Hazelwood Health Study

Recruitment Report 2

1 November 2014 – 16 March 2017

Contents

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Abbreviations

ABS	Australian Bureau Of Statistics
ACD	Australian Cancer Database
AIHW	Australian Institute of Health and Welfare
AV	Ambulance Victoria
CATI	Computer-Assisted Telephone Interview
CAWI	Computer-Assisted Web Interview
CO	Carbon Monoxide
CSIRO	Commonwealth Scientific and Industrial Research Organisation
DHHS	Victorian Department of Health and Human Services
DHS	Australian Government Department of Human Services
ELF	Latrobe Early Life Follow up Study research stream
GP	General Medical Practitioner
HACC	Home and Community Care
HHS	Hazelwood Health Study
HREC	Human Research Ethics Committee
HRF	Hunter Research Foundation
MBS	Medicare Benefits Schedule
NAPLAN	National Assessment Program –Literacy and Numeracy
NDI	National Death Index
NMD	National Mortality Database
PBS	Pharmaceutical Benefits Scheme
$PM_{2.5}$	Fine airborne particles smaller than 2.5 μm diameter
SA1	Statistical area level 1 based on Australian Statistical Geography
SA2	Statistical area level 2 based on Australian Statistical Geography
SEIFA	Socio-Economic Indexes for Areas
SF12	12-item Short Form Health Survey
μm	Micrometre = one millionth of a metre (thousandth of a millimetre)
VACAR	Victorian Ambulance Cardiac Arrest Registry
VACIS	Victorian Ambulance Clinical Integration System
VAED	Victorian Admitted Episodes Dataset

VCR	Victorian Cancer Registry
VEC	Victorian Electoral Commission
VEMD	Victorian Emergency Minimum Dataset

1 Executive Summary

This Recruitment Report details progress that has been made in regard to data collection for the various streams of the Hazelwood Health Study since the project plan was submitted in December 2014 until 16 March 2016.

Adult Survey

The Adult Survey aims to investigate the self-reported health of adults who lived in Morwell at the time of the fire (exposed group) compared with those who lived in Sale (comparison group). The Adult Survey will also measure long term health outcomes across the wider Latrobe Valley by linking to administrative datasets. Air pollution estimates provided by CSIRO will be incorporated to investigate associations between exposure levels and risk of long term health outcomes.

The Adult Survey commenced recruitment in May 2016 after protracted negotiations to obtain a nominal roll of eligible adults from the Victorian Electoral Commission. Diverse strategies were employed to engage with the eligible cohort and to address obstacles to participation. These included personalised mail, gift vouchers, information flyers and posters, media releases, radio and print advertising and free public events. Recruitment closed, a little later than planned in February 2017 with 3,073 (33%) participants from Morwell and 954 (23%) participants from Sale. The majority (56%) of the eligible cohort did not respond to repeated contact attempts.

Preliminary analyses to assess sampling bias indicate that women, older people and those who lived closest to the fire, might be over represented amongst the Adult Survey participants. Further assessment of sampling bias will inform the final analysis plan.

Custodian approval has been obtained to access identified ambulance, hospital, cancer and mortality data based on verbal or online consent. Medicare required hard-copy written consent for identified linkage, however this was not considered feasible for the Adult Survey. About 70% of the Adult Survey participants consented to identified linkage, however these data require cleaning before accurate numbers can be finalised and linked data requested.

Air pollution estimates have been received from CSIRO.

The Latrobe Early Life Follow up (ELF) stream

The Latrobe ELF stream aims to investigate the potential impacts of exposure to smoke from the coal mine fire during pregnancy or infancy on subsequent health and development of children in the Latrobe Valley. This is being achieved through a survey of an identified cohort of

eligible infants from the Latrobe Valley, a state-wide de-identified data extraction of Victorian perinatal data and an anonymised data linkage study.

Recruitment into the ELF identified cohort survey was conducted between March 2016 and February 2017. This stream successfully recruited 548 infants, exceeding expectations, and achieved a good balance across exposure groups and geographical regions. A sub-study, involving completion of monthly health diaries is being undertaken by 286 families, with a high proportion (70%) of the diaries being regularly submitted.

Data custodian approval has been obtained for identified linkage to Victorian perinatal data, hospital, Medicare, early development and educational databases however the researchers are still following up missing hard copy consent forms from survey participants.

The proposed analysis plan is unchanged for the survey, health diary and data linkages components of ELF. However the planned analysis of Victorian perinatal data is delayed because the researchers are still awaiting the data.

Recruitment in to a 2017 sub-study involving clinical testing of cardiovascular and lung development is underway.

Schools Study

The Schools Study is the child component of the Psychological Impacts stream which aims to determine whether exposure to smoke from the mine fire is associated with psychological trauma and distress. The first round of data collection for the Schools Study commenced in Term 3 of 2015 and involved all eight schools in Morwell and other schools from across the wider Latrobe City, including government and non-government primary and secondary schools. All students at these schools in academic grades 3, 5, 7 and 9 were invited, with a total of 2,138 children eligible to participate. This comprised a considerable expansion in scope, as the Schools Study had originally planned to recruit from a sample of 616 students from seven schools. Schools approached parents on behalf of the study, inviting them to consent to parents and children completing a survey as well as children potentially participating in a qualitative interview. In addition, the teachers of participating children were asked to complete a brief single measure on each child.

In total, 323 students participated, representing an overall response rate of 15.1%, with 25% of Morwell students agreeing to participate compared to 12% of non-Morwell students. This response rate is consistent with previous research on disaster and trauma in children and youth.

It was more challenging to recruit older students, particularly those in grade 9. The participation rate of parents completing surveys about their children and the family was 65.5% and the participation rate for teachers was 87.1%.

Permission was also sought from parents to access educational data for participating students. This included NAPLAN data from the 2013 and 2015 assessment rounds, providing a useful pre and post assessment of educational outcomes. NAPLAN data have been provided and are currently being analysed. The researchers are in discussions with the Performance and Evaluation Division from the Victorian Department of Education and Training regarding access to other educational data including school reporting, and school absences.

Initial analyses to assess sampling bias indicate that participating students have moderately higher scores on two NAPLAN domains than non-participants. There was no clear evidence that students from schools closest to the mine fire smoke were more likely to participate. Further analyses of sampling bias will be completed, once we have access to more educational and Census data.

In response to concerns regarding sample bias and limited sample size, alternative strategies are being followed to obtain additional data on the impacts on school children. A pilot study interviewing personnel at a Morwell specialist school in close proximity to the smoke event was completed in 2016. This work will be rolled out in more schools in Morwell in 2017. In addition, we are also keen to access de-identified NAPLAN and other educational data for the participating schools and for the wider region to compare impacted and non-impacted areas in terms of educational outcomes.

Policy Review of the Impact on Older People

The aim of this component of the study was to assess the impact of the smoke event on older people, focusing particularly on a review of the policy decisions made with respect to older people during the event, with a view to informing best practice for future emergency events. The stream targeted six groups: older people living in the community; older people in residential care; Home and Community Care (HACC) recipients; families and carers; service providers; and, decision makers.

The qualitative research methodology involved focus groups with residents and interviews with service providers and decision makers. The resident focus groups were conducted first, with initial recruitment via public advertising in local media, noticeboards etc. Seven focus groups were scheduled for late 2015, but the response was unsatisfactory. As a result, the recruitment

approach was changed to asking existing community groups to host discussions as part of their regular meetings and venues. This proved to be more successful, with five group sessions in 2016 bringing the total number of participants to 91. Efforts were made to recruit via a diverse range of groups in order to access different facets of the community.

While there was strong participation from community dwelling older people, there was little success engaging families and carers as there was no existing community group matching that profile. Similarly, attempts to target HACC clients were unsuccessful, perhaps because they were well supported during the event and mobility limitations precluded them from participating. Regardless of these limitations, the large and diverse group of older people participating provided a strong understanding of the impacts of the Hazelwood event on older people.

There were no such challenges undertaking the interviews with service providers and decision makers, with more interviews completed than originally intended. Ten interviews with service providers and seven interviews with decision makers at local and state levels were completed in April and May 2016. The transcriptions from the focus groups and interviews were thematically analysed and then combined with a desktop review of relevant literature and policy documentation to complement the information received through the focus groups and interviews. In total, almost 100 research and policy documents were cited in the stream report – making it an extensive review. Conclusions drawn from this work were verified in a workshop with key respondents in September 2016.

The qualitative data collected were considerably larger than expected, with more focus groups and interviews than planned. As a result, transcription and analysis took longer than expected. In order to do justice to the Policy Review of the Impact on Older People, it was agreed with DHHS that the stream researchers would submit an extensive interim report to meet the August milestone requirements. That detailed working paper was submitted on 15 August 2016. A more detailed final report and an accompanying Policy Brief were completed and submitted on 30 November 2016. Both documents were accepted by the DHHS in January 2017 and the findings were disseminated to participants and the public in February 2017. While the current program of work is now complete, further qualitative work targeting older people will continue via the Community Wellbeing stream.

Impact on Community Wellbeing

The first phase of this stream research program was to provide narrative evidence of the perceived impact of the Hazelwood mine fire smoke event in Morwell and surrounding communities on community wellbeing, as well as perceptions of the effectiveness of community rebuilding activities, and of communications during and after the event. To do this, the stream used a qualitative, interpretive research design with two main components: 1) a community-engaged program of work involving focus group discussions and individual interviews; and 2) media analysis of archival sources of relevant local and state news media and social media postings, as well as interviewing key local media professionals and social media practitioners from three social media streams that were initiated in response to the smoke event.

The phase 1 community-engaged program of work made use of publicly advertised focus groups in Morwell, Moe and Traralgon. However these only attracted 10 participants, primarily in Morwell. In addition, 24 interviews with key participants in community recovery activities were completed in 2015 and 2016. Additional focus groups had been planned to supplement the low numbers achieved in the earlier three attempts. However the large amount of data obtained from the interviews, coupled with earlier work conducted by stream team members as part of a 2014 Centre of Research for Resilient Communities (CoRRC) study, as well as findings from a Victorian Council of Social Services (VCOSS) study with local residents, were considered to be sufficient to address the research aims for this component.

The phase 1 media analyses covered material released by traditional media outlets and social media postings for both the period of the smoke event and for the remainder of the year. For the period of the smoke event, this equated to 807 postings and for the remainder of the year another 660 postings – so a total of over 1400 items were analysed.

The second phase of the stream program commenced in mid-2016, and involves ongoing media analysis, focus groups and interviews, and participatory action research projects in partnership with local community groups. In 2016, this involved intensive work with two community groups involving a total of six focus groups with between 8 and 25 participants in each. In 2017 the plan is to continue and extend the participatory action research by working with 10-12 community groups in Morwell over the next 6-8 months. The outcomes of this work will be disseminated to the local community via a public exhibition, which will be developed in consultation with members of the community groups and the curator at the Latrobe Regional Gallery.

Hazelinks

The aim of Hazelinks is to investigate the short, medium and long term health effects of the smoke from the coal mine fire by using routinely collected health data. Hazelinks comprises two components: i) identified linkage to databases holding ambulance, hospital, cancer and death data with the consent of Adult Survey participants; and ii) anonymised data extracts from these databases and also Medicare and Pharmaceutical Benefits Scheme (PBS) data.

The anonymised data extracts include population wide data for the period 1 January 2009 to the most recent data available for Hume, Eastern Metropolitan and Gippsland regions, and a small part of Southern Metropolitan region (Cardinia) for all ages.

Data custodian approval to access the health datasets for identified linkage and data extraction have been granted. Extracts of ambulance and hospital data have been received. Medicare and PBS data are expected in the coming weeks. Extraction of death data will be undertaken once AIHW complete geocoding of the relevant records. Extraction of cancer data from the Victorian Cancer Registry will be undertaken once 2015 data are available and geocoded (in the next few months). The estimated timeline for identified linkage to health datasets will be established once the cohort is finalised.

Clinical stream

The Clinical stream (formerly Respiratory and Cardiovascular streams) aims to determine whether exposure to smoke from the Hazelwood coal mine fire is associated with sub-clinical cardiovascular or respiratory symptoms or conditions. Participants will be recruited from those who participated in the Adult Survey. As projected in the 2014 Project Plan, recruitment for the Clinical stream should occur in the 2nd and 3rd quarters of 2017. However the late closure of the Adult Survey may delay this a little. The required procedures, equipment and facilities, databases and staffing for this stream are being finalised.

Exposure Assessment

The Commonwealth Scientific and Industrial Research Organisation (CSIRO) have completed detailed modelling of air quality in order to estimate key pollutant levels in Morwell and the wider Latrobe Valley for the period of the mine fire. This has included providing the HHS researchers with hourly air exposure estimates, which the Adult Survey and ELF streams will use to estimate each participant's cumulative exposure to air pollutants.

2 Introduction

A fire in the Morwell open cut mine adjacent to the Hazelwood power station blanketed Morwell and the surrounding area in smoke and ash for six weeks in February and March 2014. In response to community concerns about the long-term health effects, the Victorian Department of Health and Human Services (DHHS) commissioned the Hazelwood Mine Fire Health Study, hereafter referred to as the Hazelwood Health Study (HHS).

The HHS commenced in November 2014 and is led by independent researchers from Monash University in collaboration with Federation University, University of Tasmania, University of Adelaide and the CSIRO. The study comprises several streams which were separately designed to address the diverse research questions.

This Recruitment Report details progress that has been made in regard to data collection for the various streams of the HHS since the Project Plan was submitted, in December 2014, and up until 16 March 2017. For the purpose of this report, the term 'recruitment' has been broadly interpreted to include not only participants who have agreed to provide individual data, but also members of focus groups, and data from health databases, educational databases and media sources which have all been accessed (or are intended to be accessed) for the purpose of data collection. The report includes a review of how recruitment achievements may have varied from those forecast in the Project Plan, along with any associated impacts upon the research methodology or analysis plan.

For a detailed overview of all other aspects of the Hazelwood Health Study, including research aims and objectives, research stream activities, community engagement activities including dissemination of findings, governance, risk management and quality assurance please refer to the Hazelwood Health Study 2016 Annual Report which can be found at hazelwoodhealthstudy.org.au/study-reports

3 Hazelwood Health Study timeline

Figure 1 shows the HHS projected timeline for the first three years (previously provided in the 2015 and 2016 Annual Reports) against which recruitment progress in this report is compared.

