bullied or cyberbullied, how often this had occurred and how much distress it had caused the child. As parents and carers may not have known whether the child was being bullied or was involved in bullying other children, young people themselves were asked a more comprehensive set of questions about bullying in the self-report questionnaire.

# **CHAPTER 4: YOUTH SELF-REPORT QUESTIONNAIRE**

In the first survey, a self-report module was included for all adolescents aged 13 to 17 years-old. The questionnaire included the CBCL<sup>7</sup>, Child Health Questionnaire<sup>15</sup>, the Centre for Epidemiological Studies Depression Scale (CES-D)<sup>21</sup> along with questions on drug use and suicidal behaviour from the Youth Risk Behavior Surveillance System (YRBSS) questionnaire.<sup>9</sup>

It was decided that the qualifying age for the youth self-report questionnaire in the second survey would be lowered from 13 to 11 years in order to capture important changes as children transition through puberty. Due to the sensitive nature of some questions covered in the youth self-report questionnaire, only certain questions were asked of these younger participants. For example, younger children were not asked about self-harm and suicidal behaviours. The youth self-report questionnaire was completed on a tablet similar to that used by the interviewer for the parent interview.

The youth self-complete questionnaire modules were administered in the following order (although described in a different order):

- Education;
- Internet use;
- Strengths and Difficulties Questionnaire (SDQ)<sup>8</sup>;
- Child Health Utility-9D (CHU-9D)<sup>10</sup>;
- Kessler 10+<sup>12,13</sup>;
- DISC-IV Major depressive disorder<sup>5</sup>;
- Impact on functioning;
- Service use;
- Family information;
- Youth risk behaviours;
- Psychosis screener;
- Self-esteem; and
- Protective factors.

# Major depressive disorder

In order to capture major depressive disorder in young people the DISC-IV youth self-report major depressive disorder module was included in the self-report questionnaire. To minimise respondent burden this module was limited to diagnose major depressive disorder, and did not include questions for sub-threshold depressive symptoms and dysthymic disorder or to identify 30-day diagnostic status.

# Impact on functioning

Similar to the parent or carer interview, those young people who reached sub-threshold status were also asked the same impact on functioning questions to assess the impact of major depressive disorder symptoms on different domains of their life including:

- at school or work;
- on friendships and social activities;

- on family relationships, family activities and other members of the family; and
- on self (i.e. level of distress);

#### Other scales and measures of mental health and wellbeing

#### Psychosis screener

A further set of questions were included in the youth self-report questionnaire to screen for psychotic symptoms. Six questions were selected from the screener items in the DISC-IV psychosis module with selection of items based on a validation study of screening instruments for psychotic-like behaviours.<sup>22</sup> The questions focussed on hallucinations, delusions and disturbed thoughts and an additional question to help identify if these experiences were alcohol or drug related.

#### Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) was included in the youth self-report questionnaire<sup>8</sup>. This measure is routinely used as a tool to assess young people receiving State/Territory-administered specialised child and adolescent mental health services.

The SDQ provides a brief behavioural screening questionnaire comprising five scales of five items each. Items in four of these scales, that is emotional problems, conduct problems, hyperactivity and peer problems, are added together to generate a total difficulties score.

The SDQ was designed so that approximately 10% of children and adolescents fall into the 'abnormal' range on the total difficulties score, which indicates that they are at substantial risk of clinically significant problems. The SDQ also includes an impact scale that measures interference in life due to emotional and behavioural problems in the domains of home life, friendships, classroom learning and leisure activities.

#### Psychological Distress (Kessler 10+)

Level of psychological distress was assessed using the 10-item Kessler Psychological Distress Scale. The K10+ is based on 10 questions about negative emotional states in the four weeks prior to interview<sup>12</sup>.

The K10+ was scored from 0 to 40, with higher scores indicating higher levels of distress. Scores are categorised as follows:

- 0-5 Low levels of psychological distress;
- 6-11 Moderate levels of psychological distress;
- 12-19 High levels of psychological distress; and
- 20-40 Very high levels of psychological distress.

Adolescents completed an enhanced version of the K10+ with additional questions on anger, control, concentration, and feeling calm and peaceful<sup>13</sup>. The K10+ also includes questions about whether, as a result of any reported distress, they had any days when they could not carry out their normal activities.

# Child Health Utility-9D (CHU9-D)

The first survey included a health-related quality of life measure via the Child Health Questionnaire.<sup>15</sup> This questionnaire is no longer in the public domain and as a replacement to this scale the Child Health Utility-9D was included in the youth self-report questionnaire.<sup>10</sup> It captures functioning over nine different dimensions, for example, if the child or adolescent had problems with sleep, ability to do their homework or carry out their usual routine. This quality of life measure can be used in economic evaluation.

#### Service use

The service use module was developed specifically for the survey and tailored both to young people and the current Australian health care environment. Due to the more complex language in the module and the relatively small proportion of 11 and 12 year olds utilising mental health services independently without a parent or carer, the service use module was administered only to young people 13 years and above. One exception was questions about headspace services, which were administered to young people aged 12 years and older, due to the fact that headspace is aimed at providing services for 12-25 year-olds.

Similar to the parent questionnaire, questions covered services used for emotional and behavioural problems in the previous 12 months. The term 'emotional and behavioural problems' was used to capture a broader range of problems than just diagnosed mental disorders. The term was defined as meaning 'a number of things, for example, being anxious or stressed, feeling depressed, having problems concentrating, or being aggressive or hyperactive'. The focus of the survey was on service use for emotional or behavioural problems in the past 12 months to be consistent with the time period referenced in the DISC-IV modules and the SDQ.

Information was collected for the previous 12 months about the following:

- health services any service provided by a qualified health professional regardless of where that service was provided (community, hospital inpatient and emergency, and private rooms);
- school services any service provided by the school or other educational institution that a young person was attending, including individual or group counselling, a special class or school, or service provided by a school nurse;
- telephone counselling services; and
- other online services used for emotional and behavioural problems.

Although the service use questions in the youth module were similar to the parent and carer module, young people were asked more detailed questions in some areas. This included their use of specific headspace services, sources of informal help or support and other things that they do to help them manage any emotional or behavioural problems that they may have.

#### **Perceived need**

While the focus of the service use questions was on services from specific health providers and locations, the perceived need section focused on types of help that young people felt that they needed for emotional or behavioural problems. This was measured in the survey by a separate

module that determined whether the young person had any need for help with emotional or behavioural problems and whether that need was met. The module was adapted from that used in the 2007 adult survey.<sup>18</sup> Adolescents were asked the same questions as parents and carers.

The need for care was assessed across four types of help:

- Information about emotional or behavioural problems, treatment and available services;
- Prescribed medication for emotional or behavioural problems;
- Counselling or a talking therapy about problems or difficulties (either one-on-one, as a family or in a group); and
- Courses or other counselling for life skills, self-esteem or motivation.

For each of the four types of help, the level of perceived need was classified as being either fully met, partially met, unmet or not needed. For those reporting a need for more than one type of help, perceived need for any type of help was based on a composite of the individual ratings for each type of help needed. Need for any type of help was rated as being fully met if for each type of help needed, that need was assessed as being fully met. Need for any type of help was partially met if any of the types of help were partially met or if there were combined ratings of fully met and unmet need. Need for any type of help was unmet if the level of need for all types of help needed was unmet.

*Barriers to help-seeking* – If respondents identified that they needed help or more help, they were asked about the reasons that kept them from seeking or receiving more help.

## **Risk behaviours**

The first survey utilised the Youth Risk Behavior Surveillance System (YRBSS) to capture information on youth risk behaviours.<sup>9</sup> Updates made to the YRBSS questionnaire since the first survey were reviewed by the UWA survey team and the following areas of content were included in the questionnaire: tobacco use, alcohol, and other drugs, deliberate self-harm and suicide, and sexual behaviour. Questions referencing activities on school property were removed so as not to limit physical locations where adolescents engaged in risky behaviours.

As the youth self-report questionnaire was to be completed by young people 11 years and older, age cut-offs or restrictions of the number of items were set for particular questions. With regards to smoking and alcohol, young people aged 11-12 years were asked screening questions about ever trying these, while young people 13 years and older were asked more extensive questions about use and amount. Other drug use was asked of young people aged 12 years and older, and sexual behaviour was asked of young people aged 12 years and older, and sexual behaviour was asked of young people aged 13 years and older.

# Smoking

Young people aged 13 years or older who had ever tried smoking were asked if there was a time in their life when they were smoking at least once a week. If they had, further questions covered the age they first started smoking at least once a week, the number of days they smoked in the past 30 days, and the number of cigarettes smoked on these days. An additional question was added to the YRBSS questions asking if they had ever tried to quit smoking.

### Alcohol consumption

The YRBSS questions about alcohol consumption were modified for consistency with Australian standards. As the questions were being administered on a tablet computer, there was restricted capacity to present a graphical format as a prompt for what constitutes a standard drink. The type and quantity of drink questions were not seen to add value to the outcomes of the survey and were not implemented.

Young people aged 13 and over who had ever had a drink of alcohol other than a few sips were asked further questions about how old they were when they had their first drink of alcohol, how frequently they drank since then, how many days they drank in the last 30 days, how many days they had four or more standard drinks in a row, and the largest number of standard drinks in a couple of hours.

The survey also included an additional question on motives for drinking alcohol or drug use. This question was developed by the team using the Drinking Motivations Questionnaire<sup>23</sup> as a guide and explored factors and reasons associated with drinking or using drugs such as a coping strategy, to have fun, to fit in, and to enhance enjoyment of social gatherings.

### Other drug use

Questions were asked of young people aged 13 years and older about other drug use including cannabis, illegal drugs and prescription drugs for non-medical purposes. On advice from the National Drug and Alcohol Research Centre, wording on some of the questions was modified to represent current Australian language. To align with other Australian surveys the response categories were also modified.

Specific questions about cannabis included if they had ever tried cannabis, and if so, how old they were, the number of times used since that time and in the previous 30 days.

Adolescents were also asked if they had ever used illegal drugs, or sniffed petrol, glue, aerosol, paints, solvents or nitrous with no further probing; or if they had used prescription drugs for non-medical purposes.

If there was a "yes" response to use of illegal drugs or prescription drugs for non-medical purposes, further questions probed for more information about specific drugs, age at which they first started using any of the drugs, use in the past 30 days, number of times ever used, and main reason they decided to take drugs.

# Deliberate self-harm and suicidal behaviours

Several instruments were reviewed for possible sources of items. Some of these instruments restricted the scope of the harm behaviours to include only individuals requiring medical attention, while other item sets were too long and detailed for a survey format. As a result, the questions developed for measuring self-harming behaviours, while drawing upon these sources, had to be specifically worded and tailored for the survey. The questions about self-harm probed the 12-month and lifetime occurrence of deliberate self-harm or injury without intending to end life; the number of times such acts had ever occurred; their age of onset; the most recent method of harm; and,

whether the respondent had been admitted to hospital, an emergency department or been treated for self-harm in the past 12 months.

Suicidal behaviour items asked respondents whether they had feelings that life was not worth living. They also measured the lifetime occurrence of a suicide attempt and the number of lifetime attempts. Additional items then probed the 12-month prevalence of: suicidal ideation; making a plan for attempting suicide; making an actual attempt; and whether an admission or access to emergency or other medical treatment occurred in the last 12 months.

For both item sets, the item response category for the initial screening question included a "Prefer not to say" option in addition to the "No" and "Yes" response categories. Young people who selected this option were sequenced out of the item set.

### Body Mass Index (BMI) and problem eating behaviours

Young people also self-reported their height and weight, and this was used to determine their Body Mass Index (BMI). Both weight and height were reported within categories and therefore it was necessary to estimate actual values for both using statistical methods. BMI ranges specifically designed for children and adolescents were used to classify underweight or overweight status.<sup>24</sup> Approximately 8% of young people did not provide either their height or weight. These young people were excluded from the calculations of BMI.

The survey did not assess DSM-IV criteria for eating disorders. Instead, the survey sought to identify eating behaviours that may be on the pathway to eating disorders. These were eating behaviours associated with low weight, and binge eating and purging.

Questions were taken from the Avon Longitudinal Study of Parents and Children (ALSPAC) to assess a range of activities young people may undertake to control their weight in the past 12 months.<sup>25</sup> The ALSPAC used an extensive list of questions exploring in-depth eating patterns and body attitudes. Using the ALSPAC questions as the basis, the survey team developed a shortened version. These questions were:

- i) if they had gone on a diet to lose weight or keep from gaining weight;
- ii) if there was a time when they had regularly exercised instead of doing other things that they were supposed to be doing, or while they were injured, in order to lose weight or to avoid gaining any weight;
- iii) how often they had fasted for at least a day to lose weight or to avoid gaining any weight;
- iv) how often they had made themselves throw up or vomit to lose weight or to avoid gaining any weight;
- v) how often they had taken laxatives or other tablets or medicines (diet pills or water tablets) to lose weight or to avoid gaining any weight; and
- vi) how often they had been on an eating binge (defined as eating so much food that it would be like eating two or more entire meals in one sitting, or eating so much of one particular food, like lollies or ice cream, that it would make most people feel sick).

Responses to questions on eating behaviours together with BMI were used to classify low weight problem eating behaviour and binge eating and purging problem eating behaviour.

- *Binge eating and purging problem eating behaviours* Both binge eating and either vomiting or taking laxatives to control weight in adolescents with a Body Mass Index (BMI) that was not in the underweight range.
- Low weight problem eating behaviours Body Mass Index (BMI) in the underweight range and young person dieted, fasted, vomited or used laxatives to lose weight or regularly exercised when they were supposed to be doing other things.

# Sexual behaviours

The first survey did not include any questions regarding sexual activity. The inclusion of such questions raises issues such as impact on respondent participation and also ethical concerns. However research findings have identified links to youth sexual activity, low self-esteem, depression and also other risky behaviours, and so it was decided to include questions about sexual behaviour.

Questions about sexual behaviour were sourced from the YRBSS and included for young people aged 13 and over. If they had ever had sexual intercourse, further questions were asked about number of partners, use of contraception and whether they had drank alcohol or used drugs on the last occasion.

### Bullying

Questions about bullying were not included in the first survey. Considering the impact that bullying can have on a child's mental health and wellbeing it was decided to include a section on bullying in both the parent or carer, and the youth self-report questionnaires. Questions were based on those developed by Donna Cross from the Cyber Friendly Schools Project at the time based at Edith Cowan University. They were modified to incorporate cyber bullying and questions to the youth regarding them being the bully. The youth self-report questionnaire explores incidents of bullying, method, severity, impact on the child and if they sought help.

#### Self-esteem and protective factors

Self-esteem was assessed via the Adolescent Self Esteem Questionnaire. This short questionnaire, targeted specifically to adolescents, was developed by the UWA survey team and replaced the CHQ which was used to measure self-esteem in the first survey.

Questions relating to protective factors, and in particular positive mental health and resilience, were included in the youth self-report questionnaire. Questions drawn from the NCS-A about social support formed the basis of this module.

Young people were also asked about the number of hours of sleep that they usually got on a school/work night and on a night when they did not have school/work the following day.

## **Education**

#### **Education status**

Young people were asked a small number of questions about their current education status and any absences from school.

#### School connectedness

School connectedness is a term used to capture a student's perception of their school environment such as safety, belonging, feeling cared for and respected at school. Connectedness to school is thought to be a positive indicator of psychological wellbeing, school achievement and better health status. There were no pre-existing parent questionnaires for school connectedness most likely because of the highly subjective nature of these questions and the difficulty for the parent to gauge how their child feels about school.

As part of the National Longitudinal Study of Adolescent Health (Add Health), a six-item School Connectedness Scale was developed.<sup>26</sup> The SCS developed by Resnick is in the public domain. It captures children's feelings about school such as safety, closeness to people, sense of belonging, how happy they are, and if they feel they are treated fairly. As a cross-reference with the parent interview it was also suggested to include a broad school liking question.

As the Resnick SCS focuses on social connectedness to the school community, further questions were added to capture the construct of academic connectedness. One measure proposed was the School Life Instrument.<sup>27</sup> This measure has three scales capturing opportunity, achievement and adventure. The UWA survey team undertook a factor analysis of data collected using this scale and identified six items that best captured the concept of academic connectedness. These were added to the SCS items.

#### School performance

The survey team developed a set of items capturing performance compared with other children in the same year on the following core subject areas for children aged six or over:

- Maths;
- English, reading or writing;
- Science (only if child age >=11);
- Art or drawing; and
- Sports or physical education.

Young people were asked the same questions as their parents and carers.

#### Use of the internet and electronic games

A section on internet use was not included in the first survey. Developments in technology mean that young people spend more time in front of computer screens or using internet-connected devices. The internet and social media have also become common means of communication or for finding out information, therefore, a decision was made to include questions on levels of electronic use. These common technologies also have the potential to be misused and can be addictive for some young people. It was recognised that it would not be possible to include an extensive module about use of the internet, so a few key questions were included. The questions address amount of time spent on the internet, or playing electronic games on an average weekday and on an average weekend.

Questions were also asked to determine if time spent on the internet or gaming interferes with the child's normal daily activities. These questions were sourced from the EU Kids Online Survey.<sup>28</sup>

Young people were asked about five specific behaviours that may be indicative of addiction to the internet, social media or electronic gaming:

- i) going without eating or sleeping in order to be on the internet or play electronic games
- ii) feeling bothered or upset if they are unable to be on the internet or gaming
- iii) catching themselves surfing the internet or playing games even when they are not interested
- iv) spending less time than they should with family or friends or doing school work or work because of the time they spend on the internet or gaming
- v) having tried unsuccessfully to reduce the time spent on the internet or playing electronic games.

Problem internet or electronic gaming behaviour was defined by the survey team as reporting at least four of these individual indicators.

# CHAPTER 5: RELIABILITY OF ESTIMATES AND INTERPRETATION OF RESULTS

Estimates from YMM are based on information obtained from a sample of parents and carers and young people, and are therefore subject to sampling variability. Estimates from the sample may be different from the figures that would have been obtained had all eligible children and families been included in a census, just by random chance. This variability is known as sampling error. The size of the survey sample and the way the sample is designed are key factors in determining the amount of sampling error.

For some survey data items, respondents were unwilling or unable to provide the required information. Where responses for a particular data item were missing for a person or household in the parent or carer interview, they were recorded as a "don't know" or "refused". These don't know and refused responses have been treated differently, depending on the instrument, and are described further below. In the youth self-report questionnaire, there were no response options that allowed for don't know and refused and thus there was very little missing data.

This chapter describes the reliability of the survey estimates, sampling and non-sampling error; and comparisons of this survey to other data sources.

# **Response rate**

In total 6,310 parents and carers or 55% of eligible households participated in the survey. In addition 2,967 or 89% of young people aged 11-17 years for whom their parents or carers had given permission completed a questionnaire.

Based on data from the 2011 Census, about one in four Australian households contain one or more children aged 4-17 years. In calculating the response rate for the survey, it was necessary to account for the fact that not all households approached in the survey contained children within the sample age range. Interviewers approached each selected household up to six times at different times of the day, on weekdays and weekends. However, there remained some households where it was not possible to make contact with anyone living in the household despite these attempts. Census data have been used to estimate the proportion of these households that would be likely to have contained children aged 4-17 years.

The survey was voluntary and some households refused to participate. When a householder refused to participate in the actual survey, the interviewer tried to obtain some basic demographic information, in particular whether there were any children living there. About two thirds of refusing householders would not provide this basic information. Again Census data have been used to estimate the proportion of these households that would have contained children aged 4-17 years.

To estimate the overall response rate, the estimated number of non-contacts and refusals where eligibility could not be determined was added to the number of participants and the number of refusals who confirmed they had one or more children. Using this method, the overall response rate for the survey was estimated to be 55%. It is acknowledged that the inclusion of households where it was not possible to make contact makes this a strict, conservative estimate of the overall response

rate. If this group of households is excluded from the estimate, the overall response rate increases to 60%.

Response rates in social surveys have been declining for some time. While the first Child and Adolescent Survey of Mental Health and Wellbeing achieved a response rate of 70%, there has been a general trend in major surveys of declining participation rates since that time. The 2007 Adult component of the National Survey of Mental Health and Wellbeing, conducted by the ABS, achieved a 60% response rate.

# **Sampling error**

Sampling error is the expected difference that could occur between the published estimates, derived from repeated random samples of persons, and the value that would have been produced if all young people in scope of the survey had been included.

Sampling errors can be estimated from the survey data. Sampling errors can be expressed in terms of the standard error or relative standard error of an estimate from the survey, or by constructing 95% confidence intervals around survey estimates. The confidence interval measures the degree to which an estimate may vary from the figure that would have been obtained from a full population census. There are about 19 chances in 20 (i.e. about a 95% chance) that the population value will lie in the range indicated by the confidence interval.

The YMM sample was designed to produce estimates of prevalence of mental disorders for children and young people, by age group and sex, that would be sufficiently accurate for planning purposes. By oversampling young people aged 16-17 years, the survey was also designed to produce estimates of prevalence of disorder specifically for 16-17 year-olds.

Based on the sample size achieved in the survey it is anticipated that accuracy of prevalence estimates from the survey will fall in the following ranges:

- overall estimates: plus or minus 1% (i.e. a prevalence estimate of 15% would have a 95% confidence interval: 14%-16%)
- by age group and sex: plus or minus 1.5% (i.e. a prevalence estimate of 15% would have a 95% confidence interval: 13.5%-16.5%)
- for 16-17 year-olds: plus or minus 1.5% (i.e. a prevalence estimate of 15% would have a 95% confidence interval: 13.5%-16.5%)

It is thus expected that prevalence estimates by age group and sex should be sufficiently accurate for most planning purposes.

Accuracy of estimates decreases for smaller sample sizes, and analyses will be less accurate for smaller sub-groups of the population.

# Non sampling error

Non sampling error can occur at any stage throughout the survey process. Examples of non-sampling error include:

- Errors related to survey scope;
- Parents or carers selected for the survey may not respond (non-response);
- Survey questions may not be clearly understood;
- Responses may be incorrectly recorded by interviewers; or
- Errors in coding or processing survey data.

#### Errors related to survey scope

Some errors may have occurred in the blocklisting process that resulting in dwellings being incorrectly included or excluded. For example, it may not have been clear if the dwelling was private or non-private. Every effort was made to avoid these kinds of errors occurring. Interviewer address lists were drawn from the Geocoded National Address File (G-NAF) provided by the Public Sector Mapping Agency (PSMA). PSMA have created the G-NAF as the most authoritative geocoded address index for the entire country and provided it to the Telethon Kids Institute for the purposes of YMM as a charitable donation.

The G-NAF is believed to be of high quality but is known to contain some errors, as all administrative sources do. In addition, it is also believed to be less reliable in rural areas than in metropolitan areas and there is a delay between new dwellings being built and occupied and the addresses being recorded within the G-NAF system. As a result, the G-NAF was used as a starting point for the block listing exercise, but its accuracy and completeness in each SA1 was checked by the interviewer during the blocklisting procedure.

There may also have been some error in applying the inclusion criteria for individual householders such as whether the child was usually resident in the household more than 50% of the time. If the child was in a household with separated or divorced parents and divided their time between households, it may have been difficult to gauge what proportion of time that they spent in those households.

#### Non-response

Within YMM, non-response could have occurred at three levels. A household could have been a nonrespondent for the survey overall, a young person could have been a non-respondent to the youth questionnaire within a participating household, and a carer or young person may not have provided an answer to individual questions. This item-level non-response was a much smaller issue in YMM than in past paper-based surveys. The programming and automatic sequencing of the computerassisted questionnaires substantially decreased the amount of item missing data in the survey.

As the survey was voluntary, respondents could choose not to answer any questions if they wished. This happened very infrequently. This may reflect the large time commitment involved with the survey such that those who agreed to participate knowing the time commitment would be prepared to answer all questions. Also during the course of administering the questionnaire the interviewer would have been able to build some level of rapport with the respondent.

Apart from a programming error that resulted in a significant proportion of the sample skipping one of the questions in the K10+ in the parent and carer interview, the item with the highest level of respondent refusal was household income. Some 2.5% of families refused to provide their household income, and another 2.5% stated they did not know their household income. As

households with missing income may be systematically different from households where income was reported income "not stated" was treated as a separate category in analyses including household income.

Questions in the primary carer questionnaire where more than 1% of eligible respondents provided a non-informative answer (either refused or said "don't know") are shown in Table A3-1 in Appendix 3. Most of these related to respondents saying they did not know the answer to the question rather than refusing to provide an answer. This occurred for a range of questions, principally within the DISC-IV diagnostic modules, which related to emotions or behaviours of the child that the parent may not be aware of. This included behaviours at school, and internal emotional states that not all carers would know about their children.

Within the DISC diagnostic modules, the diagnostic algorithms treat a "don't know" response as a "no" response for that symptom or behaviour. Some of the questions in the service use module also had a high level of "don't know" responses and this particularly related to the use of services that the parent may not be aware of such as headspace, telephone or internet-based services. Responses to these questions were better captured in the youth self-report questionnaire.

Due to the relatively small amount of item-level missing data, no specific action was taken to impute or adjust for missing data. The "don't know" responses to DISC-IV questions are valid answers to those questions and the scoring algorithms account for don't know responses. The youth questionnaire was self-completed by the respondents on tablet computers. Each question could be skipped by the young person if they did not wish to answer it, but the tablet was programmed to prompt the young person once to provide a second opportunity to answer any questions left blank before moving to the next screen. Because of this, item level non-response to the youth questionnaire was very low. For a small number of sensitive data items, "prefer not to say" was offered as a legitimate response choice to the young person. Table A3-2 in Appendix 3 shows items on the youth questionnaire where the proportion of non-informative answers was greater than 1% of youth who were asked that question. The questions on self-harming behaviours and sexual intercourse had over 5% of respondents choosing "prefer not to say". Height and weight was reported as not known by 6% and 5% of young people respectively.

Item level response errors may have occurred due to inaccuracy of recall over the specified periods, mostly the 12-month period prior to interview. Errors may have occurred in the recall of symptoms experienced by the child within the DISC-IV modules or in the recall of services received in the past 12 months. Information in this survey is 'as reported' and therefore may differ from information available from other sources or collected using different methodologies.

Due to the sensitive nature of the questions, some respondents may have provided responses that they thought were desirable rather than those that accurately reflected their own situation. For example, they may not have wanted to admit to problems with their child or with their own mental health. Conversely, the child's symptoms may have been over-reported if the respondent perceived that they needed to provide information about mental health. Use of the CAPI tablet with standardised programming of questions, intensive interviewer training and interviewer rapport would have helped to minimise respondents reporting in a way that was socially or culturally desirable.

# **Errors in processing**

Errors may have occurred in the processing of data at any stage between the collection of data and the production of statistics for the Departmental report. These may have occurred when data was being recorded on the CAPI by interviewers, when data was uploaded and stored at RMR or during the handling and manipulation of raw data by the UWA survey team.

To minimise the likelihood of these errors occurring the following processes were used:

- Data transfer from tablets to RMR office At the end of each day RMR interviewers synchronised the CAPI and CASI tablets with the RMR computer system using the mobile phone network (usually Optus or Telstra). Effective synchronization involved the swapping of data between the tablets and the RMR system including completed interview data. All files were checked by the field supervisor on receipt at the RMR office.
- *Testing of computer programming* The programming of the CAPI and CASI tablets was extensively tested prior to the main fieldwork stages by RMR and UWA survey teams. This involved rigorously testing the sequencing and checking for errors, as well as checking question wording and validity of responses (i.e. values were within expected range).
- Data file checks A preliminary data extract based on the Dress Rehearsal was also assessed by the UWA team for errors in sequencing and out of range values. Preliminary estimates of prevalence were also checked against other survey outputs such as the first Child and Adolescent Component of the National Survey of Mental Health and Wellbeing.
- *Editing* See section on data editing in Chapter 2.