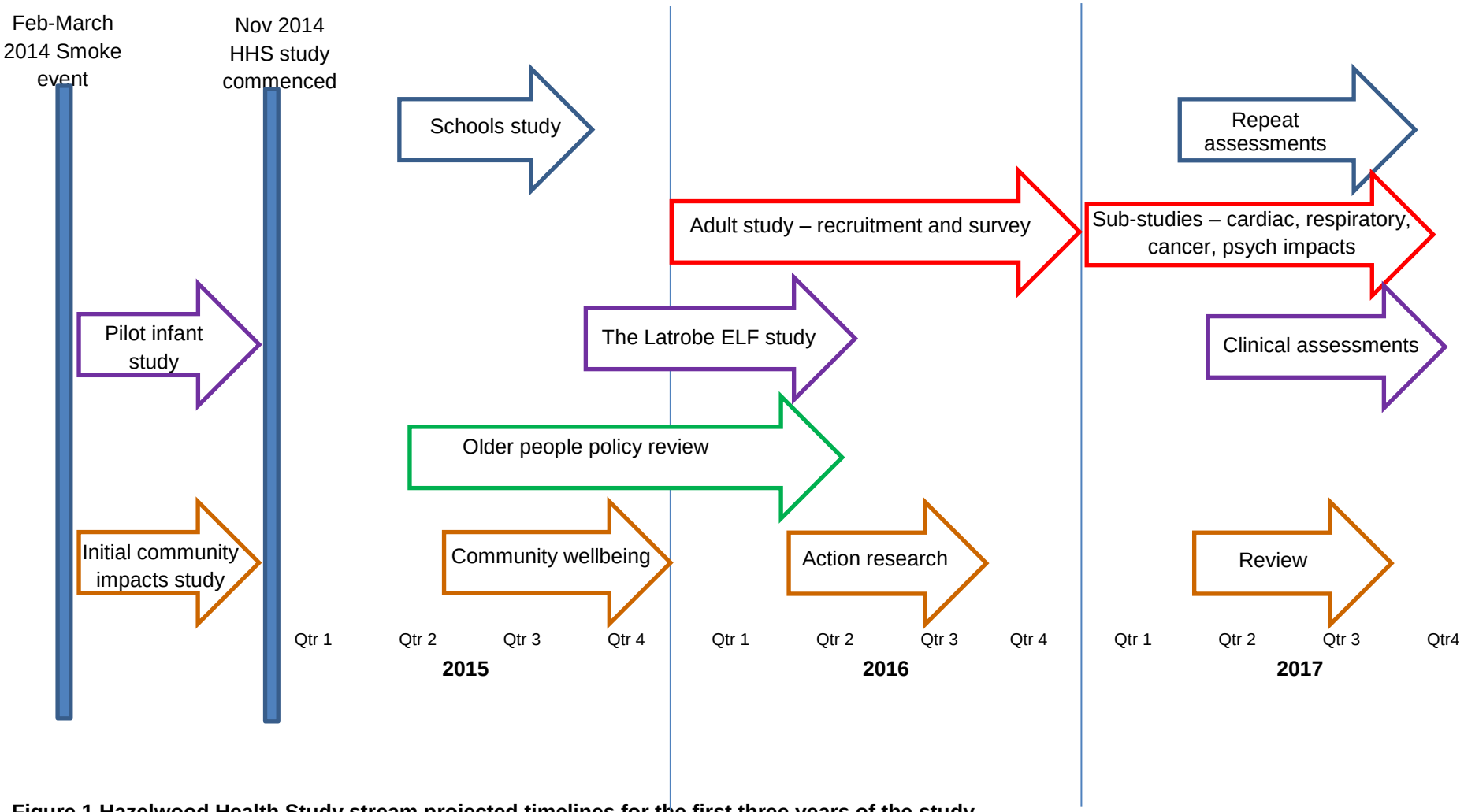


Figure 1 Hazelwood Health Study stream projected timelines for the first three years of the study

(Source: Hazelwood Health Study 2016 Annual Report)

4 Recruitment results

The following sections describe the aims of each study stream in brief and progress relevant to recruitment or accessing data sources.

4.1 Adult Survey

4.1.1 Aims and Objectives of the Adult Survey stream:

The Adult Survey aims to:

1. cross-sectionally investigate the health status of an exposed versus comparison adult population;
2. compare the incidence rates of long term health outcomes by linking to administrative health datasets in exposed versus comparison populations;
3. investigate the association between exposure level and risk of long term health outcomes by linking to administrative health datasets using fine resolution exposure metrics developed by CSIRO.

4.1.2 Eligible subjects

The Adult Survey exposed (study) group is defined as people who lived in Morwell, and were 18 years or older, on the 31st of March 2014. For the purpose of the study, Morwell is defined as the area within the township boundary.

The eligible comparison group are people aged 18 years or older on the 31st of March 2014, who live within one of 16 selected statistical areas within Sale which have comparable median age, household size, Socio-Economic Indexes for Areas (SEIFA) and population stability as Morwell. Sale was determined, via CSIRO modelling, to have had little exposure to smoke during the Mine Fire event.

The electoral roll maintained by the Victorian Electoral Commission (VEC) was determined to be the preferred sampling frame from which to identify eligible subjects, and their contact details, for the Adult Survey.

Establishing the list (nominal roll) of eligible subjects

As previously reported in detail in the 2015 and 2016 Hazelwood Health Study Annual Reports, there was a considerable delay in obtaining the nominal roll of eligible subjects from the VEC. In summary:

- The application to the VEC was initially submitted by the Adult Survey team in July 2015;
- In December 2015, the HHS Principal Investigators, Profs Michael Abramson and Judi Walker, and the Cancer research stream lead, Prof Malcolm Sim, met with the Victorian Electoral Commissioner to discuss the Commission's concerns about providing access to the data;

- Further correspondence was then sent to the Commission to address additional questions;
- Subsequently, the Victorian Electoral Commissioner forwarded the Adult Survey application to the Privacy and Data Protection Commission;
- The Privacy and Data Protection Commission's determination, that the Adult Survey passed the public interest test, was received in February 2016;
- This was followed by approval from the VEC subject to a number of conditions in regard to the privacy and confidentiality of the data and organisational liability for breaches of the *Privacy Act* 1988;
- The VEC conditions applied not only to Monash University, but also to the Hunter Research Foundation (HRF; who had been engaged to undertake the telephone- and online-interviewing for the Adult Survey), and any mailing house engaged to undertake the recruitment mailouts;
- Several mailing houses then had to be vetted by the researchers before Melbourne Mailing Pty Ltd was identified as being able to meet the VEC's rigorous privacy and confidentiality requirements;
- The VEC's conditions included the requirement that all Monash University staff, who would handle the VEC data for the Adult Survey, would have completed the Ethics and Good Research Practice training course run by Monash University's SPHPM, within the previous two years. Applicable Monash University staff attended this training course on 3 March 2016;
- Relevant HRF and Melbourne Mailing staff also undertook additional privacy training;
- After substantial negotiations between the VEC, Monash University's Office of General Counsel, the HRF and Melbourne Mailing Pty Ltd, a formal Agreement was executed on 20 April 2016;
- The relevant VEC data were released to the Adult Survey researchers on 22 April 2016.

Final sample size

The VEC identified **9,448** adults registered on the electoral roll as residents of Morwell at the time of the Hazelwood mine fire in February 2014.

The VEC identified **4,444**adults registered on the electoral roll as residents of the targeted areas of Sale in February 2014.

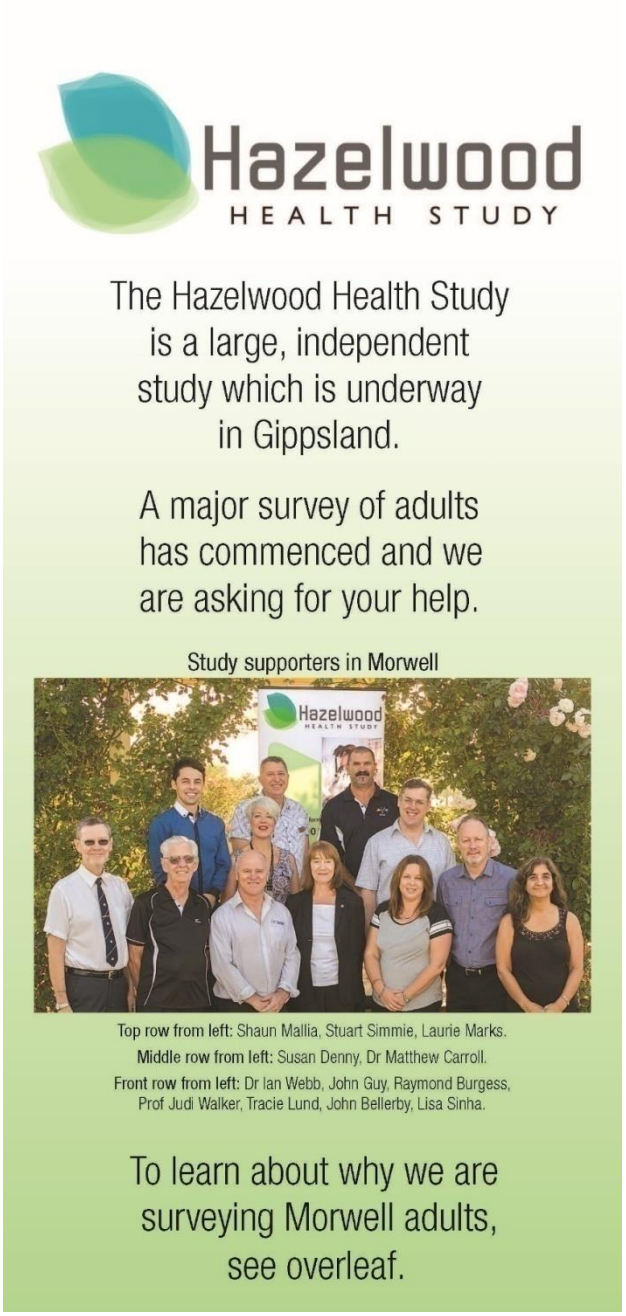
These numbers provided by the VEC excluded an unknown number of silent electors for whom the VEC could not disclose contact details.

4.1.3 Recruitment methods

The methods used to contact and recruit eligible residents have been described in detail in the 2016 Annual Report. To summarise briefly, they include:

- personalised and mailed invitation packs;

- follow-up phone calls where a publicly listed phone number could be found;
- endorsements from ‘community champions’;
- fridge magnets (shown right) dropped in letter boxes;
- information flyers, dropped in letter boxes, tailored to address community concerns or misconceptions;
- monthly media releases tailored to address community concerns or misconceptions;
- regular updates to the FAQs on the Hazelwood Health Study website;
- newspaper advertisements;
- radio advertising;
- invitations to free, catered events in public venues such as the Tribes Play Centre and Midvalley Shopping Centre;
- attendance at numerous public events such as the Morwell 50 Mile Farmers Market and the Morwell Pop-up Park;
- a dedicated 1300 number to respond to incoming enquiries;
- advertised attendance at the local libraries to provide assistance or answer enquiries
- attendance at existing community groups such as sports clubs;
- roadside banners;
- posters;
- questionnaire packs made available in public venues such as doctor’s rooms, sports clubs, laundromats and libraries.



Some examples of the flyers, posters and events are shown here:

Figure 2 Front face of a tri-fold flyer promoting free, catered events in Morwell

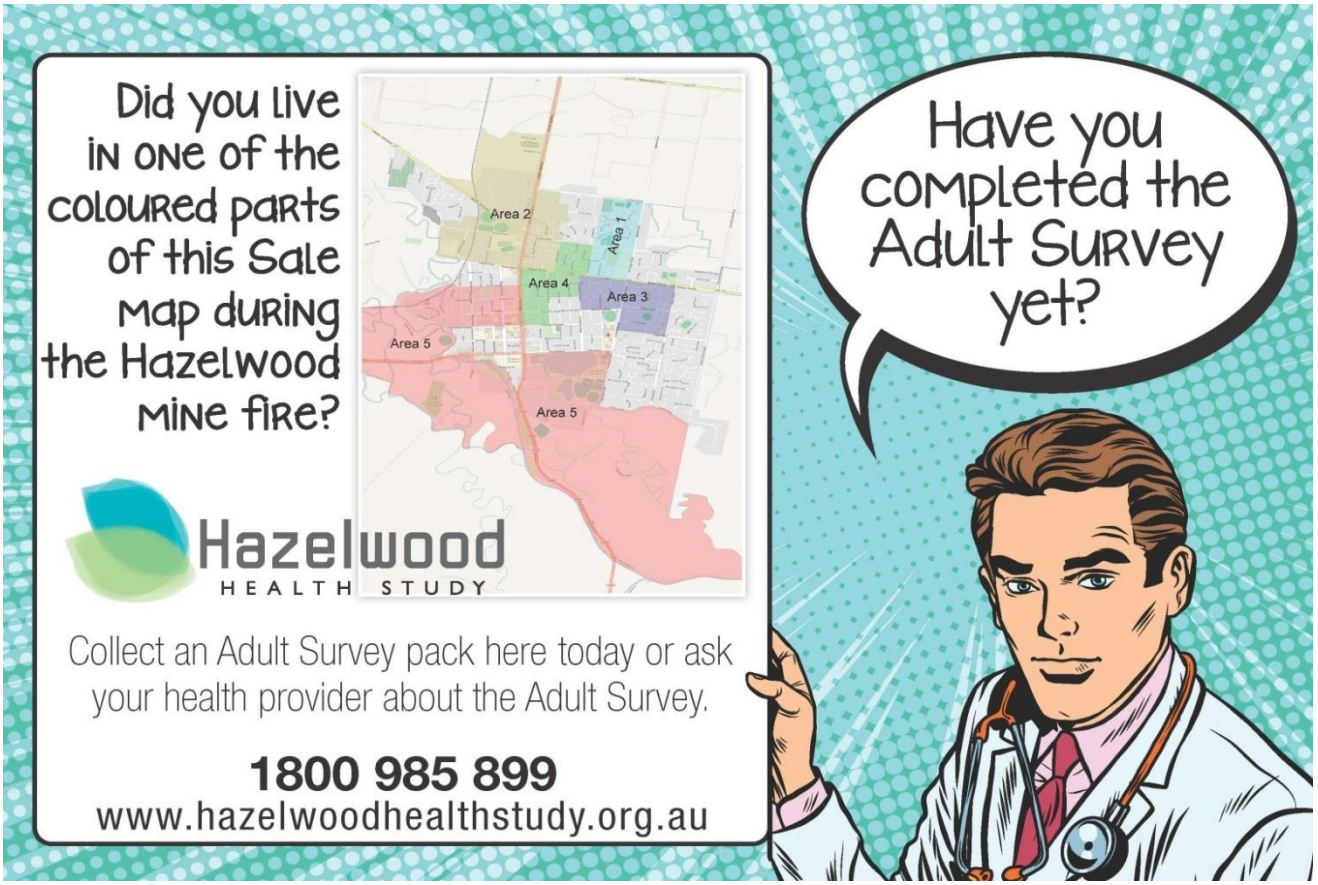


Figure 3 Example of a poster promoting Adult Survey questionnaire packs in Sale

Figure 4 Hazelwood Health Study promotional stand at Morwell Pop-Up Park in April 2016

4.1.4 Recruitment time line

It was anticipated that recruitment in to the Adult Survey would commence at the start of 2016 and close by the end of 2016 (see Figure 1). However, as reported above, there were substantial delays in obtaining the nominal roll for the Adult Survey, which was not made available until late April 2016. Subsequently, recruitment in to the Adult Survey launched in May 2016 in Morwell, and June 2016 in Sale.