# Household non-response

While the survey sample has been selected at random, the final achieved sample is a combination of the random sampling involved in sample selection, and the level of participation by selected households. Ideally, all households selected to participate in the survey would complete interviews, however, in practice some level of non-response is likely. Non-response can occur if a household member selected for participation cannot be contacted during the fieldwork phase, or if they are unwilling to participate.

If households that participate in the survey are systematically different in some way from households who refuse to participate, the result could be a sample that is not truly representative of the entire population. For instance, people may choose not to participate in a survey if they are not interested in the subject matter of the survey. The potential for non-response bias is larger when the response rate is low.

# Reasons for non-response

Interviewers were required to record a reason for non-response for those households that were in scope but refused to participate.

Despite efforts to maximise participation, it is acknowledged that the survey involved a significant investment of time, with an average time in the household of 75 minutes. Not being interested, not having enough time, or being too busy were the most commonly cited reasons why potential respondents declined to participate in the survey.

## Response analysis

While information about non-respondents was limited, there are several possible ways to assess how representative the final sample was, what factors might be associated with not participating in the survey and whether there was a significant response bias. The sample was area-based, and was constructed by selecting SA1 areas on the basis of 2011 Census data. Information about the selected SA1 areas from the Census can be used to determine if response rates were higher or lower in areas with different characteristics. It was also possible to compare the sample of families with 4-17 yearold children collected in YMM with information about the entire population of families with 4-17 year-old children in the 2011 Census. The YMM questionnaire included some key indicator variables, such as the K10+ and the SDQ which have been included in other collections, which makes it possible to compare the YMM sample with the samples in other collections using these key indicators.

Non-respondents were asked if they would be willing to provide brief information about the structure of their families. This information could potentially have been used to compare non-respondents with respondents in the survey. Most non-respondents were not willing to provide this basic information, so this potential source of information about non-respondents in the survey was not able to be used in YMM.

A comprehensive overview of the response analysis is provided in Appendix 4.

Comparisons with 2011 Census data suggest that the YMM sample is broadly representative of the overall Australian population in terms of the following major demographic characteristics:

- Socio-Economic Indicators for Areas (SEIFA) While there were some small differences between the SEIFA distributions of the sample and the population overall, these differences were modest and not always consistent between indicators. For instance, while all four indicators suggested a slightly lower sample representation in the most disadvantaged decile, the highest decile was modestly under-represented in some indexes and overrepresented in others. These data suggest that the YMM sample was highly comparable with the full population of 4-17 year-old children in Australia, according to the SEIFA measures of socio-economic disadvantage.
- Geographic area The response rate was slightly lower in New South Wales than in other States and Territories. In New South Wales, the response rate was slightly lower than the national average in the Greater Sydney area, but around average in the remainder of New South Wales. The exclusion of remote SA1s from the sampling frame also resulted in a slightly lower sample in the Northern Territory. The sample yield was as expected in the greater Darwin area, but no sample was selected in the Northern Territory outside Darwin, due to the remoteness exclusion. Overall the differences observed were modest and within normal expectations for a random sample and possible population changes between the 2011 Census and 2013.
- *Gender of child* The YMM sample was proportionally representative of both sexes.
- *Family structure* The YMM sample was comparable with the Census population by family structure.
- *Household income* Overall, the YMM sample was broadly representative in its income distribution, although there was a slightly lower number of families in the YMM sample in the bottom income category, and a slightly higher number in the top income category. The

comparison was made after excluding families from either collection where household income was not stated (4.7% of the main YMM sample).

- *Country of birth of parents/carers* The YMM sample was broadly representative of families with carers born in Australia or overseas. There was a slightly higher proportion of Australian-born carers in sole parent families in YMM compared with the Census data.
- Labour force status For families with two carers, the results were broadly comparable. For families with a sole carer, the YMM sample showed a slightly higher proportion of unemployed carers compared with the Census data. Again this issue may be related to availability of a sole carer to participate in the survey.
- *Dwelling tenure* The distributions were broadly comparable.

Comparisons with 2011 Census data suggested that the YMM sample differed to the overall Australian population in respect of age of the child and number of children in the household:

- Child age The YMM sample included a higher proportion of children aged 4-7 years than would be expected based on random sampling. This phenomenon has been observed repeatedly in social surveys. It occurred in the first Child and Adolescent Survey of Mental Health and Wellbeing, and the 1993 WA Child Health Survey and the WA Aboriginal Child Health Survey. The most likely explanation for this phenomenon is that families with younger children have a lower rate of workforce participation. It is more likely that these families will have at least one carer who is not employed or employed only part-time. This appears to be associated with both ability to make contact with these families, and ability or willingness to make time available to participate in social surveys.
- Number of children The survey sample under-represented children from families with only
  one eligible child. This phenomenon has also been observed consistently in surveys such as
  the 1993 WA Child Health Survey and the WA Aboriginal Child Health. Again this may be
  associated with labour force participation, with families with multiple children more likely to
  have a carer not working or working part-time and thus greater availability to be contacted
  and participate in surveys.

Summary of comparison of key indicators with other surveys:

- Strengths and Difficulties Questionnaire The SDQ was included in YMM under licence to its developer, Professor Robert Goodman of the Institute for Psychiatry in London<sup>8</sup>. Professor Goodman originally designed the cut-off scores for the SDQ specifically with intent that the top 10% of scores would be designated as the abnormal range. The SDQ was also included in the British Child and Adolescent Mental Health Survey (BCAMHS) which has been run twice in 1999 and 2004. The similarity of the prevalence estimates between the two surveys, and the fact that the overall prevalence of abnormal SDQ scores was estimated to be 10.1% in YMM, and by design was scaled to be 10% of the original normative British population, give some reassurance that the YMM sample was not significantly skewed in terms of overall level of mental health distress.
- Kessler 10 psychological distress. Comparisons were made between the K10 outcomes of primary carers in YMM with data for all adults from the 2007-2008 National Health Survey, and data for adults living in households with at least one child aged under 18 years in the 2007 National Survey of Mental Health and Wellbeing. The results suggest that the levels of

non-specific psychological distress in YMM primary carers were comparable with the general adult population in Australia.

Participation in the youth self-report questionnaire:

- The overall participation rate in the youth self-report questionnaire was 89% and did not fall below 80% for any category examined. Participation rate was constant by age, sex, geographic region, socio-economic status, and country of birth. Response rates were equal in each category of household income except in those families where the primary carer refused to provide the household income. In these families youth participation was lower.
- The major difference in youth response rates was by parent reported SDQ total score, with the response rate only 82% in young people in the abnormal range on the parent report. These data suggest that there was a small tendency for young people with higher degree of mental health distress to have a lower response rate in the youth questionnaire. As the deviations in response rates are relatively minor and the overall response rate is high, it is not anticipated that this will have a major impact on the representativeness of results derived from the youth sample. The youth sample data has been weighted to adjust for differences in these key characteristics.

# Weighting

One of the key reasons for undertaking random sampling is to use the sample data to estimate characteristics of the entire population from which the sample was drawn. In order to produce estimates for the population, the survey data are weighted, and these weights can then be incorporated in analyses of the data.

Weighting survey data involves accounting for the probability of selecting each participant in the survey, and adjusting for any patterns in the non-response. The first step in this procedure is to undertake a thorough analysis of the response rates in the survey and the representativeness of the sample. As noted above, the YMM sample appeared to be broadly representative of the Australian population of children aged 4-17 years in terms of geographic distribution, demographic features when compared with the Census, and in comparison to other major collections. Key patterns that were observed in the response rates included better response among families with children 7 years and under, and better response in families with more than one child aged 4-17 years.

The survey data was weighted to population totals provided by the ABS. The ABS produces Estimated Resident Population counts, and the YMM data have been weighted to the Estimated Resident Population of children 4-17 years as of 30 June 2013.

Weights were calculated using the generalised raking procedure of Deville and Sarndal (1992), also referred to as Calibration on Marginal totals.<sup>29</sup> This weighting procedure is commonly used by major statistical agencies, including the ABS and Statistics Canada. A SAS programme to implement this technique was provided by INSEE, the French National Statistical Agency.<sup>30</sup>

The generalised raking procedure is an iterative procedure that starts with a set of initial weights. In this case, these initial weights were the inverse of the probability of selection for each household. The procedure then calculates a final set of weights that match benchmark totals for a range of characteristics, while minimising the overall change from the initial weights. Based on the response

analysis described above, the data were weighted to match benchmark totals by sex, age (in single years), family size, and household income.

Due to the complex nature of the YMM sample design, several sets of weights have been derived. The survey sample was selected in a multi-stage design. First geographic areas (SA1s) were selected, then households, and then children within selected households. The data have been weighted to represent two populations:

- the population of all children aged 4-17 years in Australia
- the population of all families with one or more child aged 4-17 years in Australia

It is expected that most of the analyses from YMM data will be based on the population of all children, but the second population allows for analyses to be conducted at the family level as well, where appropriate.

Separate sets of weights have also been derived for the parent data and the youth self-report data. Although response to the youth self-report questionnaire was high, not all eligible youth completed this questionnaire. Analyses of youth reported items weighting up to the same population totals as for the parent-reported data will be able to be undertaken using the separately derived youth weights. Specific weighting variables are described in the CURF Technical Manual.

While the YMM survey data have been weighted to represent the total Estimated Resident Population as at 30 June 2013, information on distribution of the population based on demographic characteristics such as family size and household income have been derived from the 2011 Census of Population and Housing. A series of special tabulations from the 2011 Census of Population and Housing were obtained from the Australian Bureau of Statistics (ABS). There are a number of exclusions from the census data available for this purpose. Family characteristics are only provided by ABS on a Place of Enumeration basis. While there are questions on the census form to record any children who usually live in a dwelling but are not present on census night, these children are not included in cross tabulations based on characteristics of that family. Children who were temporarily away from home on census night, or children living in families where insufficient information was provided on the census form to enable family relationship coding are excluded from census tables based on family characteristics, as are children who are living in non-private dwellings on census night. Based on these exclusions 307,402 children aged 4-17 years (out of a total census population of 3,882,788 children) were excluded from the census tabluations used in this analysis.

# **CHAPTER 6: COMPARISON TO THE 1998 SURVEY**

There are a number of substantive methodological and content differences between the first and second Child and Adolescent National Surveys of Mental Health and Wellbeing. While it is possible to make some comparisons between the two surveys, all comparisons need to take into account the similarities and differences in methodology.

# **Diagnoses of mental disorders**

The first survey used modules from the DISC-IV to assess four mental disorders — major depressive disorder, dysthymic disorder, attention-deficit/hyperactivity disorder and conduct disorder. These were completed by parents and carers.

There were similarities, but also significant differences in how mental disorders were assessed in the second survey. Firstly, the DISC-IV was the primary diagnostic tool for both surveys. Major depressive disorder, attention-deficit/hyperactivity disorder and conduct disorder were also assessed in the second survey. However, the second survey also assessed four anxiety disorders, namely social phobia, separation anxiety, generalised anxiety and obsessive-compulsive disorder. Parents and carers completed DISC-IV modules for all seven disorders. Therefore direct comparisons of the overall 12-month prevalence of mental disorders cannot be made.

Comparisons are also restricted to children and adolescents aged 6-17 years as the first survey did not administer the DISC modules to parents and carers of children aged 4-5 years.

There have been minor changes to the scoring algorithms used in the DISC-IV since 1998. In the main publication of results, the 1998 survey results for major depressive disorder, ADHD and conduct disorder were recalculated using the latest algorithms to be comparable with the results from this second survey<sup>1</sup>.

In the second survey young people completed a youth version of the DISC-IV major depressive disorder module, as well as their parents and carers, providing an alternative perspective on whether they had the disorder.

The DISC-IV eating disorders module was included in the first survey. However, too few cases were identified for results to be published. For this reason the module was not included in the second survey, but rather problem eating behaviours were assessed in the youth self-report questionnaire using questions adapted from the Avon Longitudinal Study of Parents and Children.<sup>25</sup>

Questions were also added to determine the impact of symptoms of particular mental disorders from which severity could be determined. This allows for comparison of the prevalence data by severity as is possible with the other National Surveys of Mental Health and Wellbeing. The first survey did not determine severity and thus it is not possible to compare prevalence data by severity between the first and second surveys.

# **Mental health problems**

In the first survey mental health problems were assessed using three tools:

- Child Behavior Checklist (CBCL) a 113 item questionnaire designed to assess the emotional and behavioural problems in children and adolescents over the last six months, which is completed by parents and carers<sup>7</sup>;
- Youth Self-Report a 112 item questionnaire, which is derived from the CBCL for completion by young people aged 13-17 years; and
- the Center for Epidemiologic Studies Depression Scale (CES-D) a 20 item self-report scale designed to measure depressive symptomatology in the past week.<sup>21</sup>

In the current survey, mental health problems were assessed using two tools:

- Strengths and Difficulties Questionnaire (SDQ)<sup>8</sup> Parent Report Measure Baseline versions for Children (4-10 years) and for Youth (11-17 years);
- Strengths and Difficulties Questionnaire (SDQ) Youth Self Report Baseline version.

While the SDQ has a number of important benefits, comparability of the prevalence of mental health problems across time is impacted by the decision to change instruments. The CBCL is calibrated so that approximately 14% of children and young people in a normal population would be classified in the clinical range (borderline + abnormal), while the SDQ is calibrated so that approximately 10% of children and young people would be classified in the abnormal range.

It is therefore not possible to compare the prevalence of mental health problems between the first and second surveys.

# Service use

Questions on service use were completely redesigned for the second survey. The approach taken was based on that used in the 2007 National Survey of Mental Health and Wellbeing of the Australian adult population. This approach is based on identifying if services have been used in the past 12 months, if parents and carers or young people feel they needed help or support, whether they received the level of support they needed, and what barriers may have prevented them from using services they felt they needed.

The first survey asked about services used in the six months prior to the survey. By contrast, the reference period in the second survey was 12 months to match the period over which mental disorders were assessed using the DISC-IV and also to align with service data from the other National Survey of Mental Health and Wellbeing initiative surveys, including the 2007 adult survey. Direct comparison of service use over these two different timeframes is not possible and data presented on services used by young people with mental disorders is also not comparable due to the differences in disorders.

The types of services covered in the second survey were also broader than those asked about in the first, reflecting significant changes in the types of services available to young people in 2013-14 compared with 1998. Questions were added about new health services, online services and information, and additional information was collected about services used in schools.

A comparison of service use between the two surveys is included in the main publication of results.<sup>1</sup>

# **CHAPTER 7: SURVEY PRODUCTS**

# Confidentialised Unit Record File (CURF) and Detailed Unit Record File (DURF)

The Confidentialised Unit Record File is housed at the Australian Data Archive for access by researchers with ethics approval. See <a href="https://www.ada.edu.au">https://www.ada.edu.au</a> .

To protect the privacy of individuals and families who participated in the survey, a small number of variables have been omitted from the CURF. The CURF contains a parent or carer file and a youth file. Each household has been assigned a random unique identifier (householdid) and where applicable, this allows the parent or carer data to be linked to the relevant youth self report. A detailed list of the data items can be found in the metadata spreadsheets downloaded as part of the CURF documentation and described in the CURF Technical Manual.

A Detailed Unit Record File (DURF) of the survey data will be maintained by the data custodians, the Telethon Kids Institute. Customised data tables from the DURF will be provided on a cost recovery basis. Requests can be made via email to <u>youngmindsmatter.SMB@telethonkids.org.au.</u>

# **Documentation**

#### Data access statement

This document lists all of the products and sources available from the survey. It is held on the YMM website (<u>www.youngmindsmatter.org.au</u>) and accompanies the survey documentation held on the Australian Data Archive website.

#### Copies of the survey instrument

With the release of the publication, downloadable copies of the survey instruments have also been made available on the Telethon Kids Institute YMM website <u>www.youngmindsmatter.org.au</u>. Copies of the instruments together with the information brochures and consent forms can also be accessed with survey documentation at the Australian Data Archive.

The survey is based on the Diagnostic Interview Schedule for Children – Version IV (DISC-IV)<sup>5</sup>, a standardised diagnostic instrument developed under the auspices of the United States National Institute of Mental Health, which is used worldwide to assess mental disorders in large samples. The paper copy of the DISC-IV modules represents the versions that were programmed into the CAPI modules for the purposes of conducting YMM. For more information on the DISC-IV and to use any version of the DISC, contact the NIMH-DISC Training Center at Columbia University nimhdisc@child.cpmc.columbia.edu.

#### **CURF Technical Manual**

The CURF Technical Manual provides information on the release of data from YMM. It includes a brief background to the survey, instructions for using the CURF microdata, reliability of estimates, contents of the CURF, and the conditions of release.

### Additional documentation

A field report prepared by the data collection agency, Roy Morgan Research, on the survey fieldwork is also included in the survey documentation held by the Australian Data Archive.

In addition, the Measuring Severity of Mental Disorders with the YMM Parent/Carer-reported Impact Items: Technical Report is available as part of the survey documentation accessible from the Australian Data Archive. This technical report is also available via the survey website www.youngmindsmatter.org.au.

### **CURF Data Release Protocol**

The CURF and its accompanying documentation are held by the Australian Data Archive (ADA) whose access controls and processes apply. The YMM CURF is held under sub-archive ADA Social Science on the website <u>https://www.ada.edu.au</u>. Full information regarding accessing data from the ADA is available from <u>https://www.ada.edu.au/ada/data-access</u>.

The YMM CURF has a *special restricted access condition* which requires all researchers to have obtained ethics approval for their research from their own relevant ethics body before seeking access to the YMM CURF. By agreeing to the access conditions for this CURF, researchers will be providing an undertaking to maintain respondent confidentiality by using the CURF for statistical purposes only and not attempting to identify any particular persons by matching the YMM CURF information with any other list of persons or in any other way.

### **Department of Health Publication**

The publication 'The Mental Health of Children and Adolescents: Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing' presents a summary of findings from the YMM survey at the national level.<sup>1</sup> The publication was released in 2015 and is available free of charge from the Department of Health website. An electronic version of the publication tables in spreadsheet format was released with the summary publication. The spreadsheets provide proportions and Confidence Intervals for each of the publication tables.

#### **Survey Results Query Tool**

Results from the survey can be explored further via a Survey Results Query Tool accessible through a link available via the YMM website <u>http://www.youngmindsmatter.org.au</u>. Specific tabulations are provided subject to confidentiality and sampling variability constraints.

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# APPENDIX 1 – MEMBERSHIP OF THE TECHNICAL ADVISORY GROUP

This group was convened by the then Department of Health and Ageing to assist in the preparation of the survey design parameters

Ms Suzy Saw (Chair), Department of Health and Ageing

Dr John Ainley, Australian Council of Educational Research

Dr Peter Brann, Chair, Child and Adolescent National Information Development Expert Group

Mr Bill Buckingham, Technical Adviser, Mental Health, Department of Health and Ageing

Dr Brian Graetz, Project Manager on First Survey

Dr David Lawrence, epidemiologist and statistician on First Survey

Mr Mathew Montgomery, Acting Director, Health Survey Unit, Australian Bureau of Statistics

Professor George Patton, Adolescent Health Research, Centre for Adolescent Health

Professor Michael Sawyer, Lead on First Survey

Dr James Scott, child psychiatrist and epidemiologist

Dr Tim Slade, Technical Adviser on 2007 National Survey of Mental Health and Wellbeing

Dr Titia Prague, Deputy Chair, Child and Adolescent National Information Development Expert Group

Mr Gavin Stewart, epidemiologist and mental health service planning expert

Ms Sue Thompson, Australian Council of Educational Research

Professor Steve Zubrick, Lead on First Survey

Ms Jennifer Hafekost (Secretariat)

# APPENDIX 2 – MEMBERSHIP OF THE SURVEY REFERENCE GROUP

The Department of Health ran the survey with advice from the Survey Reference Group (SRG) who provided oversight in design, content and implementation of the survey. Membership of the SRG included:

# Chairperson

Professor Harvey Whiteford, Kratzman Professor Department of Psychiatry and Population Health, University of Queensland

# **Members**

Mr Brenton Alexander, Acting Assistant Secretary, System Improvement Branch, Mental Health and Drug Treatment Division, Australian Government Department of Health

Dr Paul Balnaves, Special Adviser, Engagement and Wellbeing Group at Department of Education

Mr Keiran Booth, Chief Executive Officer, ARAFMI NSW, Carer representative

Dr Peter Brann, Director of Research and Evaluation and Senior Clinical Psychologist, Eastern Health Child and Youth Mental Health Services, Victoria

Mr Bill Buckingham, Consultant/Technical Adviser, Mental Health and Drug Treatment Division, Australian Government Department of Health

Dr Brian Graetz, General Manager, Research, Child and Youth, beyondblue

Ms Colleen Krestensen, Assistant Secretary, Drug Strategy Branch, Population Health Division, Australian Government Department of Health

Mr David Mackay, Assistant Secretary, Early Intervention and Prevention Branch, Mental Health and Drug Treatment Division, Australian Government Department of Health

Associate Professor Cathrine Mihalopoulos, Head, Mental Health Economics Stream, Deakin University

Professor George Patton, Professor of Adolescent Health Research, Royal Children's Hospital, University of Melbourne

Ms Sue Phillips, Director, Disability and Mental Health, Australian Bureau of Statistics

Dr Helen Rogers, Director, Longitudinal Study of Australian Children, Australian Government Department of Social Services

Associate Professor Lena Sanci, Deputy Head, Department of General Practice, University of Melbourne

Associate Professor James Scott, Consultant Psychiatrist, Centre for Clinical Research, University of Queensland

Associate Professor Tim Slade, National Drug and Alcohol Research Centre, University of New South Wales

Dr Titia Sprague, Associate Director, Clinical Service Development and Quality, MH-Kids, New South Wales Department of Health

Mr Gavin Stewart, Principal, Applied Epidemiology

Dr Sue Thomson, Head of Educational Monitoring and Research and Director of the National Surveys Research Program, Australian Council of Educational Research

Ms Vittoria Tonin, Manager at the Australian College of Health Service Management, Consumer Representative

## **APPENDIX 3 – ITEM LEVEL MISSING DATA**

				Re	esponse sta	tus	
			Valid	Don't Know	Refused	Skipped *	% Not stated
Section	Question number	Question					
Education	PED29C	Compared to other students in the same year, how well [does/did] CHILD do in science?	3241	41	0	3028	1.2
OCD	OCD12	Did these things start suddenly?	448	29	1	5832	6.3
SOPH	SoPh4	In the last year, has child often seemed very nervous or uncomfortable when [he/she] has been with a group of [children/young people], say like (in the lunchroom at school or) at a party?	6197	113	0	0	1.8
	SoPh6	Did [he/she] say [he/she] was nervous around other people because [he/she] felt [he/she] might embarrass [himself/herself] or make a fool of [himself/herself] in front of them?	2117	67	1	4125	3.1
	SoPh7	In the last year, did [he/she] say he was afraid that other people would notice that [he/she] was nervous when [he/she] was with them?	2151	33	1	4125	1.6
	SoPh10	When child was nervous around other people, did [he/she] often keep quiet and not say anything?	1228	23	0	5059	1.8
	SoPh11	Did [he/she] usually try to leave or get away as soon as [he/she] could?	1224	26	1	5059	2.2
	SoPh12	Did [he/she] seem uncomfortable or nervous most of the time when [he/she] [was with people [he/she] didn't know well/was with a group of people/had to do things in front of other people?	1228	21	2	5059	1.8
	SoPh13	Do you think that [he/she] seemed much more nervous around other people than [he/she] should have					
		been?	1225	25	1	5059	2.1

## Table A3-1: Young Minds Matter Parent questionnaire - variables with high rates of missing data

				Re	esponse sta	tus	
			Valid	Don't Know	Refused	Skipped *	% Not stated
	SoPh14	Now, what about the last four weeks, has CHILD almost always seemed nervous or uncomfortable when [he/she] [was with people [he/she] didn't know well/was with a group of people/had to do things in front of other people?	943	24	0	5343	2.5
	SoPh15	In the last year, did [he/she] become nervous or afraid right away when [he/she] had to [be with people [he/she] didn't know well/be with a group of people/do things in front of other people]?	943	24	0	5343	2.5
	SoPh17B	Since that first time, was there ever a time when [he/she] was not nervous around other people?	853	21	0	5436	2.4
SAD	SAD4A	Were many of these nightmares about CHILD or someone in [his/her] family getting sick or dying or getting lost or about [him/her] being stopped from being with people in [his/her] family?	1028	133	0	5149	11.5
	SAD6B	Did CHILD seem to worry about spending the night away from home more than most other [children/people [his/her] age]?	436	22	0	5852	4.8
	SAD7A	Has CHILD worried about things like that more than other [children/people [his/her] age]?	1017	117	1	5175	10.4
	SAD12B	Was that worse for [him/her] than for most other[children/people [his/her] age]?	327	21	0	5962	6.0
	SAD13	Did many of these things happen around the same time, say, within the same month?	933	21	0	5356	2.2
GAD	GAD1A	In the last year, was there a time when CHILD seemed worried even when [he/she] didn't need to, say [in a subject/about something at work] where [he/she] was well prepared and always did well?	1514	27	0	4769	1.8
	GAD1B	Did it seem like it was very hard for CHILD to stop [himself/herself] from worrying before [tests or assignments/deadlines]?	1508	33	0	4769	2.1

				Re	esponse sta	tus	
			Valid	Don't Know	Refused	Skipped *	% Not stated
	GAD5A	In the last year, was there a time when CHILD seemed to worry a lot more than other [children/people [his/her] age] that [he/she] might have a sickness?	511	24	0	5775	4.5
	GAD11	In the last year, did CHILD say that [his/her] mind sometimes started to go blank when [he/she] was worried?	747	20	0	5543	2.6
	GAD26	In the last year has CHILD often worried about whether other people liked [him/her]?	6214	96	0	0	1.5
	GAD27A	Was that when CHILD was sick, say with a cold or the flu or because of another medical problem?	995	44	0	5271	4.2
	GAD28A	Was that when CHILD was sick, say with a cold or the flu or because of another medical problem?	1140	42	0	5128	3.6
	GAD29A	Was that when CHILD was sick, say with a cold or the flu or because of another medical problem?	1211	31	0	5068	2.5
MDD	MDD60	Does CHILD seem to feel very bad or get upset if [he/she] is left out of something?	5752	91	0	467	1.6
	MDD60B	Has CHILD ever dropped a friend completely because they left [him/her] out of something?	1596	49	0	4665	3.0
ADHD	ADHD1C	How about when CHILD was other places?	835	55	0	5420	6.2
	ADHD2C	How about when CHILD was other places?	605	72	0	5633	10.6
	ADHD3	In the last year, did CHILD often dislike doing things where [he/she] had to pay attention for a long time?	5770	70	1	469	1.2
	ADHD3C	How about when CHILD was other places?	404	45	1	5860	10.2
	ADHD4C	How about when CHILD was other places?	1307	151	0	4852	10.4
	ADHD5C	How about when CHILD was other places?	1619	182	1	4508	10.2
	ADHD6C	How about when CHILD was other places?	1256	105	0	4949	7.7
	ADHD6D	In the last four weeks, has CHILD had trouble finishing things [he/she] was supposed to do?	1340	21	0	4949	1.5