In regard to personalised invitation packs, Morwell was divided in to six areas (shown in Figure 5) which were targeted sequentially over a six month recruitment period; with Area 1 mailed invitation packs in May 2016, Area 2 in June 2016, Area 3 in July 2016 and so on until Area 6 was mailed invitation packs in October 2016. The VEC data included current address for residents who were registered at a Morwell address in early 2014 but had since moved out of the town. They were included in the July 2016 mailout.

Sale was divided in to five areas (shown in Figure 6) which were targeted sequentially over a five month recruitment period; with Area 1 mailed invitation packs in June 2016, Area 2 in July 2016and so on until Area 5 was mailed invitation packs in October 2016.Residents who had moved out of Sale, since the time of the mine fire, were included in the August 2016 mailout.

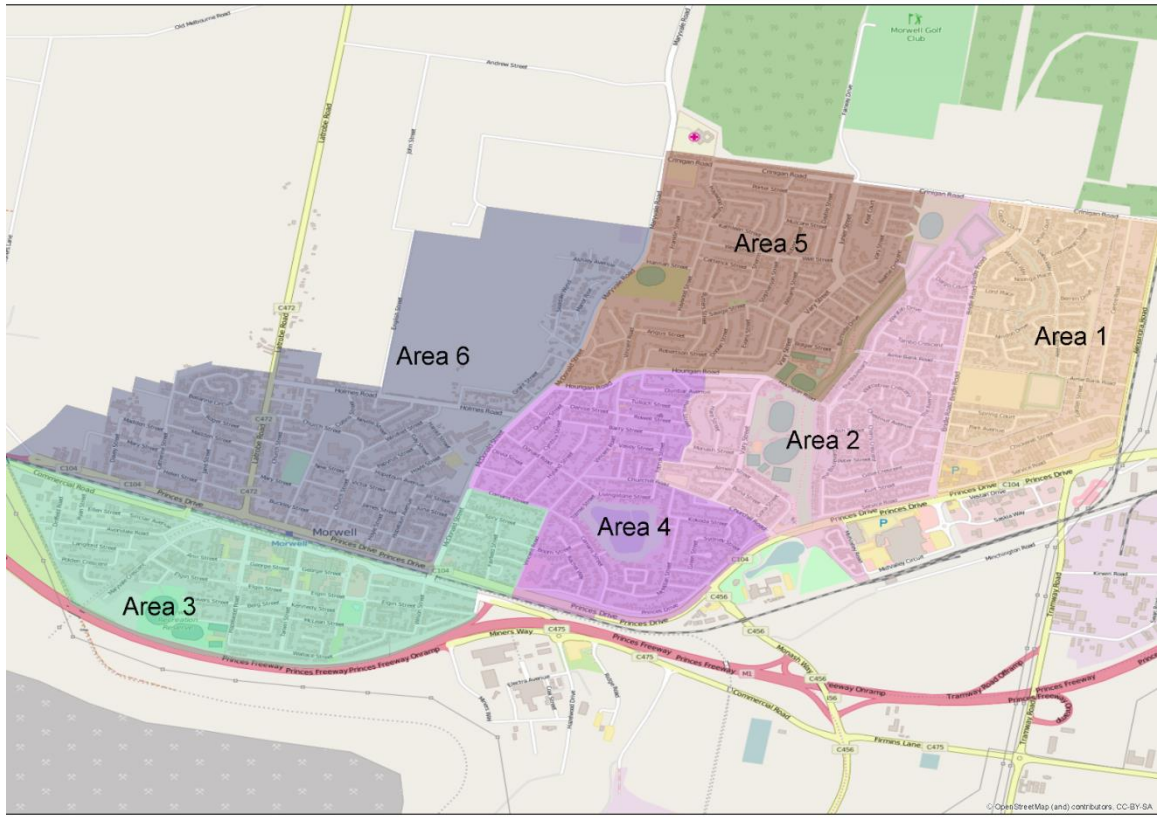


Figure 5 Map of Morwell demonstrating the Areas that were approached sequentially over a six month recruitment period from May to October 2016.

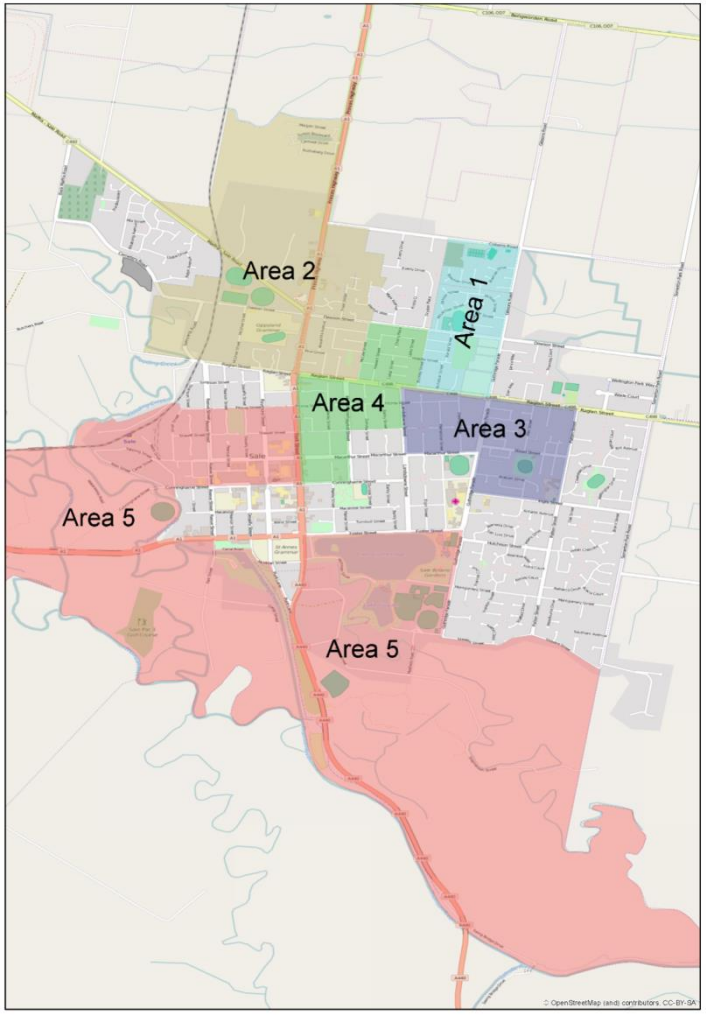


Figure 6 Map of Sale demonstrating the Areas that were approached sequentially over a five month recruitment period from June to October 2016.

Instead of closing recruitment at the end of 2016, as planned, the researchers decided to continue recruitment in to early 2017 to allow late responders maximum time to participate. Recruitment closed on 16 February 2017 and comprehensive data cleaning is currently underway

4.1.5 Recruitment results

*As recruitment only closed in mid-February 2017 and data cleaning is still taking place, all results shown here are **preliminary** and **subject to change**.*

Recruitment from the VEC list

As described above, the VEC identified a study group of **9,448** adults residing in Morwell at the time of the mine fire. Of those, 396 were removed from the recruitment denominator because they were identified as being deceased (n=324) or as ineligible. Consequently the recruitment rate denominator for residents on the VEC list for the study group was **9,052**.

The VEC identified a study group of **4,444** adults residing in the targeted areas of Sale at the time of the mine fire. Of those 215 were removed from the recruitment denominator because they were identified as being deceased (n=174) or as ineligible. Consequently the recruitment rate denominator for residents on the VEC list for the comparison group was **4229**.

Table 1 Recruitment outcomes for the Morwell (study) and Sale (comparison) residents on the VEC list

	Morwell	Sale	Study total
VEC list recruitment rate denominator	**N=9052**	**N=4229**	**N=13281**
Participants	3019 (33%)	952 (23%)	3971 (30%)
Refusers	1105 (12%)	776 (17%)	1881 (14%)
Non-responders	4928 (54%)	2501 (59%)	7429 (56%)

Table 1 shows that a third (33%) of eligible Morwell residents on the VEC list, and almost a quarter (23%) of eligible Sale residents on the VEC list, participated in the Adult Survey. Overall one seventh (14%) declined participation, whilst the majority (56%) simply did not respond to repeated contact attempts with a decision about participation during the study recruitment period.

Figure 7 shows the recruitment rates in Morwell for each of the mailout Areas 1 to 6 (as previously described in Figure 5) and also for those former Morwell residents who have moved out of the town. Residents who received their mailed invitations in the earlier mailouts had more time to participate than those who received their invitations later. The highest participation rate (40%) was in Area 3 which also happened to be the residential neighbourhood closest to the location of the mine fire. The lowest participation rate (20%) was for those residents who had moved out of Morwell, which likely reflects the more mobile nature of this group.

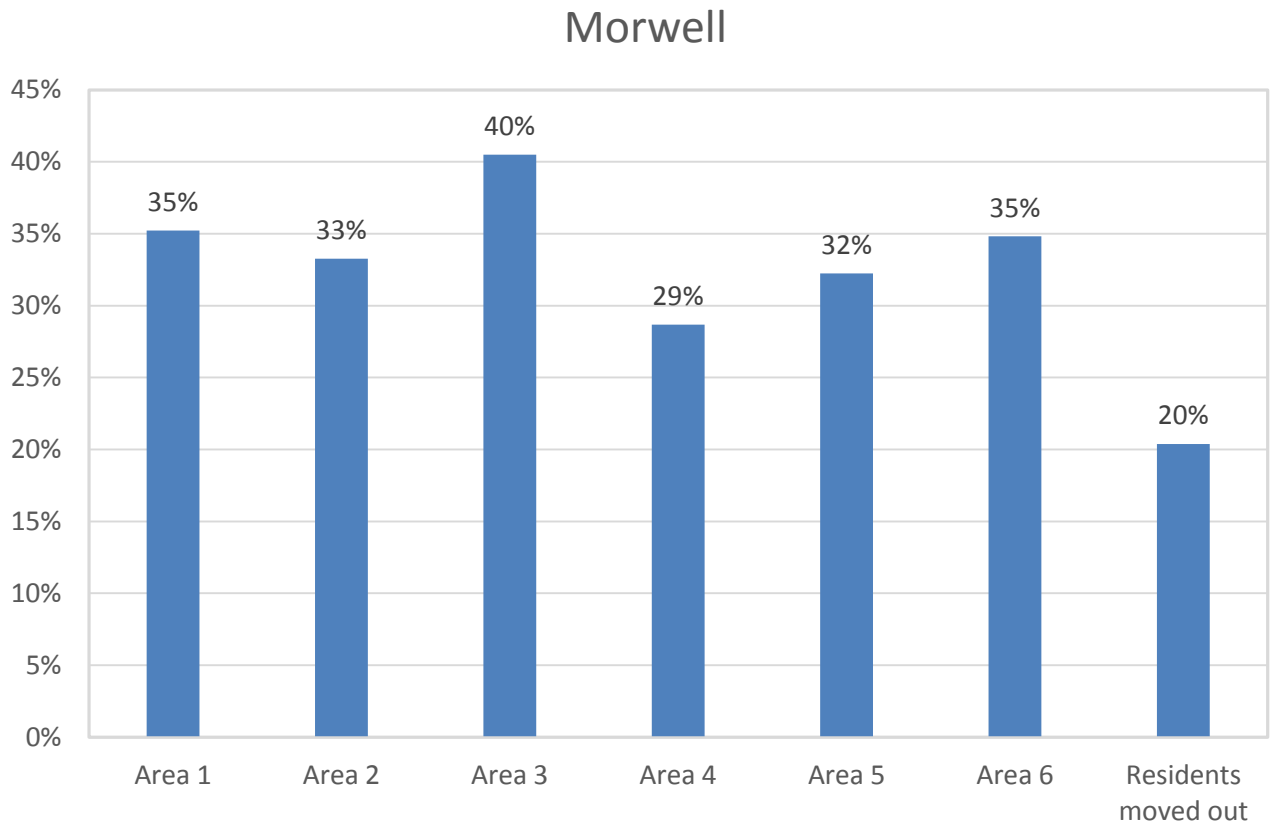


Figure 7 Adult Survey recruitment rate by mailout Area for Morwell

Figure 8 shows the recruitment rates in Sale for each of the mailout Areas 1 to 5 (as described in Figure 6) and also for those former Sale residents who have moved out of the town. There is a gradual, though consistent, increase in participation rates over time, with the highest participation rate (27%) in mailout Area 5 which received invitation packs last. In the lead up to the Adult Survey launch the Hazelwood Health Study, as a whole, had relatively less publicity in Sale than in Morwell. The pattern in recruitment across mailout Areas may reflect the fact that the Areas approached last had been exposed to several months of additional publicity by the time their invitation packs arrived; whereas Area 1 had been exposed to proportionately less publicity. However, the Areas targeted early also had the greatest amount of time to participate before recruitment closed. Consistent with the finding for the Morwell group, the lowest participation rate (12%) was for those residents who had moved out of Sale.

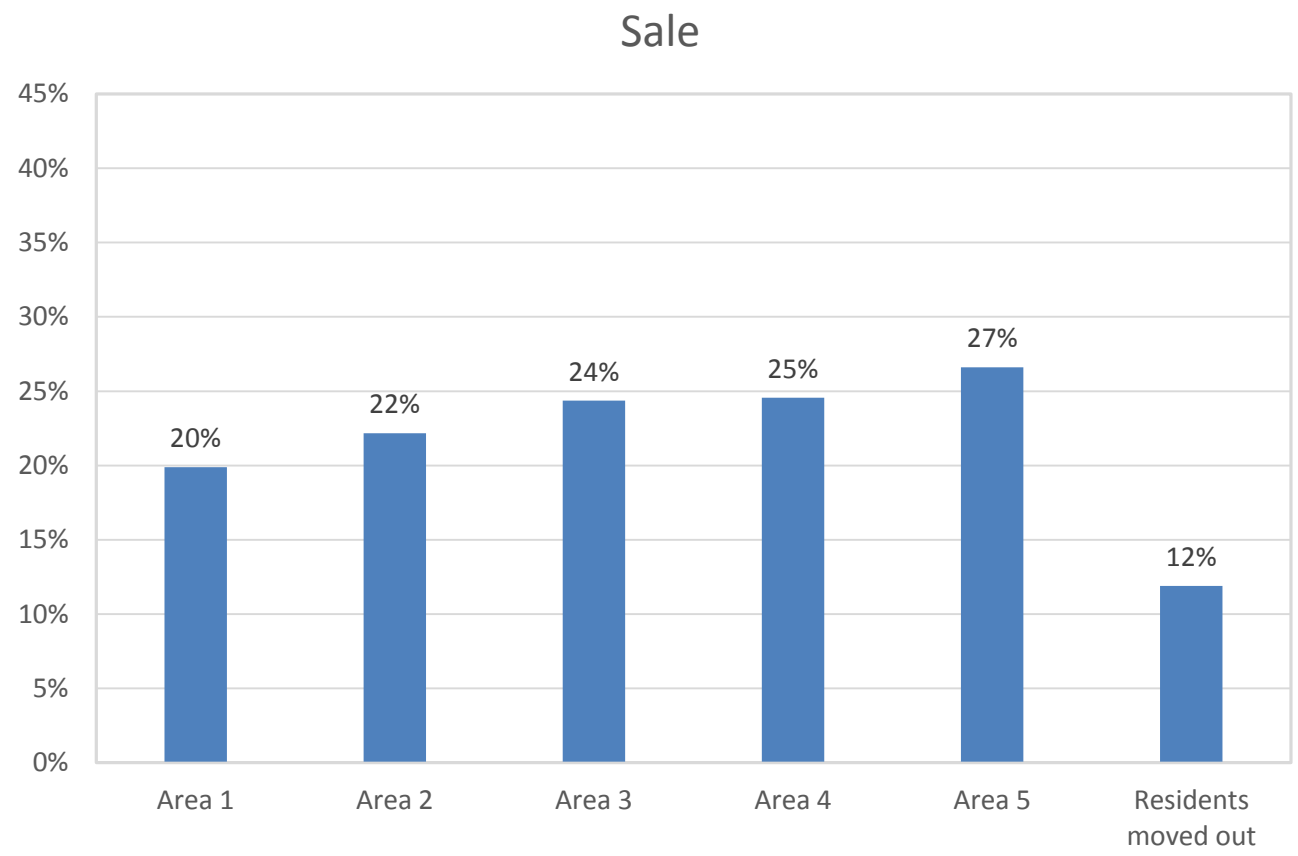


Figure 8 Adult Survey recruitment rate by mailout Area for Sale

Recruitment of Morwell and Sale residents not listed in the VEC data

Whilst registration on the Electoral Roll is compulsory in Australia, there would have been a number of Morwell and Sale residents who were not listed in the VEC data for various reasons. Silent electors were also not included with the VEC data. However, these residents remained eligible to participate in the Adult Survey. Such residents did not receive personalised, mailed invitations to participate, instead it was hoped that some might respond to the additional recruitment strategies shown at section 4.1.3. Termed "**opt-ins"**, **54** Morwell residents and **two** Sale residents, who were not included on the VEC list, participated in the Adult Survey.

Final number of participants and mode of participation

The final number of participants in the Adult Survey, adding those from the VEC list and the opt-ins, is **3,073 in Morwell** and **954 in Sale**.

Participants had the option to complete the Adult Survey by computer-assisted telephone interview (CATI), computer-assisted web interview (online CAWI) or by paper questionnaire. The researchers'

preferred mode of participation was by telephone interview, with considerable resources invested in the programming of the CATI and associated training and supervision of the interview team. Telephone interview was preferred because this mode of data collection typically results in very complete data. That is because interviewers are able to clarify questions which participants might otherwise not understand, and keep respondents on-track to completion. Telephone interview also permits participation by residents who might have difficulty with reading or writing. However, telephone interview is not suitable for all participants (for example, residents with hearing difficulties) and doesn't always permit participants to complete the Survey in several 'sittings' over different times of day or night.

The paper and online versions of the Adult Survey gave participants greater flexibility to participate in their own time; however these modes of participation are more prone to misinterpretation of questions and missing data. Whilst the online survey was programmed to be identical to the telephone survey in terms of questions and response options, the paper version had to be slightly different. Reasons for this include that *skip* and *go to* commands in the questionnaire, which are based on previous answers, could be easily programmed in to the online Survey but difficult to follow on paper.

Table 2 Percentage of participants completing the Adult Survey by telephone, online or on paper.

Total number of participants Mode of participation	Morwell N=3073	Sale N=954	Study total N=4027
	n (%)	n (%)	n (%)
Telephone interview	1164 (38%)	377 (40%)	1541 (38%)
Paper questionnaire	752 (24%)	216 (23%)	968 (24%)
Onlinequestionnaire	1154 (38%)	361 (38%)	1515 (38%)

Table 2 shows the proportions of participants by mode of Survey completion. The pattern of participation was very similar in the two study groups, with greater proportions of participants in both groups completing the Adult Survey by telephone (about 39%) or online (38%) and slightly smaller proportions participating on paper (24%).

4.1.6 Assessment of sampling bias

Sampling (participation) bias can occur if participants differ from non-participants (ie. refusers and non-responders) on characteristics which are associated with the study dependent measures, such as health status. A complete examination of sampling bias would require the collection of comprehensive and current health, demographics and mine-fire smoke exposure information for all of the non-participating study and comparison group subjects. Such comprehensive data were not available for non-participants.

However, there were some data sources available which we could use to assess the extent to which the study participants were representative of the populations from which they were drawn.

Refuser Questionnaire data

Eligible subjects who declined participation, in the Adult Survey, were invited to answer a very brief Refuser Questionnaire. The questions included age category, sex, the stem question about self-perceived health from the 12-item Short Form Health Survey (SF-12) and smoking status. The Refuser Questionnaire was completed by 353 refusers; 233 from Morwell and 125 from Sale.

As shown in Table 3 participants in Morwell were very similar to those non-participants in Morwell who completed the Refuser Questionnaire, in regard to gender and self-perceived health. However, Morwell participants were more likely to be aged in their 20s to 50s, less likely to be aged over 70, and more likely to be current smokers than these non-participants.

Table 3 Comparison of participants with non-participants who completed a Refuser Questionnaire

	Morwell		Sale	
	Participants	Refuser questionnaire	Participants	Refuser questionnaire
Question	**(N=3073)**	**(N=233)**	**(N=954)**	**(N=125)**
Gender	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Male	1361 (44)	107 (46)	406 (43)	42 (34)
Female	1701 (55)	123 (53)	546 (57)	80 (64)
Age category				
20s	241 (8)	11 (5)	83 (9)	n<5
30s	269 (9)	5 (2)	95 (10)	n<5
40s	413 (13)	14 (6)	127 (13)	7 (6)
50s	625 (20)	28 (12)	187 (20)	20 (16)
60s	681 (22)	53 (23)	194 (20)	24 (19)
70+	775 (25)	116 (50)	256 (27)	62 (50)
SF-12 stem question: In general would you say your health is:				
Excellent	278 (9)	19 (8)	121 (13)	18 (14)
Very good	809 (26)	54 (23)	313 (33)	40 (32)
Good	1066 (35)	86 (37)	298 (31)	30 (24)
Fair	639 (21)	43 (18)	160 (17)	25 (20)
Poor	253 (8)	25 (11)	56 (6)	10 (8)
Smoking status				
Current	611 (20)	24 (10)	140 (15)	12 (10)
Former	953 (31)	81 (35)	312 (33)	44 (35)
Never	1499 (49)	118 (51)	498 (52)	64 (51)

Participants in Sale were more likely to be male, more likely to be aged in their 20s to 50s, less likely to be aged over 70, more likely to rate their health as good and less likely to rate it as fair or poor, and more likely to be current smokers than non-participants in Sale who completed the Refuser Questionnaire.

Because the most elderly residents and current smokers were underrepresented in **both** participating groups (Morwell and Sale) these factors were unlikely to notably effect the magnitude or direction of any observed differences in health outcomes between study groups. However, the underrepresentation of women among Sale participants, which is not reflected in the Morwell participants, could possibly effect the magnitude or direction of differences in health outcomes between study groups. For this reason it will be important to adjust for gender as a potential confounder in the statistical analyses.

An important limitation, in regard to the use of Refuser Questionnaire data to assess sampling bias, is that the people who complete the Refuser Questionnaire may not be representative themselves of the remaining non-participant group. For example, people who completed the Refuser Questionnaire were often those with publically listed landline phone numbers and, therefore, they may have been older residents at long-term addresses.

Australian Bureau of Statistics data

Australian Bureau of Statistics (ABS) 2011 Census data provides population estimates by age and gender for the Morwell and Sale areas. The breakdown is shown in Table 4 along with the Adult Survey participant proportions from Table 3. Adult Survey participants in **both** the Morwell and Sale groups were more likely to be female and aged in their 50s or above, compared with the 2011 ABS estimates for the two towns respectively.

Table 4 ABS estimated adult resident population by age and gender for Morwell and Sale compared with Adult Survey participants

	Morwell		Sale	
	Participants (N=3073)	**ABS (N=10644)**	**Participants (N=954)**	**ABS (N=10494)**
Gender				
Male	44%	49%	43%	47%
Female	55%	51%	57%	53%
Age category				
20s	8%	19%	9%	18%
30s	9%	14%	10%	17%
40s	13%	17%	13%	18%
50s	20%	16%	20%	18%
60s	22%	15%	20%	13%
70+	25%	18%	27%	16%

* Data source Population Estimates by Age and Sex, Victoria by Statistical Geography [ASGS 2011], 2011, ABS, http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3235.02011?OpenDocument

Victorian Population Health Survey 2011-12 estimates of self-perceived health and smoking status are available for the municipalities of Latrobe City (which includes Morwell and several surrounding towns) and the Shire of Wellington (which includes Sale and several surrounding towns). The breakdown is shown in Table 5 along with the participant proportions from Table 3.

Adult Survey participants in the Morwell study group were more likely to report fair to poor health and slightly more likely to be former smokers, compared with estimates for Latrobe City. The pattern of differences between Sale participants and the estimates for the Wellington Shire were less clear; with Sale participants more likely to report fair to poor health, also slightly more likely to report very good to excellent health, less likely to be current smokers but more likely to be former smokers.

Table 5 Self-reported health and smoking status in Latrobe City and Shire of Wellington compared with Adult Survey participants

	Morwell participants	Latrobe City	Sale participants	Shire of Wellington
In general would you say your health is:				
Excellent / Very Good	35%	41%	45%	43%
Good	35%	44%	31%	44%
Fair / Poor	29%	15%	23%	13%
Smoking status				
Current	20%	20%	15%	19%
Former	31%	26%	33%	28%
Never	49%	54%	52%	53%

* Data source: Victorian Population Health survey 2011-12 Findings, https://www2.health.vic.gov.au/Api/downloadmedia/%7B14305C13-A130-4AB1-A5E1-4E94370DBC78%7D

Interpretation of the meaningfulness, of the differences shown between Adult Survey participants and the population estimates, is still being considered. As with the Refuser Questionnaire data, an important limitation in regard to the use of the Latrobe City and Shire of Wellington data to assess sampling bias, is that the people across the wider municipality regions may not be representative themselves of the non-participants in Morwell and Sale.

Exposure to the mine fire smoke

Described in more detail in Section 4.8, the Commonwealth Scientific and Industrial Research Organisation (CSIRO) have modelled hourly and 12-hourly cumulative exposure to air pollution particles smaller than 2.5 micrometres (µm; $PM_{2.}$) for each Statistical Areas Level 1 (SA1s) in Morwell for the period of the mine fire. By mapping each Adult Survey participant's residential address (at the time of the mine fire) to the SA1s, the CSIRO modelled data can be used to assess whether participants are representative of the wider Morwell population in regard to their likely mine fire exposure.

Figure 9 shows the Adult Survey participation rates in the various SA1s across Morwell and also the cumulative 12 hourly $PM_{2.5}$ exposure level modelled for those SA1s. In general, participation rates were slightly higher among residents in the areas to the south of Morwell which were most highly exposed to the mine fire smoke. This may mean that more highly exposed residents were over represented amongst the Adult Survey participants which may result in the study over-estimating the average difference in health between the Morwell and Sale groups.

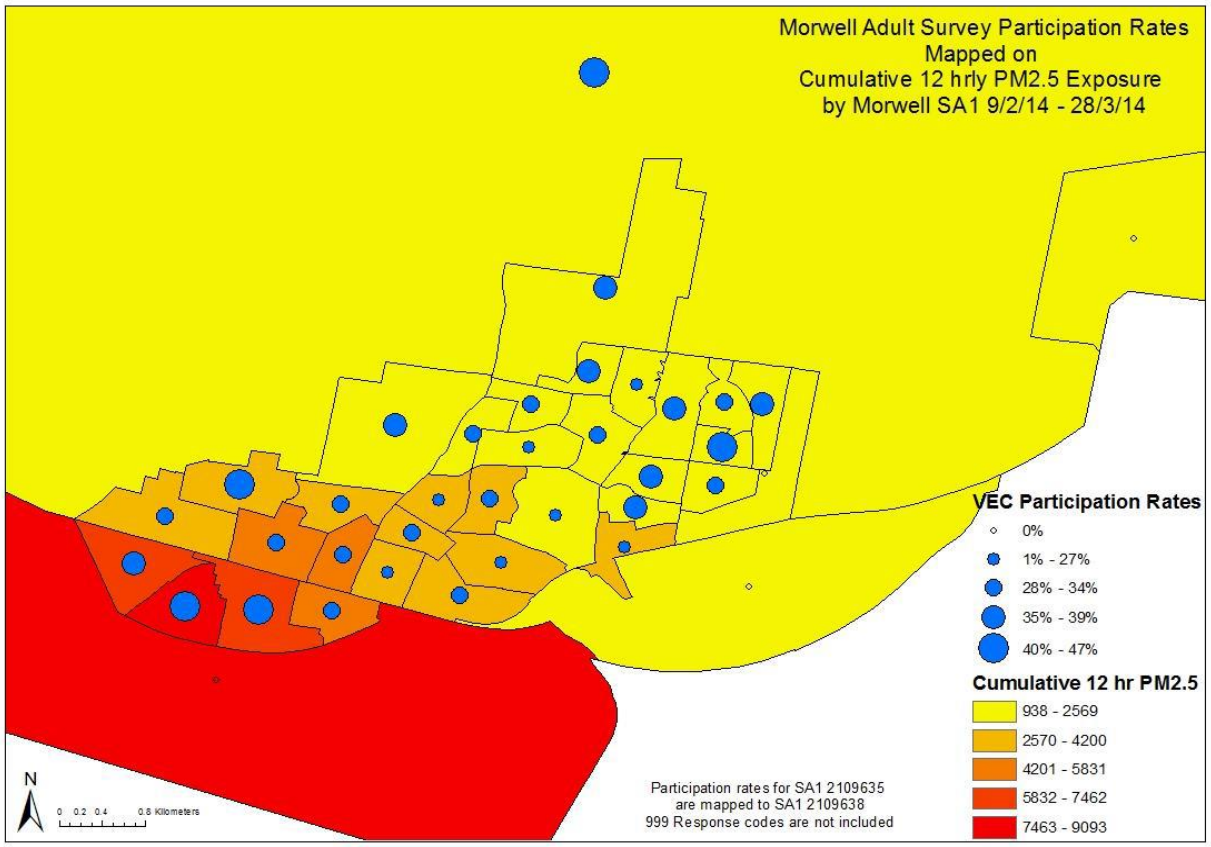


Figure 9 Adult Survey participation rate by CSIRO modelled cumulative 12 hourly $PM_{2.5}$exposure

4.1.7 Identified linkage to health databases

Data collection in the Adult Survey included identified linkage to several health databases. Because the Adult Survey's primary methods of data collection were by over-the-phone interview or online questionnaire, the researchers sought data custodian approval to access the data having obtained only verbal or online consent from participants, as opposed to the more usual hard-copy written consent.