			Re	esponse sta	tus	
		Valid	Don't Know	Refused	Skipped *	% Not stated
ADHD7C	How about when CHILD was other places?	1046	89	0	5175	7.8
ADHD8C	How about when CHILD was other places?	717	101	0	5492	12.
DHD9C	How about when CHILD was other places?	578	61	0	5671	9.
DHD10C	How about when CHILD was other places?	1202	139	0	4969	10.
ADHD10E	Did CHILD not listen because [he/she] had difficulty hearing?	1321	20	0	4969	1.
DHD11C	How about when CHILD was other places?	761	157	0	5392	17.
DHD12	How old was CHILD the first time [he/she] started to have trouble paying attention or concentrating?	1534	50	2	4724	3.
ADHD12_ I	What grade was CHILD in?	24	26	0	6260	52.
ADHD12B	Since that first time, was there ever a time when CHILD did not have trouble with paying attention or concentrating?	1444	42	1	4823	2.
ADHD13	How old was CHILD when trouble paying attention or concentrating started to cause problems for [him/her]?	1304	163	20	4823	12
ADHD13_ 1	What grade was CHILD in?	80	80	3	6147	50
ADHD14	Did CHILD have problems in first grade or kindergarten because [he/she] had trouble paying attention or concentrating?	1552	34	0	4724	2
ADHD22C	How about when CHILD was other places?	632	68	0		9
ADHD23C	How about when CHILD was other places?	824	122	0		12
ADHD24C	How about when CHILD was other places?	517	67	0		11
ADHD25C	How about when CHILD was other places?	495	72	0		12
ADHD26C	How about when CHILD was other places?	366	73	0		16
ADHD27C		500	, ,	0	5071	10

				Re	esponse sta	tus	
			Valid	Don't Know	Refused	Skipped *	% Not stated
	ADHD27D	In the last four weeks, has CHILD often talked a lot more than other children [his/her] age?	951	21	0	5338	2.2
	ADHD28C	How about when CHILD was other places?	560	82	0	5668	12.8
	ADHD29C	How about when CHILD was other places?	1060	247	0	5003	18.9
	ADHD30C	How about when CHILD was other places?	170	53	0	6087	23.8
	ADHD31	In the last year, did CHILD often blurt out answers before someone could finish asking the question?	6226	83	1	0	1.3
	ADHD31C	How about when CHILD was other places?	653	159	0	5498	19.6
	ADHD32C	How about when CHILD was other places?	504	87	0	5719	14.7
	ADHD33E	How about when CHILD was other places?	257	27	0	6026	9.5
	ADHD34	How old was CHILD the first time [he/she] started to be overactive?	1169	22	4	5115	2.2
	ADHD35	How old was CHILD when being overactive started to cause problems for [him/her]?	841	233	44	5192	24.8
	ADHD35_ 1	What grade was [he/she] in?	121	108	4	6077	48.1
CD	CD2	Has CHILD ever shoplifted, that is stolen something from a store when [he/she] thought no one was looking?	6242	67	1	0	1.1
	CD6	How old was CHILD the first time [he/she] [stole/shoplifted/faked someone's name]?	736	26	2	5546	3.7
	CD6_1	What grade was CHILD in?	5	21	0		80.8
	CD17	How old was CHILD the first time [he/she] lied to get something [he/she] wanted or to get out of something?	570	20	1	5600	6.4
	CD17_1	What grade was CHILD in?	572 6	38 32	1 0	5699 6272	6.4 84.2
	CD25B	Has CHILD bullied other people besides [his/her] brother or sister?	389	22	0	5899	5.4
	CD27A	Has CHILD ever started a physical fight in which someone was hurt or could have been hurt?	889	42	1	5378	4.6
ODD	ODD5B	Has CHILD done things to annoy other people besides [his/her] brother or sister or to make other people mad?	1467	34	0	4809	2.3

				Re	esponse sta	tus	
			Valid	Don't Know	Refused	Skipped *	% Not stated
	ODD9B	Has CHILD gotten angry at other people besides [his/her] brother or sister because [he/she] thought things were unfair?	1374	21	0	4915	1.5
	ODD12A	Was there a time in the last year when CHILD swore or used dirty language at least once a week?	1994	32	0	4284	1.6
	ODD13	How old was CHILD the first time [he/she] began to do these things?	1785	32	1	4492	1.8
	ODD13_1	What grade was CHILD in?	7	25	0	6278	78.1
Impact	SEV3	Anxiety/Depression - When these problems were at their worst, how much did they affect CHILD's grades or [his/her] ability to do [his/her] schoolwork?	1783	20	0	4507	1.1
		Conduct - When these problems were at their worst, how much did they affect CHILD's grades or [his/her] ability to do [his/her] schoolwork?	935	24	0	5351	2.5
		ADHD - When these problems were at their worst, how much did they affect CHILD's grades or [his/her] ability to do [his/her] schoolwork?	1871	29	1	4409	1.6
	SEV4	Anxiety/Depression - When these problems were at their worst, did these difficulties limit CHILD in participating in voluntary school activities such as leading a group, volunteering for an activity or contributing to class discussions?	1738	64	1	4507	3.6
		Conduct - When these problems were at their worst, did these difficulties limit CHILD in participating in voluntary school activities such as leading a group, volunteering for an activity or contributing to class discussions?	936	23	0	5351	2.4
		ADHD - When these problems were at their worst, did these difficulties limit CHILD in participating in voluntary school activities such as leading a group, volunteering for an activity or contributing to class discussions?	1838	63	0	4409	3.3
	SEV5	Anxiety/Depression - As a result of these difficulties, how often has CHILD been unwilling or unable to participate in extracurricular activities such as	1700	22	0	AE07	1 3
		sports, music, arts or drama activities?	1780	23	0	4507	1.3

			Re	esponse sta	tus	
		Valid	Don't Know	Refused	Skipped *	% Not stated
	ADHD - As a result of these difficulties, how often has CHILD been unwilling or unable to participate in extracurricular activities such as sports, music, arts or drama activities?	1872	29	0	4409	1.5
SEV13	Anxiety/Depression - Have these difficulties resulted in the breakup of a friendship in the previous 12 months?	661	25	0	5624	3.6
	ADHD - Have these difficulties resulted in the breakup of a friendship in the previous 12 months?	532	23	0	5755	4.1
SEV15	Anxiety/Depression - When these problems were at their worst how much difficulty did CHILD have dealing with people [he/she] didn't know well?	1881	27	0	4402	1.4
	ADHD - When these problems were at their worst how much difficulty did CHILD have dealing with people [he/she] didn't know well?	2000	26	0	4284	1.3
SEV20	Anxiety/Depression - In the last 12 months, when these problems were at their worst, did these difficulties distress CHILD or make [him/her] feel bad or upset?	1887	20	1	4402	1.1
	ADHD - In the last 12 months, when these problems were at their worst, did these difficulties distress CHILD or make [him/her] feel bad or upset?	1997	29	0	4284	1.4
SEV22	Anxiety/Depression - When these problems were at their worst, how much did these difficulties impact on CHILD's sleeping?	1880	28	0	4402	1.5
	ADHD - When these problems were at their worst, how much did these difficulties impact on CHILD's sleeping?	2004	22	0	4284	1.1
SEV7	ADHD - When these problems were at their worst, how often did CHILD have difficulties completing school work or home work on time?	1881	20	0	4409	1.1
SEV12	ADHD - In the last 12 months, when these problems were at their worst, did these difficulties cause problems					
	with CHILD's ability to make or maintain friendships?	2003	23	0	4284	1.1

				Re	esponse sta	tus	
			Valid	Don't Know	Refused	Skipped *	% Not stated
Service Use	SUP2a.1	In the past 12 months, about how many times has CHILD had individual counselling at school?	544	43	3	5720	7.8
	SUP4	In the past 12 months has CHILD used a telephone counselling service such as Kids Helpline?	6083	227	0	0	3.6
	SUP4.2	In the past 12 months has CHILD visited a headspace centre?	1461	71	0	4778	4.6
	SUP16	In the past 12 months has CHILD used the Internet to get help or information about emotional or behavioural problems that [he/she] may have?	5874	436	0	0	6.9
	SUP17a	In the past 12 months has CHILD received informal help or support for emotional or behavioural problems from his or her teacher?	6153	155	2	0	2.5
	SUP17b	In the past 12 months has CHILD received informal help or support for emotional or behavioural problems from other school staff?	6148	159	3	0	2.6
	SUP17c	In the past 12 months has CHILD received informal help or support for emotional or behavioural problems from sporting coach or other team leader?	6215	92	3	0	1.5
	SUP17d	In the past 12 months has CHILD received informal help or support for emotional or behavioural problems from religious or spiritual advisor?	6234	74	2	0	1.2
	SUP34	Do you think CHILD would have benefited from help when these problems were first identified?	643	41	0	5626	6.0
	SUP41	In the past 12 months do you think CHILD got as much help as needed?	1204	21	0	5085	1.7
Bullying	PB1	To the best of your knowledge has [CHILD] been bullied, teased or picked on to the point of distress, including in person, or via mobile phone, text message, internet or email?	6206	103	1	0	1.6
	PB1A	How often has this bullying occurred in the past 12 months?	1945	33	0		1.7
Family Inform-	PFI24D	Do you think the separation currently causes [child] distress?	1285	24	0	5001	1.8
ation	PFI7	In the last four weeks, about how often did you feel depressed?	1437			4873	77.2

			Response status				
			Valid	Don't Know	Refused	Skipped *	% Not stated
Demog- raphics	SCD2	What is the level of the highest post- school qualification that [CAREGIVER 2] has completed?	5020	69	11	1210	1.6
	SCD4	Thinking back to when [CAREGIVER 2] was in [high school/school], how would you describe [his/her] overall academic performance?	4893	150	3	1264	3.0
	HHD1	Household income before tax	5997	149	164	0	5.0

\* question skipped based on answers to previous questions

# Table A3-2: Young Minds Matter youth questionnaire - variables with high rates of missing data

				R	esponse sta	tus	
			Valid	Prefer not to say	Don't know	Skipped *	% Not stated
Section	Question number	Question	2456	202	0	311	7.6
Youth risk behav- iours	YRB34	Have you ever deliberately done something to yourself to cause harm or injury, without intending to end your own life?					
	YRB41	During the past 12 months, did you ever seriously consider attempting suicide?	2502	155	0	312	5.8
	YRB47	What is your current height?	2795	0	174	0	5.9
	YRB48	What is your current weight?	2856	0	113	0	3.8
	YRB69	Have you ever had sexual intercourse?	2158	158	0	653	6.8

\* question skipped based on answers to previous questions, or young person not in the age range for that question

## **APPENDIX 4 – RESPONSE ANALYSIS**

The overall response rate to YMM was 55%. Significant efforts were made during the fieldwork phase to maximise response rates. A minimum of six calls at each dwelling was required to make contact with householders. Once contact had been made and it had been determined that a dwelling was in-scope for the survey, a minimum of six re-contacts was required to be made to complete the interview if necessary. All interviewers were trained in gaining co-operation techniques and in refusal conversion strategies in cases where potential respondents were passively resisting.

Despite these initiatives it is acknowledged that the survey involved a significant investment of time, with an average time in the home of 75 minutes including completing the questionnaire and consent forms. Not being interested, not having enough time, or being too busy were the most commonly cited reasons why potential respondents declined to participate in the survey.

Response rates in social surveys have been declining for some time. While the first Child and Adolescent Survey of Mental Health and Wellbeing achieved a response rate of 70%, there has been a general trend in major surveys of declining participation rates since that time. The 2007 Adult component of the National Survey of Mental Health and Wellbeing, conducted by the ABS, achieved a 60% response rate.

#### Potential impact of non-response

While the survey sample has been selected at random, the final achieved sample is a combination of the random sampling involved in sample selection, and the level of participation by selected households. If households that participate in the survey are systematically different in some way from households who refuse to participate, the result could be a sample that is not truly representative of the entire population. For instance, people may choose not to participate in a survey if they are not interested in the subject matter of the survey. The potential for non-response bias is larger when the response rate is low.

While information about non-respondents is limited there are several possible ways to assess how representative the final sample is, what factors might be associated with not participating in the survey and whether there is a significant response bias. The sample was area-based, and was constructed by selecting SA1 areas on the basis of 2011 census data. Information about the selected SA1 areas from the census can be used to determine if response rates were higher or lower in areas with different characteristics. It is also possible to compare the sample of families with 4-17 year-old children collected in YMM with information about the entire population of families with 4-17 year-old children in the 2011 census. The YMM questionnaire includes some key indicator variables, such as the K10+ and the Strengths and Difficulties Questionnaire (SDQ) which have been included in other collections, which makes it possible to compare the YMM sample with the samples in other collections using these key indicators.

Non-respondents were asked if they would be willing to provide brief information about the structure of their families. This information could potentially be used to compare non-respondents with respondents in the survey. Most non-respondents were not willing to provide this basic

information, so this potential source of information about non-respondents in the survey was not able to be used in YMM.

### Comparison of YMM sample with 2011 Census of Population and Housing

There are several points of comparison between YMM and Census data. These include:

- comparing the distribution of the YMM sample with the population by SEIFA, the ABS measures of socio-economic status
- comparing the geographic distribution of the YMM sample with the population distribution
- comparing the YMM sample children with basic characteristics of the total population of 4-17 year-old children (e.g. age and sex)
- comparing the YMM sample families with demographic characteristics of families with children aged 4-17 years in the census.

#### SEIFA, Census and Young Minds Matter

A key indicator from the Census is the Socio-Economic Indicators for Areas (SEIFA) product. These indicators summarise census data at SA1 level to describe the overall socio-economic status of each SA1 area in four domains:

- an overall index of advantage and disadvantage
- an index of relative disadvantage that focuses on indicators of disadvantage including low income, unemployment, low education and sole parent families
- an index of economic resources
- an index of education and occupation.

In the 2011 Census, the geographic area of Australia was subdivided into approximately 55,000 SA1 areas which are small geographic areas with an average size around 200-250 households. Tables 1-4 compare the YMM sample with the total population of children aged 4-17 years by the four SEIFA indicators. Each indicator has been split into deciles with the lowest decile representing the greatest level of disadvantage and the highest decile representing greatest advantage.