Data custodian approval to access data based on verbal or online consent has been successfully obtained for:

- Victorian Ambulance Clinical Integration System (VACIS) and the Victorian Ambulance Cardiac Arrest Registry (VACAR) held by Ambulance Victoria (AV).

- Victorian Emergency Minimum Dataset (VAED) and the Victorian Admitted Episodes Dataset (VEMD) held by the Victorian Data Linkage Unit at DHHS.
- National Death Index (NDI) for mortality data and the Australian Cancer Database (ACD) for the national cancer incidence data held by the AIHW.
- Victorian Cancer Registry (VCR) for Victorian cancer incidence data held by the Victorian Cancer Registry.

The proportion of Adult Survey participants who have consented to identified data linkage with the above data sets is approximately 70%. Further data cleaning is required before this figure can be finalised.

An application for identified linkage to Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) was submitted to the Australian Government Department of Human Services (DHS) in December 2015. Substantial negotiation ensued with this data custodian. In February 2016, the DHS approved identified linkage to the MBS and PBS databases, however the DHS did not approve the verbal or online consent protocol. Instead, the DHS required that consent be obtained in writing with the use of a detailed hard-copy consent form.

The researchers evaluated the feasibility of adding hard-copy consent for MBS and PBS data to the Adult Survey protocol. This included an assessment of the additional administrative burden to researchers, the additional responder-burden on potential participants, and the likely response rate. The researchers determined that obtaining hard-copy written consent for identified MBS and PBS data was not feasible and therefore, this data linkage was removed from the Adult Survey protocol.

4.1.8 Variations from Project Plan

Variation to recruitment protocol

The 2014 Project Plan forecast that the Adult Survey contact and recruitment phase would span a period of about 15 months, commencing in the last quarter of 2015 and closing at the end of 2016. However, the researchers did not anticipate the 10 month delay in receiving the VEC data for this stream, resulting in an April 2016 launch of the Adult Survey contact and recruitment. However the researchers and HRF have worked successfully to reduce the recruitment period for the Adult Survey, which closed in mid February 2017, only one and a half months later than planned.

An important addition to the Adult Survey protocol has been the participant reimbursement ($20 gift vouchers) which was not included in the Project Plan or budget. Based on the recruitment challenges experienced by the Schools Study, Community and Wellbeing stream and Older Persons stream in 2015, the HHS Project Steering Committee saw the need to proactively workshop strategies to enhance Adult Survey recruitment. Substantial research went in to participant reimbursement options and the $20

Latrobe City Gift cards and Shop in Sale E-vouchers were determined to be excellent options which effectively returned the funds to the local community.

In the 2014 Project Plan, it was also proposed that we might undertake door-knocking in an effort to engage with non-responders. There are a number of reasons why this was not pursued, including:

- The Victorian Electoral Commissioner was opposed to this strategy on the basis that it was too intrusive.
- Door knocking was assessed as unlikely to be cost-effective, on the basis that considerable staffing would be required over an extended duration to cover such a large area as Morwell and Sale, particularly considering that numerous visits to any one household might be needed before a resident is found to be home. The ELF stream was only able to engage one in ten targeted households using a door knocking methodology.
- The Adult Survey budget did not include funds for project staff to undertake door knocking.
- Options to use local volunteers, to do door knocking, were discarded on the basis of participant confidentiality, privacy, liability and safety.
- The VEC imposed substantial conditions upon the HHS staff who would have access to the names and addresses of the Adult Survey participants, which would likely have applied to any staff engaged to undertake door knocking.

Variation to data linkage protocol

As described above, the Adult Survey intended to request that participants consent to identified MBS and PBS data linkage. However Medicare did not approve a verbal or online consent protocol and, on that basis, the researchers determined that this linkage was not feasible. An anonymous extraction of MBS and PBS data, has instead been requested as part of the Hazelinks stream.

Variation to data analysis

The less than hoped for recruitment rate in the Adult Survey has rendered the study vulnerable to sampling bias. A full evaluation of the differences between participants and non-participants is still being explored. When complete, the sampling bias analysis will be incorporated in the further analysis, possibly using weighting methods and post-stratification for bias correction.

4.2 The Latrobe Early Life Follow Up (ELF) Study

4.2.1 Aims and Objectives of the ELF Study stream:

The overall aim is to investigate the potential impacts of exposure to smoke from the Hazelwood coal mine fire during pregnancy or infancy on subsequent health and development of children in the Latrobe Valley. This is being achieved through:

1. following an **identified cohort** of children who have been enrolled by their parents to participate in the study;
2. analysing **a state-wide de-identified data extraction** of from the Victorian Perinatal Data Collection; and
3. establishing **a long-term anonymised data linkage study** of children born in the Latrobe Valley.

Specific objectives include:

- to compare perinatal outcomes, particularly foetal growth and maturity, of those exposed, and not exposed, to smoke from the Hazelwood mine fire in (1) the identified cohort of children, and (2) the de-identified data extraction from the Victorian Perinatal Data Collection;
- to compare the frequency of parental reports of minor illnesses in infants over a three year period of those exposed and not exposed to smoke from the Hazelwood mine fire in the identified cohort of children;
- to follow and compare the development of respiratory and vascular function in children exposed and not exposed to smoke from the Hazelwood mine fire in the identified cohort of children;
- to assess long-term indicators of health and development using an anonymised data linkage study of children born in the Latrobe Valley comparing those exposed and those not exposed to smoke from the Hazelwood mine fire.

This report focusses on recruitment of participants for the identified cohort study.

4.2.2 Eligible subjects

The geographic region for the identified cohort is the municipality of Latrobe City. Families whose primary residential addresses were in this region during the fire were eligible to enrol their children. Sampling from the wider Latrobe Valley, rather than the town of Morwell alone was planned to ensure that there was an adequately sized population base from which to draw participants and to enable the study to evaluate the impact of different levels of exposure to smoke from the mine fire on health outcomes.

Eligible children are those born from 1 March 2012 until 30 November 2015. This time frame includes infants who were aged up to 2 years or *in utero* at the time of the fire, and a comparison group of children from the same location who were conceived after the fire. Drawing participants from the wider Latrobe Valley also allows comparisons between infants of the same age across a gradient of exposure.

Establishing the list (nominal roll) of eligible participants

In May 2015, discussions commenced with Sara Rhodes-Ward General Manager, Community Liveability, at Latrobe City Council, regarding obtaining access to a nominal roll of infants and children born in the eligible time period. The council's Maternal Child Health Service routinely collects contact details of families with children aged from birth to six years of age for the purpose of providing maternal and child health care. All relevant ethics committees governing the implementation of the study approved this approach.

Amid concerns from Council about privacy issues, it was suggested that Council first approach eligible participants, with multiple options for opting out provided. Only the names of those who did not actively opt out would be passed on to ELF Study researchers. Due to Council's continued concerns around releasing contact details without active consent, the Chief Investigator, Dr Fay Johnston, approached the Health Services Commissioner to query relevant legislation pertaining to Council. The Health Services Commissioner responded that the contact information being held by Council was classified as "health information" and therefore could be used for the purposes of research without seeking individual consent. As a result, and in line with the approved protocol, Council agreed to the strategy outlined above for approaching eligible subjects.

In December 2015, Latrobe City Council sent an initial list of names of children born between 1/3/2012 and 30/9/2015 (data for the rest of 2015 were not then complete) to Births Deaths and Marriages Victoria, for matching with registered deaths (n=4,194). After removing a number of duplicate records and any children matched to a death record, the Council then approached the families of 3,620 children with information about the Latrobe ELF Study. Families who subsequently opted out, had invalid mailing addresses (return to senders) or duplicate records were removed from this list. The contact details for the families of the remaining 3,267 children were provided to ELF Study researchers.

A further list of 258 names of children born between 1/10/2015 and 31/12/2015 was sent from Latrobe City Council to Births Deaths and Marriages in March 2016 and the resultant matched file was received on 17th May. Approach letters were sent out from Council on the 8th June to families of a further 189 children and, after data cleaning as described above, a final file containing contact details for 177 children was received by the ELF Study researchers in July 2016.

After some further de-duplication of records was carried out by the researchers, a population of 3,371 was available to be approached for enrolment into the ELF Study. Invitation packages were sent to families of another 12 children who approached the study team requesting inclusion in the study. Although these children were eligible for inclusion their names had not appeared on the nominal roll provided from Latrobe City Council. These study subjects have been allocated ID numbers which identify them as being "self-selected".

In total, the families of **3,383 children** were identified as eligible for inclusion.

Sample size

The targeted sample size for recruitment to the identified cohort was 500 children. After reviewing previous studies evaluating similar outcomes, it was determined that a sample of 100 children in each exposure group (exposed in utero, exposed in infancy, and not exposed) would be ideal, giving a minimum sample size of 300. The target of 500 was set for initial recruitment to allow for loss to follow-up, especially given the intended long time-frame for the study. Whilst not specified in the project plan, it was desired that the 500 participants would be balanced fairly evenly across the three exposure groups, with approximately half from Morwell and half from other Latrobe Valley locations.

The ELF identified cohort was not intended to be a representative survey of the community. It was purposefully designed to have a balance of ages and exposures for detailed clinical follow up through time, to enable the study questions to be addressed.

Data collected from the complementary **data extraction** and **data linkage** studies are representative of the community, as they include the complete cohort of children from the State of Victoria (perinatal extraction) and the Latrobe Valley (anonymised linkage cohort). These parallel studies were included because they are not subject to recruitment bias, recall bias, or loss to follow up, and they provide a much larger sample size for statistical analysis. However, they do not provide the depth and detail of clinical and exposure information that is possible to collect from participating individuals.

4.2.3 Recruitment time line

Recruitment was conducted in a staggered approach as follows:

- The first mail out of invitations, on the 21/3/16, was to the families of 96 children, including all eligible children from southern Morwell.
- Invitees were given a two week period to contact ELF Study researchers to actively opt-out.
- At the end of the two week period, contact details for all of these participants who had **not** opted out were passed on to HRF who were contracted to invite participants to the study and complete the baseline survey.

- The mail out process was repeated every two weeks, with recruitment rates closely monitored. Names for each mail out were randomly drawn from each of the six strata described above in proportions designed to achieve a recruited cohort made up of the desired mix. It was decided that, for the purpose of reducing participant burden, children should not be included in the random draw if they had a sibling already approached in a previous mail out.
- Recruitment closed on 1 March 2016.

4.2.4 Recruitment results

Recruitment attempts revealed that the dataset included invalid address and/or phone contact details for 15% of the families, therefore they could not be contacted by the study team or HRF. Despite this problem, the ELF study exceeded its recruitment target for the baseline questionnaire achieving **548 completed surveys** (n=217 in Morwell and n=321 in other Latrobe Valley locations; refer Table 6). Response rates were higher in Morwell than in other parts of the Latrobe Valley. As Morwell has a smaller population than the rest of the Valley combined, the greater response was helpful in allowing the study to achieve balance between the two geographic regions.

Overall, the ELF study also achieved the desired balance across the three groups according to timing of exposure. The group with the smallest pool of potential participants was those exposed during pregnancy. While the response rate were higher amongst those exposed during pregnancy in Morwell, a greater number of children recruited for this group came from other parts of the Latrobe Valley.

Table 6 Recruitment numbers for eligible infants in Morwell and other Latrobe Valley locations

Group	Completed survey (n)	Response rate (%)[1]	Opted Out[2]	Refused[3]
Morwell only				
Infant Exposure	106	40	7	33
Maternal Exposure	54	47	1	18
No Exposure	57	44	2	14
TOTAL	217	43	10	65
Other Latrobe Valley				
Infant Exposure	**80**	**32**	**7**	**12**
Maternal Exposure	141	26	15	13
No Exposure	100	24	14	16
TOTAL	321	27	36	41

[1]Includes only those participants having valid contact details (i.e. an active phone number)
[2]Contacted researchers to refuse participation in study
[3]Refused survey when contacted by Hunter Research Foundation

4.2.5 Identified linkage to health databases

Data custodian approval for identified data linkage has been obtained for:

- Victorian Perinatal Data Collection
- Victorian Emergency Minimum Dataset
- Victorian Admitted Episodes Dataset
- Medicare and PBS
- Australian Early Development Census
- National Assessment Program – Literacy and Numeracy (NAPLAN)

Comparison of participants in the identified ELF cohort with the Latrobe Valley and Victorian de-identified birth cohorts

We will evaluate the characteristics of our identified Latrobe ELF cohort, and the potential generalisability of the findings from this group, by comparing aggregated results for key outcomes (such as maternal smoking, infant birth weight, and infant gestational age), with the same-age de-identified birth cohorts from i. the Latrobe Valley, and ii. the entire state of Victoria. The perinatal data extraction was originally scheduled for 2016 and all necessary ethical and administrative approvals were completed during 2015. However, we have still not received the data from DHHS.

4.2.6 Recruitment to ELF sub-studies

In addition to the baseline survey, ELF participants are currently being invited to participate in several sub-studies. These include data collected from monthly health diaries, identified data linkage and clinical testing for cardiovascular and lung development.

1. The families for 286 (52%) of participating infants have consented to complete monthly symptom diaries. To date, these electronic diaries are being returned by 70% of the consenting families.

2. The identified data linkage requires written consent. A hard-copy information and consent form was mailed to each participant after they completed the baseline survey. The return of these forms has been slow and approximately half have been received to date. The researchers are actively contacting the remainder of the cohort to facilitate return of the consent forms.

   There is a high likelihood that participation in the identified data linkage in this group will be lower than anticipated. However the risk to the overall ELF study from low participation in this part is low. The parallel de-identified data linkage study, from all the same datasets, will provide much more complete information from the full Latrobe Valley cohort. In those who do provide consent for identified linkage, we will be able to use the data to triangulate clinical information collected directly from participants or their parents (e.g. for birth weight, diagnoses of asthma). That will be valuable in assessing the validity of the data.

3. As described in the Project Plan and Figure 1, clinical testing of cardiovascular and lung development will occur in 2017. The researchers are currently, actively recruiting participants in to this clinical sub-study. There is some likelihood that participation rates in the clinical assessments will be lower than the planned target of 400. However, as recruitment progresses this assessment could change.

4.2.7 Variations from Project Plan

There have been very few variations to the Project Plan. Minor variations to the recruitment protocol have mainly been implemented to achieve the target numbers and balance across different exposure groups. For example, we included siblings if families requested this and we invited siblings in under-represented areas. Furthermore, we conducted house to house door-knocking, at the Morwell addresses of non-responders, to facilitate recruitment through personal contact.

The proposed analysis plan is unchanged for the baseline survey, health diary and data linkages components of ELF. The timing of the analysis of the de-identified perinatal data has been delayed as we are still awaiting the data from DHHS. If the final sample size for the clinical testing sub-study is lower than anticipated, then the statistical power to detect associations with some health outcomes, should they be present, will be reduced. In practice, this could mean that some secondary sub-group analyses might not be possible, such as the ability to evaluate the impact of exposure during different trimesters of pregnancy.