Index of Relative Socio-economic	2011 Cens	us	Young Minds M	Young Minds Matter		
Advantage and Disadvantage - decile	Population	%	Sample size	%		
Lowest	381,557	9.9	443	7.0		
2	359,564	9.3	574	9.1		
3	363,936	9.5	667	10.6		
4	367,871	9.6	479	7.6		
5	369,590	9.6	709	11.2		
6	380,159	9.9	648	10.3		
7	383,344	10.0	667	10.6		
8	394,196	10.2	671	10.6		
9	404,888	10.5	769	12.2		
Highest	442,961	11.5	683	10.8		
Total	3,848,066	100.0	6,310	100.0		

### Table 1: SEIFA comparison of Young Minds Matter sample and total population of 4-17 yearolds from 2011 Census - Index of Relative Socio-economic Advantage and Disadvantage

## Table 2: SEIFA comparison of Young Minds Matter sample and total population of 4-17 yearolds from 2011 Census - Index of Relative Socio-economic Disadvantage

Index of Relative Socio-economic	2011 Cens	us	Young Minds Matter		
Disadvantage - decile	Population	%	Sample size	%	
Lowest	387,053	10.1	524	8.3	
2	356,561	9.3	531	8.4	
3	355,613	9.2	583	9.2	
4	360,935	9.4	597	9.5	
5	370,253	9.6	635	10.1	
6	380,626	9.9	553	8.8	
7	383,746	10.0	757	12.0	
8	400,413	10.4	679	10.8	
9	413,170	10.7	676	10.7	
Highest	439,696	11.4	775	12.3	
Total	3,848,066	100.0	6,310	100.0	

Index of Economic Resources - decile	2011 Cens	us	Young Minds Matter	
index of Economic Resources - decile	Population	%	Sample size	%
Lowest	342,668	8.9	404	6.4
2	316,948	8.2	380	6.0
3	334,887	8.7	559	8.9
4	344,764	9.0	452	7.2
5	358,703	9.3	561	8.9
6	375,209	9.8	594	9.4
7	393,644	10.2	875	13.9
8	416,122	10.8	759	12.0
9	447,099	11.6	769	12.2
Highest	518,022	13.5	957	15.2
Total	3,848,066	100.0	6,310	100.0

### Table 3: SEIFA comparison of Young Minds Matter sample and total population of 4-17 yearolds from 2011 Census - Index of Economic Resources

### Table 4: SEIFA comparison of Young Minds Matter sample and total population of 4-17 yearolds from 2011 Census - Index of Education and Occupation

Index of Education and Occupation -	2011 Censu	JS	Young Minds Matter		
decile	Population	%	Sample size	%	
Lowest	391,790	10.2	575	9.1	
2	388,811	10.1	709	11.2	
3	399,690	10.4	588	9.3	
4	404,866	10.5	755	12.0	
5	407,412	10.6	517	8.2	
6	398,743	10.4	813	12.9	
7	391,516	10.2	774	12.3	
8	385,934	10.0	674	10.7	
9	363,604	9.4	540	8.6	
Highest	315,700	8.2	365	5.8	
Total	3,848,066	100.0	6,310	100.0	

These data are also illustrated in Figures 1-4 which show the distribution of both the YMM sample and the total population of 4-17 year-old children by SEIFA scores. Table 5 shows the mean SEIFA scores for each index in the sample and in the 2011 Census.

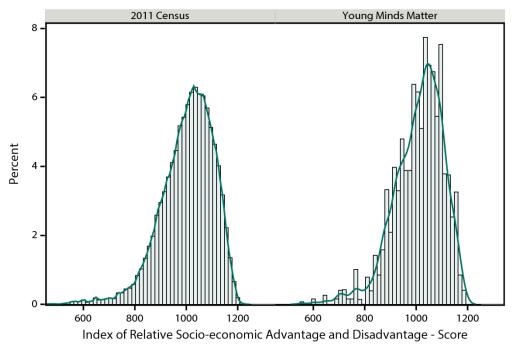
While there are some small differences between the SEIFA distributions of the sample and the population overall these differences are modest and not always consistent between indicators. For instance, while all four indicators suggest a slightly lower sample representation in the most

disadvantaged decile, the highest decile is modestly under-represented in some indexes and overrepresented in others. These data suggest that the YMM sample is strongly comparable with the full population of 4-17 year-old children in Australia, according to the SEIFA measures of socio-economic disadvantage.

## Table 5: Census of Mean SEIFA index values in the Young Minds matter sample and total population of 4-17 year-olds from 2011

SEIFA index	2011 Census	Young Minds Matter
SEIFAINGEX	Mean	Mean
Index of Relative Socio-economic Advantage and Disadvantage	1003.5	1009.7
Index of Relative Socio-economic Disadvantage	1002.7	1010.7
Index of Economic Resources	1011.9	1025.3
Index of Education and Occupation	994.9	990.9

### Figure 1: Distribution of Young Minds Matter sample, and all children aged 4-17 from 2011 Census, by SEIFA Index of Relative Socio-economic Advantage and Disadvantage



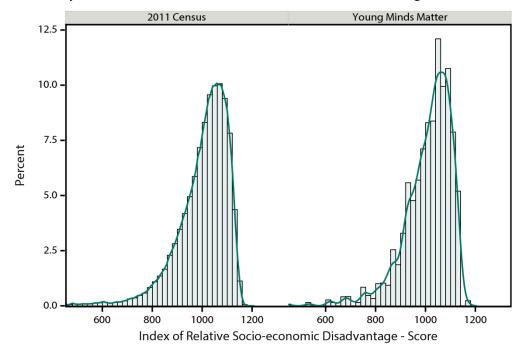
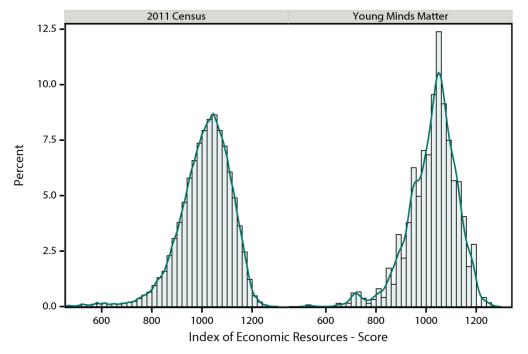
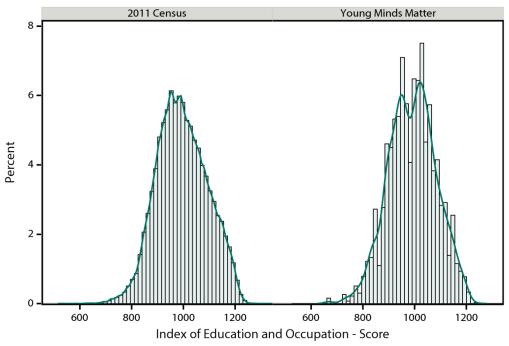


Figure 2: Distribution of Young Minds Matter sample, and all children aged 4-17 from 2011 Census, by SEIFA Index of Relative Socio-economic Disadvantage

Figure 3: Distribution of Young Minds Matter sample, and all children aged 4-17 from 2011 Census, by SEIFA Index of Economic Resources







## **Geographic distribution of YMM sample**

In the initial sample design of YMM several key decisions were taken concerning the geographic distribution of the sample:

- the main survey aim would be to produce reliable figures for Australia. Producing estimates for individual jurisdictions would not be a major aim of the study, and as a consequence the sample distribution by jurisdiction would be in proportion to the population in each jurisdiction.
- the survey would not aim to produce specific estimates for Aboriginal and/or Torres Strait Islander peoples recognising that sampling in proportion to population would yield too small a sample of Aboriginal and/or Torres Strait Islander persons to produce useful estimates, and that measuring mental health and wellbeing in Aboriginal and/or Torres Strait Islander children and young people would require a different and more culturally appropriate process, and separate study design. As a consequence Aboriginal and/or Torres Strait Islander people would be sampled in proportion to population only, except that the most remote 1% of SA1s in Australia were excluded from the sampling frame in order to reduce field costs.

61-1-	2011 Censu	IS	Young Minds Matter		
State	Population	%	Sample size	%	
New South Wales	1,232,243	32.0	1,891	30.0	
Victoria	928,610	24.1	1,590	25.2	
Queensland	814,326	21.2	1,296	20.5	
South Australia	271,827	7.1	464	7.4	
Western Australia	407,813	10.6	746	11.8	
Tasmania	89,120	2.3	164	2.6	
Northern Territory	43,825	1.1	46	0.7	
Australian Capital Territory	60,302	1.6	113	1.8	
Australia	3,848,066	100.0	6,310	100.0	

## Table 6: Young Minds Matter sample, and all children aged 4-17 from 2011 Census, by State or Territory

Table 6 shows the final distribution of the YMM sample by state. The response rate was slightly lower in New South Wales than other states. The exclusion of remote SA1s from the sampling frame has resulted in a slightly lower sample in the Northern Territory. Table 7 shows the final sample distribution in comparison to the census distribution by state and part of state. This shows that in New South Wales, the response rate was slightly lower than the national average in the Greater Sydney area, but around average in the remainder of New South Wales, and that the sample yield was as expected in the greater Darwin area, but no sample was selected in the Northern Territory outside Darwin.

Overall the differences observed are modest and within normal expectations for a random sample and possible population changes between the 2011 Census and 2013.

Cuester en ital situ aves norse	2011 Censu	JS	Young Minds Matter		
Greater capital city area name	Population	%	Sample size	%	
Greater Sydney	766,737	19.9	1,127	17.9	
Rest of New South Wales	465,506	12.1	764	12.1	
Greater Melbourne	679,256	17.7	1,197	19.0	
Rest of Victoria	249,354	6.5	393	6.2	
Greater Brisbane	382,698	9.9	601	9.5	
Rest of Queensland	431,628	11.2	695	11.0	
Greater Adelaide	204,989	5.3	315	5.0	
Rest of South Australia	66,838	1.7	149	2.4	
Greater Perth	309,959	8.1	602	9.5	
Rest of Western Australia	97,854	2.5	144	2.3	
Greater Hobart	37,173	1.0	43	0.7	
Rest of Tasmania	51,947	1.3	121	1.9	
Greater Darwin	22,923	0.6	46	0.7	
Rest of Northern Territory	20,902	0.5		•	
Australian Capital Territory	60,302	1.6	113	1.8	
Australia	3,848,066	100.0	6,310	100.0	

Table 7: Young Minds Matter sample, and all children aged 4-17 from 2011 Census, by State or Territory and part of state

Table 8 shows the distribution of the YMM sample by levels of remoteness. Because of the exclusion of the 1% most remote SA1s from the sampling frame, Remote Australia and Very Remote Australia have been combined. A higher response rate was achieved in areas in Inner Regional Australia than other levels of remoteness. Table 9 shows the final sample distribution by region, and the sample breakdown by metropolitan/ex-metropolitan is as expected.

# Table 8: Young Minds Matter sample, and all children aged 4-17 from 2011 Census, by level of remoteness

	2011 Cens	us	Young Minds Matter		
ABS Remoteness areas	Population	%	Sample size	%	
Major Cities of Australia	2,603,493	67.7	4,134	65.5	
Inner Regional Australia	748,115	19.4	1,554	24.6	
Outer Regional Australia	391,934	10.2	516	8.2	
Remote Australia or Very Remote Australia	104,524	2.7	106	1.7	
Australia	3,848,066	100.0	6,310	100.0	

Region	2011 Census	S	Young Minds Matter	
	Population	%	Sample size	%
Metropolitan	2,464,037	64.0	4,044	64.1
Non-metropolitan	1,384,029	36.0	2,266	35.9
Australia	3,848,066	100.0	6,310	100.0

#### Table 9: Young Minds Matter sample, and all children aged 4-17 from 2011 Census, by region

## **Comparison of YMM children with population distribution in 2011 census**

To compare the YMM sample to the Australian population, a series of special tabulations from the 2011 Census of Population and Housing were obtained from the Australian Bureau of Statistics (ABS). While the Census is a complete enumeration and no sampling error is involved, there are field and processing issues with Census data that may impact on its comparability with survey data.

Family characteristics are only provided by ABS on a Place of Enumeration basis. While there are questions on the census form to record any children who usually live in a dwelling but are not present on census night, these children are not included in cross tabulations based on characteristics of that family. Children who were temporarily away from home on census night, or children living in families where insufficient information was provided on the census form to enable family relationship coding are excluded from census tables based on family characteristics, as are children who are living in non-private dwellings on census night. Based on these exclusions 307,402 children aged 4-17 years (out of a total census population of 3,882,788 children) were excluded from the census tabulations used in this analysis.

The final YMM sample of 6,310 children included 5,508 children selected in the main sample, and an addition 802 young people selected in the oversample of 16-17 year-olds. For the purpose of examining the age distribution of the sample, only the 5,508 families in the main sample were included.

Table 10 shows the distribution of the YMM sample by single year of age, also illustrated in Figure 5. It can be clearly seen that the YMM sample includes a higher proportion of children aged 4-7 years than would be expected based on random sampling. This phenomenon has been observed repeatedly in social surveys. It occurred in the first Child and Adolescent Survey of Mental Health and Wellbeing, and the 1993 WA Child Health Survey and the WA Aboriginal Child Health Survey. One possible explanation for this phenomenon is that families with younger children have a lower rate of workforce participation. It is more likely that these families will have at least one carer who is not employed or employed only part-time. This appears to be associated with both ability to make contact with these families, and ability or willingness to make time available to participate in social surveys.