4.3 Psychological Impacts

4.3.1 Aims and Objectives of the Psychological Impacts stream:

The aim of the psychology research stream is to determine whether exposure to smoke from the mine fire is associated with psychological trauma and distress. Given that the study commenced more than a year after the smoke event, it is also important to examine recovery and resilience. The Psychological Impacts research stream is targeting both adults and school-aged children.

The specific objectives include:

1. Investigate the extent of trauma and distress symptoms in adults and school-aged children exposed to the mine fire event
2. Examine the role of individual, family and social factors on recovery and wellbeing outcomes
3. Explore the qualitative perceptions of adults and school-aged children regarding the fire and the ensuing circumstances.

The Psychological Impacts stream comprises two sub-studies a study of adults and a study of school children. The sub-study of adults is a component of the Adult Survey and therefore, recruitment results for that sub-study are as per the Adult Survey in section 4.1. The recruitment outcomes for the study of school children (Schools Study) are reported here.

4.3.2 Eligible subjects

Establishing the list (nominal roll) of eligible subjects

The Schools Study involved 20 schools from across Latrobe City, including government and non-government primary and secondary schools. All students at these schools in academic grades 3, 5, 7 and 9 were eligible to participate in the study. Recruitment was conducted via local schools, who approached parents on behalf of the study and invited them to consent to parents and children completing a survey as well as children potentially participating in a qualitative interview, along with consent to link to educational outcome data including NAPLAN results. In addition, the teachers of participating children were asked to complete a brief single measure on each child.

As a result, each school had its own nominal roll but due to issues of consent, this information could not be provided to the researchers. The names of participating students were only provided once parents returned the study consent form indicating their consent for their child to participate.

Final sample size

As part of the invitation process, schools were asked to provide the number of students in the relevant grades. The final sample size was the sum total across all participating grades and schools. This equated to 2138 students, with the breakdown by school type shown in Table 7.

Table 7 Sample size by school type

School type	Number
Government Primary	652
Government Secondary	666
Non-government Primary	262
Non-government Secondary	558
Total sample size	**2138**

4.3.3 Linkage to educational databases

In addition to surveys and interviews, permission was sought from parents to access NAPLAN and other educational data for participating students, including data recorded prior to and following the smoke event. In the case of NAPLAN, this relates to the 2013 and 2015 assessment rounds, providing a useful pre and post assessment of educational outcomes (except for our grade 3 students who were too young to complete NAPLAN in 2013). NAPLAN data for all participating students has been provided by the Victorian Curriculum and Assessment Authority and is currently being analysed.

We are also involved in extensive discussions with the Performance and Evaluation Division from the Victorian Department of Education and Training regarding access to other educational data including school reporting, absences, and other data. The Department has approved access to these data but the process of extracting them has proved challenging.

In addition to seeking data for our participating students, we are also keen to access de-identified NAPLAN and other educational data for the participating schools and for the wider region. This will enable us to further examine sampling bias (see 4.3.6 below) as well as conduct further analyses comparing impacted and non-impacted areas in terms of educational outcomes – similar to the work being conducted for health outcomes through the Hazelinksstream (refer Section 4.6). We have received MUHREC approval to undertake this analysis of de-identified data but are waiting to hear from the Victorian Department of Education and Training regarding whether they can extract the required data for us.

4.3.4 Recruitment time line

Student recruitment took place during 2015-2016. After extensive consultations with schools, it was decided that recruitment should be focused on Term 3, in order to avoid the NAPLAN round in May and the reporting periods in Terms 1 and 4. In order to ensure that the recruitment procedures were appropriate, they were piloted in a single school at the start of Term 3. Following this, recruitment commenced in the rest of the schools from week six of Term 3. Recruitment was a multi-staged process taking at least six weeks in each school, that included advance notices to be sent home, the invitations dispatched, followed by three reminders sent to parents by multiple means (written notices, emails (where possible within the school), and finally phone calls from school administrative staff).

In addition to student surveys, parents were asked to complete a survey providing information about the student and about their family background (including child and parent mental health history). Teachers were also asked to complete a single scale for each child (the Strengths and Difficulties Questionnaire). Parent and teacher surveys commenced later in 2015, after students consent was obtained and surveys completed. The parent and teacher data collection extended into 2016 and was closed off in April 2016.

During the data collection process we received considerable feedback from school staff regarding the need to consult with them regarding the impact of the smoke event on the students, the staff, and the school operations. As a result, we decided to undertake a pilot study with one specialist school in Morwell. Our intent was to conduct qualitative interviews with up to eight staff members in mid-2016.

4.3.5 Recruitment results

Table 8 outlines the number of eligible students from the 20 participating schools and child participation rates broken down by academic grade and location.

The overall response rate was 15%, with 25% of Morwell students agreeing to participate compared to 12% of non-Morwell students. This finding, that less exposed groups were least likely to participate, mirrors the experience of the Adult Survey where residents from the Sale comparison community were also less likely to participate. In addition, it was more challenging to recruit older students, particularly those in grade 9. When secondary students were excluded, the response rate was 22% overall and 31% within, and 17% outside, Morwell.

The recruitment rate achieved here was in line with previous literature on the impact of disasters and trauma on children and youth where the rates were between 15-35%. It is apparent from this review of the literature that recruiting into trauma studies is considerably harder than into other general studies, perhaps as a result of ‘trauma fatigue’.

Table 8 Eligible students, completions and participation rates for Morwell and Outside Morwell schools according to year levels.

Grade	8 Morwell schools		12 schools outside Morwell		All 20 schools	
	Eligible	participants n (%)	Eligible	participants n (%)	Eligible	participants n (%)
3	174	58 (33.3)	300	55 (18.3)	474	113 (23.8)
5	162	47 (29.0)	278	43 (15.1)	440	90 (20.5)
7	77	16 (20.8)	550	68 (12.4)	627	84 (13.4)
9	90	5 (5.6)	507	31 (6.1)	597	36 (6.0)
Total	**503**	**126 (25.0)**	**1635**	**197 (12.0)**	**2138**	**323 (15.1)**
3+5+7	413	121 (29.3)	1128	166 (14.7)	1541	287 (18.6)
3+5	336	105 (31.3)	578	98 (17.0)	914	203 (22.2)

As noted above, in addition to asking students to complete the survey, a sub-sample of students were invited to participate in qualitative interviews. The full complement of 69 interviews were completed, providing rich and extensive qualitative data and a large enough cohort to follow over time.

The participation rate of parents completing surveys about their child and the family was 65.5% and the participation rate for teachers was 87.1%. In addition, we were successful in interviewing eight staff members from one Morwell specialist school as part of the small pilot project.

It should be noted that, upon the advice of the Community Advisory Committee, the Schools Study did not reimburse participants with a gift card or voucher. The later decision, by the Adult Survey and ELF to provide reimbursement gift cards was made in response to the recruitment challenges faced by the Schools Study. We believe that had the Schools Study offered reimbursements the participation rate would have been equivalent to the Adult Survey. We now have approval to reimburse participants in the next round of data collection.

4.3.6 Assessment of sampling bias

As with all studies that do not achieve a very high participation rate, there is the possibility that the recruited sample differs in some way from the target population. Because we were unable to access any details about eligible students until receiving parental consent for them to participate, we were not able to administer a Refuser Questionnaire along the lines of that included in the Adult Survey. To identify reasons for non-participation, we interviewed the school administrative personnel who were involved in the recruitment activities. They reported that the most frequent reason cited by for not participating in the study was that parents did not think it was relevant to their children. This was particularly the case for those children who attended school outside of Morwell. This was regardless of the fact that the invitation material, and all notices about the study, emphasised the importance of all children in the targeted schools and grades participating, regardless of whether they thought they were impacted by the smoke event, so that we could better understand of the depth and spread of the impacts. Other reasons, for not participating, included finding the survey challenging to complete and resistance to filling out surveys.

One way to assess sampling bias was to compare the characteristics of the recruited sample with data available from other sources. We have begun this process using ABS data from the 2011 Census, comparing our age groups with the 2011 age-matched cohort from the Latrobe City local government area (e.g. the majority of our grade 3 students in 2015 were eight years old in 2015 so we have compared them with 2011 census data on four year olds). Table 9 provides the comparison data in terms of gender and indigenous status.

Table 9 Comparison between Schools Study participant group and aged-matched 2011 Census data

	Schools Study participants		2011 Census data	
	Gender	Indigenous status	Gender	Indigenous status
School grade	(% male)	(% ATSI*)	(% male)	(% ATSI*)
3	53.1	5.3	53.0	8.7
5	53.3	7.8	50.8	7.2
7	37.2	4.7	52.9	8.2
9	50.0	0.0	52.6	9.7
Total	**48.6**	**5.2**	**52.4**	**8.5**

*ATSI: Aboriginal or Torres Strait Islander

It is apparent that the participant group are comparable to their age-cohort on the above two measures. With further mining of the ABS data, we expect to be able to make additional comparisons between our participants and their age-cohorts.

The 2013 NAPLAN data provides another important comparison point as it was collected prior to the smoke event and so could not have been influenced by that event. Table 10 below summarises this comparison, making use of published NAPLAN data from the MySchool website for each of the grade levels in each of the participating schools.

Table 10 NAPLAN 2013 domain scores for Schools Study participants compared with their school by grade cohort

NAPLAN Domains	Schools Study (mean, S.E)	MySchool (mean, S.E)	Mean Difference	% difference	p-value
Reading	472.87 (83.55)	458.00 (64.55)	14.87	3.25	0.05
Persuasive writing	447.65 (68.34)	436.47 (55.40)	11.18	2.56	0.17
Spelling	450.31 (86.90)	443.12 (65.59)	7.19	1.62	0.31
Grammar	470.55 (74.94)	450.88 (56.66)	19.67	4.36	0.01
Numeracy	440.83 (80.58)	439.00 (67.71)	1.83	0.42	0.80

Across all NAPLAN domains, the Schools Study participants scored modestly higher than their larger grade by school cohort, with an increase of up to 4% (on grammar). This increase was statistically significant for the two NAPLAN domains of reading and grammar. While this suggests that children scoring higher on NAPLAN were more likely to participate, the sizes of these differences were modest and, therefore, likely to have had a minimal impact on the Schools Study findings.

Another likely bias was that students with greater exposure to the smoke event may have been more likely to participate compared to those with lesser exposure. As seen in Table 8 above, this seems to have been the case with Morwell students being more likely to participate than those in schools outside Morwell. Similar bias may have also influenced participation within Morwell, as schools toward the south of Morwell were more exposed to the smoke than their northerly counterparts.

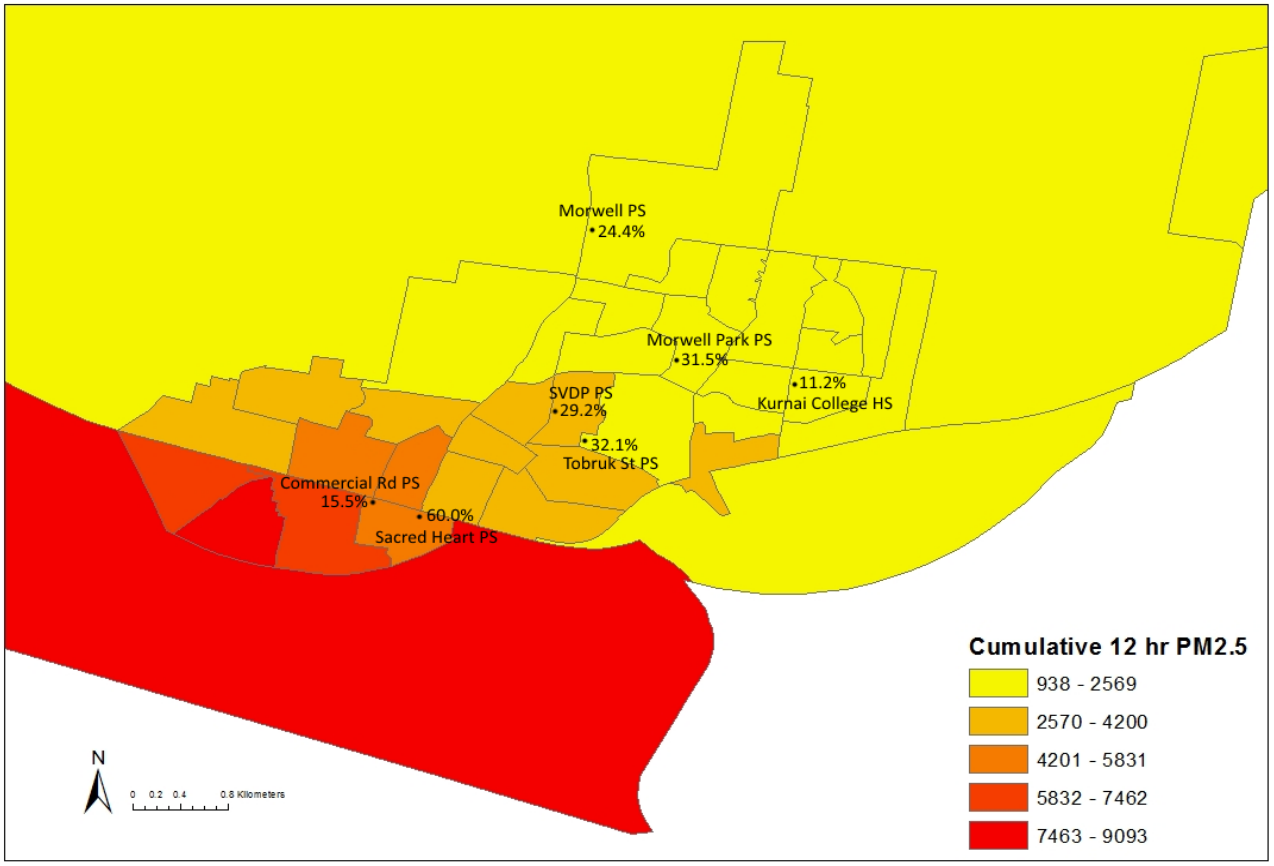


Figure 10 School participation rates in Morwell by CSIRO modelled cumulative 12 hourly $PM_{2.5}$ exposure

Figure 10 provides a mapping of cumulative 12-hourly $PM_{2.5}$ exposure across Morwell for the period of the mine fire, along with the location and participation rates of seven Morwell schools. There was no clear evidence for participation being higher in more exposed schools, with divergent results between the two most exposed schools, and relatively consistent participation in the primary schools spanning the other exposure levels, suggesting that we have an appropriate sample upon which to base comparisons within Morwell.

4.3.7 Variations from Project Plan

Variation to recruitment protocol

In the original project plan we proposed to target only seven schools, in Morwell and Moe-Newborough, and to randomly select one class from each of the targeted grade levels (3, 5, 7 & 9) at each school. The estimated sample size was 616 students. Moe-Newborough had been selected as the comparison community based on the assertion, at the time, that Moe-Newborough had received little exposure to the smoke event. While the CSIRO air quality modelling has since confirmed that there was a considerable difference between the exposure levels in the two communities, it was clear that Moe-Newborough had received more exposure than originally thought. As a result, the decision was made to expand the Schools Study to include schools from across Latrobe City. This facilitated a wide gradient of actual and perceived exposure, access to schools from larger and smaller towns and also rural localities like Hazelwood North.

In addition, and after considerable consultation with schools, local and state education departments, the Community Advisory Committee and other stakeholders, the decision was made to approach all schools within Morwell and all classes in the target grades in all participating schools - resulting in the total sample of 2138 students which was more than three times the original target. While this expansion added considerable depth and validity to the study, it also made recruitment substantially more challenging and the researchers had to find resources and staff which were additional to those included in the HHS budget and contract. Even with this significant expansion, we have received feedback from some parents who were unhappy that we hadn't included all school grades and had, therefore, excluded their child. It was felt, however, that it was beyond the scope of the study to attempt to target further school children and that the focus on the NAPLAN years provided a useful framework.

To further supplement the data collection beyond the original scope of the Project Plan, a small qualitative study was conducted with a specialist school in Morwell which was located in relatively close proximity to the smoke event. Instead of targeting students, this project targeted school staff such as teachers and support personnel. We were able to recruit eight of the school staff members, representing half of the personnel. They participated in qualitative interviews regarding the impacts of the smoke event on the students, on their educational outcomes, and on the operations of the school.

Variation to data linkage protocol

In the original project plan we had proposed to link to NAPLAN and other educational data for the participating students. We are now seeking to also access de-identified data for the participating school by grade cohorts in order to assess sampling bias, as well as de-identified data for all schools in Latrobe City and the wider region in order to investigate whether educational outcomes for schools in the

impacted region differ from those for schools further away. As noted above, we are still seeking access to this additional data.

Variation to data analysis

The data analysis conducted to date is in line with the original analyses proposed.

4.3.8 Future recruitment and analysis

As per the original project plan, we will be seeking to re-survey the round 1 participants who were in grades 3, 5 and 7, and to recruit a new cohort of grade 3 students. As noted above, we are intending to provide a reimbursement for participating in the study (proposing $20 per survey and interview completion) which we believe will improve recruitment and retention.

In addition to our analyses above, we are also keen to extend the pilot work conducted last year interviewing school staff by rolling this out in one or two of the more impacted schools. Finally, as noted above, we are keen to conduct analyses utilising de-identified educational outcome data for the participating schools and the wider region.

4.4 Policy Review of the Impact on Older People

4.4.1 Aims and Objectives of the Impact on Older People stream:

The aim of this component of the study was to assess the impact of the smoke event on older people, focusing particularly on a review of the policy decisions made with respect to older people during the event. The objective of this work is to inform best practice for future emergency events.

4.4.2 Eligible subjects

This stream targeted the following six groups:

1. Older people living in the community – in order to be inclusive, no age cut-offs were used.
2. Older people living in a residential aged care setting – one facility which was evacuated during the smoke event was targeted.
3. Home and Community Care (HACC) service users – via the lead HACC provider in Latrobe City.
4. Families and carers of older people.
5. Service providers – including service staff from local government, community health organisations, multicultural services, neighbourhood house etc.
6. Decision makers – including lead executives from local government, Health Department (Regional and Head Office), community health.

Targeted number of participants

It is not possible to nominate a set sample size for qualitative work. Instead, the work continues until the point of data saturation is reached, i.e. the point at which no further new information is forthcoming. However, we decided to cap focus groups at 15 and predicted that we would require at least three such discussions for the community dwelling older people, and the families and carers of older people. In addition, we expected to run at least one focus group with HACC clients and residential aged care residents. The discussions with service providers and decision makers were to be conducted using face to face interviews and we expected that there would be at least ten interviews required.

Based on the above, the expected numbers were as follows:

- Older people living in the community	up to 45
- Older people in residential care	up to 15
- HACC service users	up to 15
- Families and carers of older people	up to 45
- Service providers and decision makers	up to 10
Expected total	**up to 130 people**

4.4.3 Recruitment timeline

In accordance with the planned stream timeline (see Figure 1) preparations to recruit people in to the Older People stream focus groups began in the 2nd quarter of 2015. Subsequently, the first focus groups with older people living in the community and with families and carers took place in August and September 2015. As noted in more detail below, attracting people to these sessions by using public advertisements was not very successful. However, in October 2015 the researchers approached an existing community group of older people with the request to run a focus group during one of their routine meetings, and this resulted in greater participation. Thus, the decision was made to change the recruitment strategy to target existing community groups instead of relying on publicly advertised forums. It was necessary to have this change, to the recruitment strategy, approved by the Human Research Ethics Committees (HRECs) which oversee this research. HREC approval was received in late 2015 and recruitment activities recommenced.

The remaining group-based discussions, including a session involving older people in residential care, were completed by March 2016.

The interviews with service providers and decision makers were conducted once the community focus group discussions were completed, taking place in April and May 2016. Following the completion of the focus groups and interviews, a workshop involving key community and organisational participants was run in September 2016.

4.4.4 Recruitment results

As reported above, the Impact on Older People stream found it difficult to attract participants to open community-based sessions via public announcements, at times and locations determined by the researchers. A total of 14 people attended two such sessions made available in two different community locations. Consequently, the decision was made to recruit via existing community groups by inviting them to host focus group discussions at their regular meetings and venues. This approach proved to be very successful with five group sessions completed in 2016 yielding a further 63 participants from different facets of the Morwell community. In addition, we completed one-on-one interviews with six older people in a residential aged care facility, and a focus group discussion with eight older volunteers from a community service group.

These recruitment activities yielded a suitably large and diverse group of 91 participants in total and, as no further information was forthcoming in the latter sessions, the community-based discussions were brought to a close. Whilst no age cut-off was used to limit inclusion, most participants were in the range of 60 – 90 years of age.

These sessions were transcribed and thematically analysed to inform the second phase of the research, which included conducting interviews with ten service providers and seven decision makers at local and state levels.

Data collection for this stream included a desktop review of relevant literature and policy documentation to complement the information received through the focus groups and interviews. In total, almost 100 research and policy documents were cited in the stream report – making it an extensive review.

Conclusions drawn were verified in a workshop with key respondents in September 2016.

4.4.5 Variations from Project Plan

Variation to recruitment protocol

As noted above, recruitment through public announcements of sessions being run at key local venues proved to be challenging and we needed to modify our approach to target existing groups at their current meetings and venues. Once this change was made we had no difficulty reaching the target number of groups. In fact, we ended up speaking with more community dwelling older people than originally planned, providing a much richer dataset. We made considerable efforts to speak to a variety of groups, including both healthy older people and those with more significant health needs.

The original plan had been to recruit families and carers of older people, but this proved to be extremely challenging as there is no existing community group matching that profile. As a result, we abandoned this component of the work. Similarly, we had planned to conduct a focus group with HACC service recipients as we were aware that they had received considerable support during the mine fire event. However, efforts to recruit from this cohort were unsuccessful, even with the support of the lead agency responsible for the provision of HACC services in Latrobe City which approached HACC clients on our behalf. The challenges accessing HACC recipients is likely to be a reflection of the less mobile nature of this group of people making it hard for them to attend meetings. It may also be the result of this group having received considerable support during the event, and so they may have felt that there was nothing to gain from participating. While we were unable to recruit family members and HACC recipients, we are very confident that the large and diverse group of older people gave us a strong understanding of the impacts of the Hazelwood event on older people.

Another change, from the 2014 Project Plan, relates to the timeline, with the initial plan being to complete the stream activities by August 2016. Our revised recruitment strategy was so successful that we ended up running more sessions with more participants than originally planned. Similarly, we were able to interview more stakeholders than planned. This meant that we had a much larger qualitative data set to analyse, taking considerably more time to complete. In order to do justice to the Policy Review of the

Impact on Older People it was agreed with DHHS that the stream researchers would submit an extensive interim report to meet the August milestone requirements. That detailed working paper was submitted on 15 August 2016.

An unplanned verification workshop, with key informants, primarily community members and local service providers, was undertaken in September 2016 to inform the final report. The final report and an accompanying Policy Brief were completed and submitted as a milestone requirement on 30 November 2016.

Variation to data analysis

There were no variations to the data analysis plan as proposed in the 2014 Project Plan. The qualitative data from the community focus groups were transcribed and imported into the NVivo qualitative analysis, package. An initial thematic analysis of the text was undertaken to identify recurring themes which informed the final question schedules for the interviews with key stakeholder organisations. A systematic thematic analysis of the focus groups and interviews was subsequently completed. A desktop review of the research and policy literature informed the interpretation of the findings which were verified and extended through further discussion with key community and organisational contacts.

4.4.6 Impact on future recruitment and analysis plans

The Older People Policy Review was designed to be a discrete piece of work to be completed in 2016. As a result, there is no current plan for future recruitment and analysis for this component. As outlined in the project plan, the focus on older people will continue through targeted analyses of the impacts of the smoke event on older people via the Adult Survey, the Psychological Impacts stream and the Clinical streams.

While the current program of work is now complete further qualitative work targeting older people will continue via the Community Wellbeing stream.

4.5 Impact on Community Wellbeing

4.5.1 Aims and Objectives of the Community Wellbeing stream:

The initial (phase 1) focus of this stream was to provide narrative evidence of the perceived impact of the Hazelwood mine fire smoke event in Morwell and surrounding communities on community wellbeing. Specific objectives were to identify community perceptions of:

- the impact of the smoke event on community wellbeing;
- the effectiveness of community rebuilding activities; and
- effective communication during and after the smoke event.

To achieve these aims, this stream used a qualitative, interpretive research design with two main components:

1. A community engaged component conducting focus groups and individual interviews;
2. A media analysis component analysing archival sources of mine-fire-related media and interviewing media stakeholders.

The second (phase 2) focus of this stream engaged with community groups in participatory action research, focusing on strengthening identified aspects of community wellbeing.

The projected activities in relation to recruitment and data collection were:

- Media analysis to be conducted in years 1, 3, 6 and 10 of the Hazelwood Health Study.
- Focus groups with community residents and stakeholder groups in years 1 and 3.
- Individual interviews with organiser and participants in community recovery and rebuilding activities in year 1.
- Two participatory action research projects in year 2.

4.5.2 Eligible subjects and data sources

The *community engaged* component targeted the following community members and groups:

- Key informant interviews were drawn from health professionals, social agencies, media stakeholders, aged care facilities, schools, and community groups. Focus groups targeted members of the Morwell community and also two nearby communities, Moe and Traralgon.

The *media analyses* aimed to capture:

- Media associated with the mine fire for the period 10/2/14 to 25/03/14. This included local media and social media sources available to the Latrobe Valley community, in which they may be represented or their views expressed. Full-text collection of local news media articles (ABC

Gippsland online, *Latrobe Valley Express*) and social media (Voices of the Valley Facebook, The Air That We Breathe Facebook, and Occupy Latrobe Facebook).

- Media after the fire event (26/03/14-31/12/15) with the focus widened to include local, state and national news media sources, including ABC (state TV news and current affairs), ABC Gippsland (regional radio and online news), *Latrobe Valley Express, The Herald Sun, The Age,* WIN TV, Voices of the Valley Facebook, Occupy Latrobe Facebook, The Air That We Breathe Facebook.

The *participatory action* research is targeting a range of community groups in Morwell irrespective as to whether individuals were Morwell residents or not.

4.5.3 Recruitment and data collection

Phase 1 - Community-engaged component

As stated in the stream report for the Policy Review on the Impact on Older People, it is not possible to nominate a set sample size for qualitative work. Instead, the research continues until the point of data saturation is reached, i.e. the point at which no further new information is forthcoming.

Initially three focus groups were scheduled, one each in Morwell, Traralgon and Moe. Although advertised through a variety of means, these did not attract the numbers we anticipated:

- Morwell (8 participants)
- Moe (2 participants)
- Traralgon (no participants)

Interviews have also been conducted with 24 key informants (13 in 2015 and 11 in 2016), recruited from organisers, supporters and participants in community recovery activities. These community recovery activities were identified during an earlier 2014 study by the Centre of Research for Resilient Communities (CoRRC) and through continuing media analysis and community network information.

It was planned that an additional focus group would be run with either residents or stakeholder groups within the indigenous community. However the Victorian Council of Social Services (VCOSS) had already conducted similar work (VCOSS 2015 *Submission to the 2015 Hazelwood Mine Fire Inquiry*; http://vcoss.org.au/documents/2015/08/SUB_150804_2015-VCOSS-Submission-to-the-Hazelwood-Mine-Fire-Inquiry-.pdf) and we did not want to burden this small community further by seeking similar information. In addition, the VCOSS report seemed to reflect what we were already hearing in our interviews with members of the broader community.

Many of those interviewed, or approached for interview, expressed some fatigue in retelling their initial experiences and perceptions of the smoke event and frustration at the apparent lack of recovery processes. This also may explain the lack of expected participants in the focus groups. From analysis of the focus group and stakeholder interview material, as well as the VCOSS report and material from nineteen stakeholder interviews conducted for the smaller CoRRC project undertaken in 2014, it was decided that saturation had been reached in obtaining community narratives about the initial experiences of the smoke event.

Phase 1 - Media analysis component

As noted above, data collection for the media analysis component covers two periods, during the period of the mine fire (10/2/14 to 25/03/14) and for the remainder of 2015 (26/03/14-31/12/15), which equates to year 1 of the study. Data collection is currently being repeated for Year 3. The number of media articles and social media posts collected for analysis is shown in Tables 11-13 below.

Table 11 Social media by Facebook group

Collection phase	Voices of the Valley	Occupy Latrobe	The Air that we Breathe	Total
Period 1	385	17	73	***475***
Period 2	407	0	20	***427***

Table 12 Media by outlet

Collection phase	Latrobe Valley Express	Herald Sun	The Age	ABC Gippsland online	WIN TV*	Total
Period 1	142	26	37	127	-	***332***
Period 2	43	33	56	101	19	***233***

* Data collection begins April 2015. WIN TV is not covered by online databases such as ProQuest/Factiva and therefore data collection relied on the media alert service forwarded to the Health Study by DHHS. Missing data will be sought directly from WIN TV.

Table 13 Combined media and social media

Collection phase	Media	Social media	Total
Period 1	332	475	**807**
Period 2	233	427	**660**
Both periods	*565*	*902*	***1467***

To complement the above media analysis, interviews were conducted in Year 2 with four local journalists/media professionals and four social media site administrators.

Phase 2 - Participatory action research

Human Research Ethics Committee approval was granted for the participatory action research component in late July 2016. This research focuses on how communities may strengthen identified aspects of community wellbeing. Participatory Action Research acknowledges research as a process of collaboration, whereby researchers and those being researched work together at all stages of the

research project. The aim is to facilitate and enhance capacities already held within these communities. This methodology is time consuming, involving three separate meetings: (1) introduction to project and discussion about what is involved, (2) discussion about the significance of the group to its members and its relationship to Morwell, as well as finalising what participants would like to do in terms of data collection, e.g. interviews, photographs, ethnographic material and so on; and (3) a meeting to collect data. In addition, this methodology requires a significant amount of time to develop the relationships of trust between members of the groups and the research team, as well as ensuring that the projects reflected the concerns and direction these community groups wanted to take.