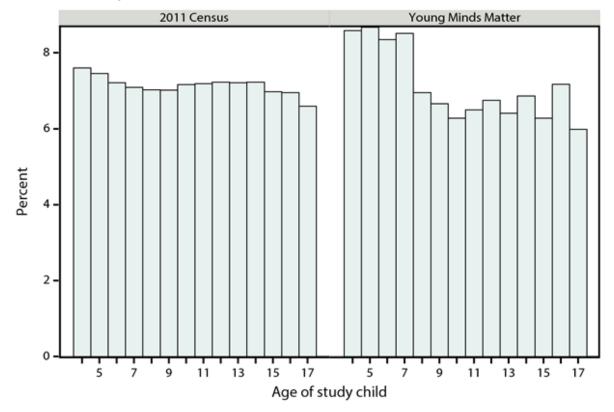
As seen in Table 11, the YMM sample is proportionally representative of both sexes.

Are of shild	2011 Census		Young Minds Matter		
Age of child	Population	Per cent	Sample size	Per cent	
4	271,840	7.6	473	8.6	
5	266,846	7.5	478	8.7	
6	258,050	7.2	460	8.4	
7	253,745	7.1	469	8.5	
8	251,354	7.0	383	7.0	
9	251,091	7.0	367	6.7	
10	256,324	7.2	346	6.3	
11	257,227	7.2	358	6.5	
12	258,438	7.2	372	6.8	
13	257,853	7.2	353	6.4	
14	258,567	7.2	378	6.9	
15	249,492	7.0	346	6.3	
16	248,732	7.0	395	7.2	
17	235,825	6.6	330	6.0	
Total	3,575,384	100.0	5,508	100.0	

Table 10: Number of children aged 4-17 years, Census compared with Young Minds Matter
main sample, by age of child

## Table 11: Number of children aged 4-17 years, 2011 Census compared with Young Minds Matter sample, by sex

Sov	2011 Census		YMM Main Sample		YMM Main + oversample	
Sex	Population	Per cent	Sample size	Per cent	Sample size	Per cent
Males	1,837,747	51.4	2840	51.6	3260	51.7
Females	1,738,097	48.6	2668	48.4	3050	48.3
Persons	3,575,384	100.0	5508	100.0	6310	100.0



### Figure 5: Number of children aged 4-17 years, 2011 Census compared with Young Minds Matter main sample

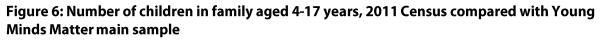
Another phenomenon that has been observed consistently in surveys such as the 1993 WA Child Health Survey and the WA Aboriginal Child Health Survey is that participation has been higher in families with larger numbers of children. In particular families with only one eligible child are less likely to participate in surveys about child health. Table 12 and Figure 6 show the distribution of the Census population and the YMM main sample by number of children aged 4-17 in the household. The survey sample under-represents children from families with only one eligible child. Again, one possible explanation for this observation may be related to labour force participation, with families with multiple children more likely to have a carer not working or working part-time and thus greater availability to be contacted and participate in surveys.

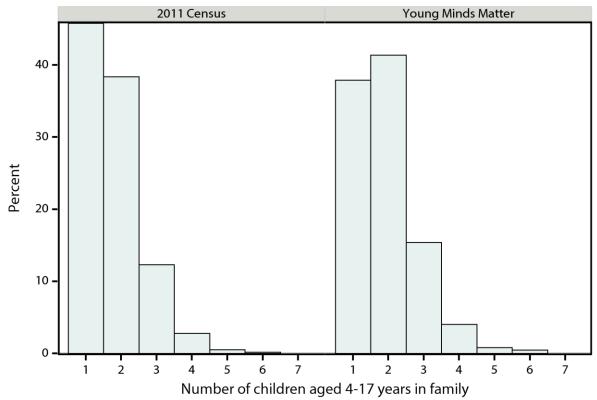
Number of children aged 4-17 years in family	2011 Censo	JS	Young Minds Matter		
	Population	Per cent	Sample size	Per cent	
1	938,328	45.8	2,088	37.9	
2	786,158	38.4	2,279	41.4	
3	252,511	12.3	848	15.4	
4	57,016	2.8	223	4.0	
5	10,913	0.5	44	0.8	
6	3,846	0.2	26	0.5	
Total	2,048,772	100.0	5,508	100.0	

 Table 12: Number of children in family aged 4-17 years, 2011 Census compared with Young

 Minds Matter main sample

The YMM sample data has been weighted to adjust for differences in the age profile and number of eligible children in the household.





## Demographic characteristics of families with children aged 4-17 years

A series of custom data extracts from the 2011 Census were commissioned from the ABS. The YMM questionnaire included several demographic variables designed to be as close as possible to census

variables. However, because of key differences in the 2011 Census and the YMM survey there are several factors that need to be considered in comparing Census data and the YMM survey sample:

- The Census, being self-report, has considerably more missing data for most demographic variables than YMM.
- The Census and YMM take a different approach to identifying carers of children. The Census identifies a household reference person, and the relationship of other family members to that reference person. In YMM, a primary carer has been identified as the person who knows most about the selected survey child. Often the Census reference person is male, while in YMM a greater proportion of primary carers are female.
- The Census collection is based primarily on place of enumeration. Where the primary carer or partner is away from home on Census night, they are not coded back to the family. These families are coded as "partner not present" in the Census tables, and it is not possible to extract from the Census data demographic information about carers away from home on Census night.

In comparing Census and YMM data by demographics of carers, Census records where the demographic information is missing or the partner is not present on Census night have been excluded. This leads to some differences in the proportion of sole and two parent families based on Census data when looking at additional demographics of the carers. This also means that the total population numbers vary between Census tables depending on the amount of missing data that was excluded from each table.

#### Family type

The ABS derives a family type variable, called "family blending" based on relationships to the primary reference person in each household. The Household Record Form in YMM included a relationship grid that recorded the relationship between every possible pair of individuals in each household. To compare family structure between the Census and YMM, the same coding rules have been applied to the YMM relationship grid data that the ABS uses to derive their family blending variable.

Comparison of the YMM sample to all children aged 4-17 years in the Census by family type is shown in Table 13. The YMM sample is comparable with the Census population by family structure.

Matter					
Family type	2011 Cens	us	Young Minds Matter		
Family type	Population	Per cent	Sample size	Per cent	
Original family	2,445,992	68.4	4,360	69.1	
Step family	157,829	4.4	235	3.7	
Blended family	189,246	5.3	360	5.7	
Other family	14,240	0.4	19	0.3	
Sole parent family	766,575	21.4	1,336	21.2	
Total	3,573,882	100.0	6,310	100.0	

#### Table 13: Number of children 4-17 years by family blending, Census and Young Minds Matter

Table 13 shows that 21.4% of children aged 4-17 years were living in sole parent families. It should be noted that in some of the later tables in this analysis, the proportion of sole parent families from the Census data appears different from this figure. This is due to the exclusion of families where demographic information about the carers was missing in the Census data or of the household reference person's partner was away from home on Census night in the later tables. In so far as it includes the greatest number of children enumerated in the Census, table 13 is the most representative table of family structure as derived from the 2011 Census data.

#### **Household income**

Household income is generally regarded as a sensitive variable to collect in any survey, and has one of the highest rates of respondents not being willing to answer an individual question. Approximately 4.7% of the YMM main sample declined to provide or did not know their household income in YMM. In comparison around 12% of families with 4-17 year-old children did not provide their household income in the 2011 Census. As the Census is compulsory but YMM was a voluntary survey, it is possible that people who would not provide their income in a census or survey were less likely to participate in YMM.

Table 14 shows the comparison of the household income distribution from YMM with the 2011 Census figures, after excluding families from either collection where household income was not stated.

Overall, the YMM sample is broadly representative in its income distribution, although there is a slightly lower number of families in the YMM sample in the bottom income category, and a slightly higher number in the top income category. This is consistent with the SEIFA comparison which also showed strong comparability between YMM and the SEIFA indicators.

	2011 Cer	nsus	Young Minds Matter		
Household income before tax	Population	Per cent	Sample size	Per cent	
Nil income/Negative income (loss)	26,777	0.9	15	0.3	
\$52-\$20,799 per year (\$1-\$399 per week)	148,359	4.7	190	3.6	
\$20,800-\$31,199 per year (\$400-\$599 per week)	221,015	7.0	388	7.4	
\$31,200-\$41,599 per year (\$600-\$799 per week)	248,661	7.9	374	7.1	
\$41,600-\$51,999 per year (\$800-\$999 per week)	230,794	7.3	328	6.3	
\$52,000-\$64,999 per year (\$1,000-\$1,249 per week)	285,686	9.1	410	7.8	
\$65,000-\$77,999 per year (\$1,250-\$1,499 per week)	286,059	9.1	463	8.8	
\$78,000-\$103,999 per year (\$1,500-\$1,999 per week)	497,077	15.8	895	17.1	
\$104,000-\$129,999 per year (\$2,000-\$2,499 per week)	365,278	11.6	703	13.4	
\$130,000-\$155,999 per year (\$2,500-\$2,999 per week)	367,214	11.7	568	10.8	
\$156,000-\$208,799 per year (\$3,000-\$3,999 per week)	328,493	10.4	541	10.3	
\$208,800 or more per year (\$4,000 or more per week)	138,580	4.4	373	7.1	
Total	3,143,993	100.0	5,248	100.0	

## Table 14: Household income, 2011 Census (number of children) and Young Minds Matter Main Sample<sup>1</sup>

1 Excluding income not stated or unknown

#### **Country of birth**

Table 15 compares country of birth of carers of children aged 4-17 years between the 2011 Census and YMM. Because of differences in the methodology for assigning the primary carer (in YMM) or the household reference person (in the Census) these Census comparison tables do not attempt to distinguish between primary and secondary carers.

The data in Table 15 suggest the YMM sample is broadly representative of families with carers born in Australia or overseas. There is a slightly higher proportion of Australian-born carers in sole parent families in YMM compared with the Census data.

		201	1 Census		Young N	/linds Matt	er
		Population	% overall	% within family type	Sample size	% overall	% within family type
Number of carers	Country of birth						
Two carers	Both born in Australia	846,980	43.9	57.7	2,546	46.2	58.5
	One born in Australia, One born						
	overseas	267,171	13.8	18.2	803	14.6	18.5
	Both born overseas	352,942	18.3	24.1	1,002	18.2	23.0
	Total	1,467,093	76.0	100.0	4,351	79.0	100.0
Sole	Country of birth						
carer	Born in Australia	347,164	18.0	74.9	908	16.5	78.5
	Born overseas	116,468	6.0	25.1	249	4.5	21.5
	Total	463,632	24.0	100.0	1,157	21.0	100.0

## Table 15: Country of birth of carers, 2011 Census and Young Minds Matter

#### Labour force status

Table 16 compares reported labour force status for carers in the survey with the 2011 Census data. For families with two carers, the results are broadly comparable. For families with a sole carer, the YMM sample shows a slightly higher proportion of unemployed carers compared with the Census data. Again this issue may be related to availability of a sole carer to participate in the survey.

		20	011 Census		Young	g Minds Ma	tter
		Population	% overall	% within family type	Sample size	% overall	% within family type
Number of carers	Labour force status						
	Both employed full- time	333,336	17.5	24.3	1,098	19.9	25.2
	1 employed full-time, 1 employed part-time	508,858	26.7	37.1	1,708	31.0	39.3
	Both employed part- time	55,906	2.9	4.1	145	2.6	3.3
	1 employed full-time, 1 unemployed	37,935	2.0	2.8	174	3.2	4.0
	1 employed part-time, 1 unemployed	12,564	0.7	0.9	41	0.7	0.9
Two carers	Both unemployed	5,956	0.3	0.4	14	0.3	0.3
	1 employed full-time, 1 not in labour force	286,833	15.0	20.9	879	16.0	20.2
	1 employed part-time, 1 not in labour force	56,264	3.0	4.1	151	2.7	3.5
	1 unemployed, 1 not in labour force	16,324	0.9	1.2	59	1.1	1.4
	Both not in labour force	58,433	3.1	4.3	82	1.5	1.9
	Total	1,372,409	72.0	100.0	4,351	79.0	100.0
	Labour force status						
	Employed full-time	166,270	8.7	31.2	348	6.3	30.1
Sole carer	Employed part-time	160,059	8.4	30.0	343	6.2	29.6
	Unemployed	36,374	1.9	6.8	124	2.3	10.7
	Not in labour force	170,766	9.0	32.0	342	6.2	29.6
	Total	533,469	28.0	100.0	1,157	21.0	100.0

## Table 16: Labour force status primary and secondary carers, 2011 Census and Young Minds Matter

#### **Dwelling tenure**

Table 17 compares dwelling tenure between the YMM sample and the Census. The distributions are broadly comparable.

	2011 Censu	5	Young Minds Matter		
Housing tenure	Population	%	Sample size	%	
Owned outright	519,219	14.8	670	12.2	
Owned with a mortgage	1,931,421	55.0	3,035	55.1	
Rented - real estate agent	594,275	16.9	1,107	20.1	
Rented - public housing	154,680	4.4	215	3.9	
Rented - other	296,250	8.4	389	7.1	
Other	13,667	0.4	92	1.7	
Total	3,509,512	100.0	5,508	100.0	

#### Table 17: Dwelling tenure, 2011 Census and Young Minds Matter

#### Comparison of key indicators with other surveys

Comparisons with 2011 Census data shown above suggest that the YMM sample is broadly representative of the overall Australian population in terms of major demographic characteristics. Key factors that have been found to be associated with response rates in the survey, such as age of child and number of children living in the household, have been incorporated in the weighting strategy to ensure that the survey results are as representative of the Australian population as possible.

Another possible question relating to participation in the survey is whether the survey topic is associated with participation rates. Are families with experience of mental health problems more likely to volunteer for the survey because the topic of the survey is more relevant to them? While this question cannot be directly answered, as we lack information about the mental health status of the non-respondents, key indicators of mental health and wellbeing used in YMM can be compared with other major collections.

#### **Strengths and Difficulties Questionnaire**

The Strengths and Difficulties Questionnaire (SDQ) was included in YMM under licence from its developer, Professor Robert Goodman of the Institute for Psychiatry in London. Professor Goodman originally designed the cut-off scores for the SDQ specifically with intent that the top 10% of scores would be designated as the abnormal range.

The SDQ was also included in the British Child and Adolescent Mental Health Survey (BCAMHS), which has been run twice in 1999 and 2004. Great Britain is the only other country besides Australia that has undertaken a national survey of child and adolescent mental health. The United States conducted a national survey of adolescent mental health in 2004 (The National Comorbidity Survey—Adolescent Supplement or NCS-A).

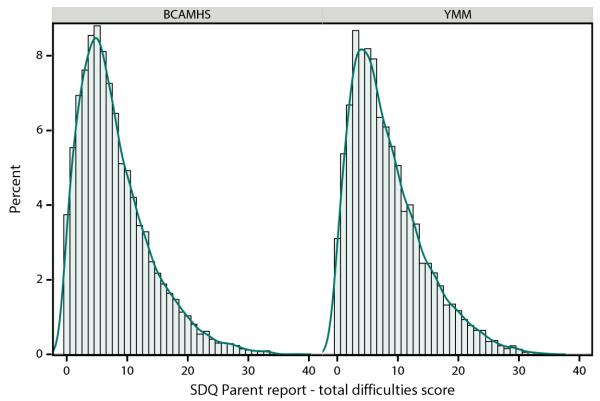
The 2004 BCAMHS covered the age range 5-16 years. Table 20 shows the estimated proportion of children in the normal, borderline and abnormal ranges on the SDQ by age group and sex in the BCAMHS from 2004 and in YMM. There are potentially many reasons why the mental health of children and young people in Great Britain in 2004 may well be different from Australia in 2013. Nonetheless, the similarity of the prevalence estimates between the two surveys, and the fact that the overall prevalence of abnormal SDQ scores was estimated to be 10.1% in YMM, and by design was scaled to be 10% of the original normative British population, give some reassurance that the YMM sample is not significantly skewed in terms of overall level of mental health distress.

5 - 10 years Females Bo Ab Persons Bo Ab No Persons Bo Ab		BCAMHS		YMM	
Age group child lev No Males Bo Ab S - 10 years Females Bo Ab Persons Bo Ab No No		Per cent	95% CI	Per cent	95% CI
5 - 10 years Females Bo Ab 5 - 10 years Females Bo Ab Persons Bo Ab No	)Q total score - vels	79.7	(77.9 - 81.5)	78.7	(76.3 - 81.1)
5 - 10 years Females Bo Ab Persons Bo Ab No	ormal				
5 - 10 years Females Bo Ab Persons Bo Ab No	orderline	7.6	(6.5 - 8.8)	8.9	(7.2 - 10.6)
5 - 10 years Females Bo Ab Persons Bo Ab No	onormal	12.7	(11.2 - 14.2)	12.3	(10.3 - 14.4)
Ab No Persons Bo Ab No	ormal	86.9	(85.4 - 88.5)	85.8	(83.7 - 87.9)
No Persons Bo Ab No	orderline	6.6	(5.4 - 7.7)	5.7	(4.3 - 7.1)
Persons Bo Ab No	onormal	6.5	(5.3 - 7.6)	8.5	(6.8 - 10.2)
Ab No	ormal	83.2	(82.0 - 84.4)	82.2	(80.6 - 83.9)
No	orderline	7.1	(6.3 - 7.9)	7.3	(6.2 - 8.4)
	onormal	9.7	(8.7 - 10.6)	10.4	(9.1 - 11.8)
Malas Pa	ormal	83.2	(81.6 - 84.9)	80.6	(78.3 - 82.9)
Males DO	orderline	6.3	(5.3 - 7.4)	6.6	(5.1 - 8.0)
Ab	onormal	10.4	(9.1 - 11.8)	12.9	(10.8 - 14.9)
No	ormal	87.2	(85.7 - 88.7)	85.5	(83.3 - 87.7)
11 - 16 years Females Bo	orderline	5.3	(4.3 - 6.3)	6.7	(5.2 - 8.3)
Ab	onormal	7.5	(6.3 - 8.7)	7.8	(6.1 - 9.4)
No	ormal	85.2	(84.1 - 86.3)	82.9	(81.3 - 84.6)
Persons Bo	orderline	5.8	(5.1 - 6.6)	6.6	(5.6 - 7.7)
Ab	onormal	9.0	(8.1 - 9.9)	10.4	(9.1 - 11.8)
No	ormal	81.5	(80.3 - 82.7)	80.4	(78.7 - 82.0)
Males Bo	orderline	7.0	(6.2 - 7.8)	7.6	(6.5 - 8.6)
Ab	onormal	11.5	(10.5 - 12.5)	12.0	(10.7 - 13.4)
5 - 16 years No	ormal	87.1	(86.0 - 88.2)	85.8	(84.4 - 87.2)
Females Bo	orderline	5.9	(5.2 - 6.7)	6.2	(5.3 - 7.2)
Ab	onormal	7.0	(6.2 - 7.8)	8.0	(6.9 - 9.1)
Persons No	ormal	84.2	(83.4 - 85.0)	83.0	(81.9 - 84.1)

#### Table 20: Parent or carer reported SDQ, by age group and sex, BCAMHS and Young Minds Matter

	BCA	MHS	YI	MM
	Per cent	95% CI	Per cent	95% CI
Borderline	6.5	(5.9 - 7.0)	6.9	(6.2 - 7.6)
Abnormal	9.3	(8.7 - 10.0)	10.1	(9.2 - 11.0)





#### Kessler 10 - Non-specific psychological distress

The Kessler 10 measure of non-specific psychological distress was included for the primary carer in YMM<sup>13</sup>. As noted above, due to a questionnaire programming error one of the K10 items was missed for a large part of the sample. However, the missing data item was imputed with a high degree of accuracy, and as a result the K10 data from the survey provides a strong indicator of the primary carer's level of psychological distress.

The K10 is used as an indicator of general mental health distress in a number of collections. Table 21 compares K10 outcomes between the primary carers in YMM, with data for all adults taken from the 2007-08 National Health Survey (NHS), and data for adults living in households with at least one child aged under 18 years in the 2007 National Survey of Mental Health and Wellbeing (NSMHWB). These are imperfect comparisons. Not all adults in the NHS will be carers of children let alone primary carers of children. However the NHS is a compulsory ABS survey and achieved a response rate of around 90% in 2007-08. Similarly not all adults living in households with children in the 2007 NSMHWB will be primary carers of those children. Nonetheless this comparison suggests that the levels of non-specific psychological distress in YMM primary carers are comparable with the general adult population in Australia.

Table 21: K10 Level of non-specific psychological distress, primary carers in Young Minds Matter, adults in the 2007-08 Australian National Health Survey, adults living with one or more children aged under 18 years in the 2007 Australian National Survey of Mental Health and Wellbeing

	Primary carers in YMM	Adults in 2007-08 NHS	Adults living with children in 2007 NSMHWB
Low	70.2%	67%	72.2%
Moderate	18.2%	21%	18.3%
High	8.0%	9%	6.7%
Very High	3.4%	4%	2.9%

## Modelling response rates by area level characteristics

Another approach to assessing the possibility of response bias in the survey is to examine whether response rates varied by area, and if so if there was any relationship between any characteristics of individual areas and participation rates in the survey.

The main survey sample of 5,508 participating families was generated from an original sample of over 500 SA1 areas. The response rate in each of these SA1 areas was calculated, and regression modelling was used to test if the SA1 level response rate was associated with any area characteristics. These included state, part of state, remoteness, each of the SEIFA indicators, and a number of Census measures derived at the SA1 level including number of younger and older children in each SA1, proportion of overseas born, proportion of people speaking languages other than English, proportion with limited proficiency in English, proportion of sole parent families, proportion of families with low household income, highest level of schooling completed, and proportion of households living in rented accommodation.

Of all the factors considered, only one was found to be significantly associated with response rate in the survey. It was identified that the response rate was higher in areas classified as "inner regional Australia" in the ABS Remoteness classification compared with major cities. This finding was consistent with the comparison of the YMM sample with Census characteristics shown above.

### Participation in the youth self-report questionnaire

Another important aspect of the overall response rate to the survey is the participation in the youth questionnaire. For all families where the selected child was aged 11 years or over, consent was sought from the primary carer and from the young person for the young person to complete a separate questionnaire on a tablet computer. Traditionally, obtaining responses from young people to survey questionnaires is difficult and this has been an area of low participation rates in previous surveys.

In the YMM main sample, of all participating families where the selected child was 11 years or older, the young person completed the youth questionnaire in 89% of cases. This is a very high rate of

participation in this type of questionnaire in an age group where obtaining study participation is traditionally difficult.

In past surveys there has always been the concern that the young people with the greatest problems are the ones least likely to participate in the youth component of a survey. This is less likely to cause any significant response bias when the overall response rate was so high for this component of the survey.

Because parent or carer report data is available for all young people selected in the survey, there is a large amount of information about families where the young person has and has not completed the youth questionnaire. Table 22 shows response rates in the youth questionnaire by a range of characteristics of the family and the young person, as reported by the parent or carer.

The overall participation rate in the youth questionnaire was 89% and did not fall below 80% for any category examined. Participation rate was constant by age, sex, geographic region, socio-economic status, and country of birth. Response rates were equal in each category of household income except in those families where the primary carer refused to provide the household income. In these families youth participation was lower. The major difference in youth response rates was by parent or carer reported SDQ total score, with the response rate only 82% in young people in the abnormal range on the parent or carer report.

These data suggest that there was a small tendency for young people with higher degree of mental health distress to have a lower response rate in the youth questionnaire. As the deviations in response rates are relatively minor and the overall response rate is high, it is not anticipated that this will have a major impact on the representativeness of results derived from the youth sample. The youth sample data was weighted to adjust for differences in these key characteristics.

	Youth participated?				
	No		Yes	\$	
	Number	Per cent	Number	Per cent	
Sex of study child—					
Male	201	11.6	1533	88.4	
Female	164	10.3	1435	89.7	
Age of study child—					
11	46	12.9	311	87.1	
12	31	8.4	340	91.6	
13	43	12.1	311	87.9	
14	34	9.1	341	90.9	
15	37	10.6	312	89.4	
16	87	10.8	718	89.2	
17	87	12.0	635	88.0	
Region—					
Metropolitan	220	10.4	1895	89.6	

## Table 22: Participation rate in the youth self-report questionnaire, by selected characteristics of the family and young person

	Yo	outh par	ticipated?	
	No		Yes	;
	Number	Per cent	Number	Per cent
Non-metropolitan	145	11.9	1073	88.
Index of Relative Socio-economic Advantage and Disadvantage -	115	11.5	10/5	00.
Quintile—				
Lowest quintile (most disadvantaged)	62	12.0	454	88.
Second quintile	55	9.2	541	90.
Third quintile	82	11.7	620	88.
Fourth quintile	74	10.2	651	89.
Highest quintile (most advantaged)	92	11.6	702	88.
Study child - Country of birth—				
Australia	313	10.9	2554	89.
Overseas	52	11.2	414	88.
Equivalised annual household income—				
Less than \$27,999 per year	120	12.0	879	88.
\$28,000-\$49,999 per year	97	9.4	938	90.
\$50,000 or more per year	113	10.1	1006	89.
Not stated	35	19.4	145	80.
External condition of dwelling—				
Immaculate	65	9.7	607	90.
Well-kept and clean, in good repair	212	10.9	1730	89.
Fair condition	71	11.4	554	88.
Poor condition and in need of repair	13	16.0	68	84.
Family type—				
Original family	230	10.8	1903	89.
Step family	12	7.6	145	92.
Blended family	23	11.6	176	88.
Other family	2	14.3	12	85.
Sole parent family	98	11.8	732	88.
Family Functioning—				
Very good	188	10.1	1681	89.
Good	99	11.6	753	88.
Fair	58	12.5	405	87.
Poor	20	13.4	129	86.
SDQ parent or carer report - total difficulties—				
Normal	277	10.0	2489	90.
Borderline	27	11.9	200	88.
Abnormal	61	17.9	279	82.
SDQ parent or carer report - peer relations subscale—				
Normal	268	10.7	2233	89.
Borderline	34	9.8	312	90.
Abnormal	63	13.0	423	87.
SDQ parent or carer report - emotional problems subscale—	264	10.5	2242	89.

	Youth participated?			
	No		Yes	5
		Per		Per
	Number	cent	Number	cent
Normal				
Borderline	22	8.2	245	91.8
Abnormal	79	14.1	481	85.9
SDQ parent or carer report - hyperactivity subscale—				
Normal	288	10.4	2489	89.0
Borderline	23	11.1	185	88.9
Abnormal	54	15.5	294	84.
SDQ parent or carer report - conduct problems subscale—				
Normal	283	10.1	2522	89.
Borderline	31	14.4	184	85.0
Abnormal	51	16.3	262	83.
SDQ impact scale - parent or carer report—				
Normal	268	10.6	2256	89.4
Borderline	17	8.0	195	92.
Abnormal	80	13.4	517	86.
Child ever diagnosed with a mental health problem by a doctor or other health professional—				
No	277	10.2	2435	89.8
Yes	88	14.2	533	85.
Parent or carer DISC - Any Anxiety Disorder - Last year - Diagnosis—				
No	328	10.8	2711	89.
Yes	37	12.6	257	87.
Parent or carer DISC - Major depressive disorder - Last year - Diagnosis—				
No	349	11.1	2809	88.
Yes	16	9.1	159	90.9
Parent or carer DISC - Any Behavioural Disorder - Last year -		211		
Diagnosis—				
No	326	10.6	2736	89.4
Yes	39	14.4	232	85.0
Parent or carer DISC - any DISC Disorder - Last year - Diagnosis—				
No	295	10.7	2471	89.
Yes	70	12.3	497	87.
Parent or carer DISC - number of DISC disorders - Last year—				
	295	10.7	2471	89.
1	46	12.3	328	87.
2	14	12.3		87.
3	7	14.0		86.0
4 or more	3	14.0	43 26	89.7
Total	365	10.5		89. 89.(