In July 2016, intense work commenced with members of two community groups – i.e. Morwell Neighbourhood House (three focus groups each with 8-11 participants) and the Morwell Rose Garden (three focus groups each with 20-25 participants).

In 2017 we plan to continue and extend the participatory action research. The goal is to work with between 10-12 community groups in Morwell in the next 6-8 months. We are particularly interested in working with youth communities, as this is a cohort that has been difficult to access for the overall project.

Stream lead Dr Michelle Duffy attended the first 2017 Community Advisory Committee meeting to request assistance in determining appropriate community groups for recruitment, and we now have a significant list of potential community groups to invite as participants.

In addition, and integral to this component of the project, is dissemination of the findings in a manner accessible to the community. The stream is planning to hold an exhibition, which will be developed in consultation with members of the community groups and the curator at the Latrobe Regional Gallery.

4.5.4 Variation from the Project Plan

Year 1 (2015)

Phase 1 Community-engaged component

The low participant numbers in the community focus groups were due to two key factors:

- Many of those interviewed, or approached, expressed some fatigue in retelling their experiences and perceptions of the mine fire smoke event.
- The focus group for Traralgon was scheduled on a day that unfortunately had very bad weather and included an electricity outage shortly before the meeting was to commence, which accounts for the lack of any participants.

From an analysis of the interview and focus group material that was collected, as well as 19 stakeholder interviews conducted for a small project undertaken in 2014 prior to the Hazelwood Health Study (which included residents, volunteers, and employees), we decided that we had reached saturation in obtaining community narratives about the initial experiences of the smoke event.

As explained above, we decided not to pursue a focus group with either residents or stakeholder groups within the indigenous community, because similar work had already been conducted which reflected what we were already hearing in our interviews with members of the broader community.

Year 2 (2016)

Phase 2 Participatory Action Research

Given the interview fatigue expressed by participants and poor recruitment in Year 1 (2015), we decided to a move away from an open call to the community to participate, and instead establish more targeted discussions with specific community groups – so instead of requesting community members to come to us, we decided to go to community groups and attend their meetings and activities. This is similar to the strategy adopted by the Policy Review of the Impact on Older People Stream.

The initial plan for the Participatory Action Research component was a focus on the opportunities and challenges of living in Morwell, and more specifically what 'recovery' meant or looked like following the mine fire. In early 2016, members of the Community Wellbeing Stream met with the Morwell Neighbourhood House and VCOSS, who were very supportive of this focus.

We had planned to interview participants who attended and were involved in community rebuilding activities in the time period soon after the mine fire. However, many of these were one-off events such as the 'Snow' day at Morwell Neighbourhood House. This made it difficult to source potential interview participants. Nonetheless the perception of many people in the community about recovery events and initiatives is that there are no activities associated with recovery (although not necessarily correct, this is the perception held). The interviews we conducted confirmed that the perception in the community is that not much had happened in terms of recovery and that generally their concerns and issues had not been adequately addressed.

Given this we decided to talk more broadly to community members about their views on community recovery – what has happened in this area; their sense of how the community is travelling; and what still needs to happen for a sense of community recovery. Therefore instead of interviewing people who had attended or participated directly in recovery events, we decided to approach representatives of community organisations that we could identify as either having run an event, are involved in the recovery more generally, or who represent sectors of the community that were likely to have been particularly impacted by the fire event.

In 2016 we worked with the men's group at the Morwell Neighbourhood House and had some initial discussion with members of the Sudanese community and Mitchell House Aged Care Facility (discussion facilitated by the Morwell Neighbourhood House). The Sudanese Community and Mitchell House did not

continue with this project. In 2016 we worked very closely with Morwell Neighbourhood House in devising and revising the approach to be taken. We then invited the Morwell Rose Garden to participate in this project.

After working intensely with Morwell Neighbourhood House and the Morwell Rose Garden Group, we have refined the focus by asking participating communities to reflect upon what membership of that community means to the individual, and how this membership may (or may not) be important during events like the Hazelwood Mine fire. This focus has resonated strongly with our participating communities, and is likely to entice other community groups to participate.

Phase 2 Media analysis component

There is no variation of the recruitment plan for the media component.

Year 3 (2017)

Phase 2 Community-engaged component

This year we will also interview up to eight members of key stakeholder groups that were interviewed in 2014 (prior to the Hazelwood Health Study) and 2015 (the first year of the Study) to get a sense as to their perceptions of community wellbeing and/or vulnerability, particularly if there are significant changes since 2014.

Phase 2 Media analysis component

There is no variation to the recruitment protocol for this component of the project

Variation to data analysis

There have been no changes to the planned analytic approach.

4.5.5 Impact on future recruitment and analysis plans

We need to acknowledge that we continue to meet with people who express some fatigue in retelling their experiences and perceptions of the mine fire smoke event, especially as it is now three years since the mine fire. This is compounded by the presence of a number of research groups working in the Latrobe City interested in similar community issues.

The imminent closure of the Hazelwood power station and Morwell open cut mine, as well as other possible industry closures, is causing additional stress on the Morwell community. This will have some impact on our findings in terms of recovery, as well as community resilience and vulnerability.

4.6 Hazelinks

There are two components of Hazelinks: identified data linkage and anonymised data extraction. A flow chart of data sources for Hazelinks identified linkage and anonymous extraction is presented in Figure 11.

4.6.1 Overview of identified linkage with consent

As described in section 4.1.5, identified Adult Survey participant information will be linked to routinely collected ambulance, hospital, cancer and death registry data health databases, for the purpose of investigating the potential health effects from the Hazelwood coal mine fire. The linkage may identify members of the Adult Survey cohort who subsequently develop respiratory or cardiovascular conditions, develop cancer, and/or die. This identified linkage can only be undertaken with participant consent.

4.6.2 Overview of anonymised data extraction

Anonymised data extracts from relevant health registries will be used to investigate the short, medium and longer term health effects of exposure from the mine fire smoke. These include routinely collected ambulance, hospital, cancer and death registry data. Data extracts will be requested for all ages for the period 1 January 2009 to the most recent available data (not provisional) for areas that were most affected by the smoke, as well as areas that were minimally exposed (for the purpose of comparison). These include the East of Victoria (Hume, Gippsland and Eastern Metropolitan regions), and a small part of the Southern Metropolitan region (Cardinia).Medicare and PBS data have also been requested however this dataset will only include records for the whole of Latrobe Valley (due to privacy restrictions) and only four years of data from 1 July 2012 onwards (as the Department of Human Services only holds 4.5 years of data).

4.6.3 Datasets for identified linkage and data extraction

It is intended that identified linkage will be undertaken with datasets 1-5 below, and anonymised data extraction will be undertaken for datasets 2-7 below.

1. National cancer incidence data from the Australian Cancer Database (ACD) held by the AIHW.
2. Victorian cancer incidence data held by the Victorian Cancer Registry (VCR).
3. Hospital admissions and emergency presentations data from the Victorian Emergency Minimum Dataset (VEMD) and the Victorian Admitted Episodes Dataset (VEAD) respectively, held by the Victorian DHHS.
4. Ambulance data from the Victorian Ambulance Clinical Integration System (VACIS) and the Victorian Ambulance Cardiac Arrest Registry (VACAR) held by Ambulance Victoria.
5. Mortality data from the National Death Index (NDI) held by AIHW.
6. Mortality data from the National Mortality Database (NMD) held by AIHW.

7. Medicare data (GP, specialist and consultant attendances) and PBS data (for medication use), held by the Commonwealth DHS.

It is planned that identified data linkage and data extraction will be repeated approximately every 2-3 years for the duration of the project. Each dataset provided will include a measure of geographical location for each unit record (geocodes, SA1, SA2, SA3 or postcodes) which will be linked to air quality data.

4.6.4 Data custodian approval

Approval has been obtained from the relevant data custodians to access the following databases:

1. Ambulance: VACAR and VACIS data (identified linkage and data extraction).
2. Hospital: VAED and VEMD data (identified linkage and data extraction).
3. Cancer: VCR data (identified linkage and data extraction).
4. Cancer and Mortality: ACD and NDI data (identified linkage only).
5. Mortality: NDI and NMD (data extraction only).
6. Medicare and PBS data (data extraction only).

4.6.5 Progress to date

Table 14 Data extraction: Identified linkage

Datasets	Received	Date range of received data	Status
Ambulance Data (VACAR)	✓	1/01/2009 - 31/03/2015	Checked
Ambulance Data (VACIS)	✓	01/01/2013 - 31/03/2015	Checked
	✓	01/01/2009 - 31/12/2012	To be checked
Hospital data (VAED)	✓	01/01/2009 - 30/06/2015	Checked
Hospital data (VEMD)	✓	01/01/2009-30/06/2015	Checked
Death data (NDI and NMD)	×	N/A	Extract expected in the next few months
Medicare data (MBS)	×	N/A	Extract expected in the next few weeks
Pharmaceutical Benefits Scheme data (PBS)	×	N/A	Extract expected in the next few weeks
Victorian Cancer Registry data (VCR)	×	N/A	Extract expected in the next few months

The estimated timeline for identified linkage to health datasets will be established when the Adult Survey cohort is finalised and data cleaning is complete.

4.6.6 Variation from Project Plan

In the original project plan we proposed to undertake identified linkage with Medicare and PBS data. As the Department of Human Services did not approve verbal consent the researchers determined that this linkage was not feasible. Therefore we have now replaced the identified linkage to Medicare and PBS data with anonymous data extraction.

Another variation relates to the fact that the original Project Plan included only identified linkage. Hazelinks has been expanded to include anonymised data extraction of ambulance, hospital, cancer, death, Medicare and PBS data. As the identified linkage was limited to residents who participated in the Adult Survey and who consented to linkage, the anonymised extraction was introduced to include population wide health data for the geographical regions of interest, as well as surrounding areas (for comparison purposes). These data will be linked to air quality data from the CSIRO using geo-coded addresses, SA1 or postcodes (depending on the variables released in each health dataset). It is intended that the anonymised data extraction will be repeated approximately every 2-3 years for the duration of the study.

An expanded period of data, for up to five year before the mine fire, will be requested to account for the varying weather conditions across the years. This will ensure that the mine fire period is not solely compared to another year of extreme weather conditions. However, it should be noted that Medicare and PBS data are only available for the previous four years.

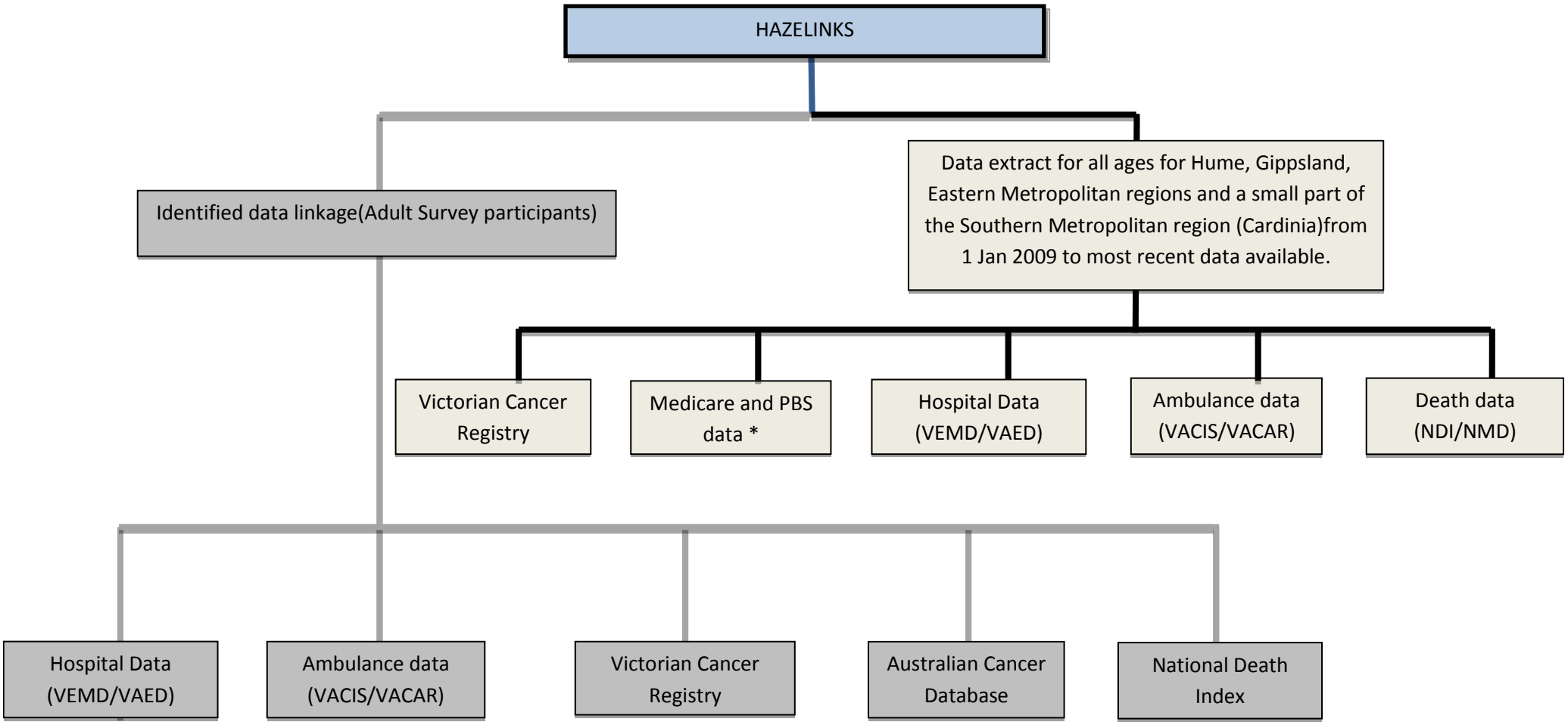


Figure 11 Flow chart of data sources for Hazelinks identified linkage and anonymous extraction

4.7 Clinical stream

The specific research questions relevant to the Clinical stream (formally separate Respiratory and Cardiovascular streams) are as follows:

Is there evidence that people in general, and susceptible sub-populations in particular, who were heavily exposed to emissions from the Hazelwood fire, compared with otherwise similar people who were minimally exposed to emissions from the fire:

a) currently have clinical or sub-clinical cardiovascular or, respiratory conditions that could be associated with clinically important adverse health consequences in the future?
b) over time develop clinical or sub-clinical cardiovascular or respiratory conditions that could be associated with clinically important adverse health consequences in the future?

The aims of the Clinical stream are to determine whether exposure to smoke from the Hazelwood coal mine fire is associated with:

- Respiratory symptoms
- Asthma control and lung inflammation
- Rate of decline in lung function.
- Gas transfer and small airway function
- Blood pressure
- Abnormal Electrocardiographs (ECG).
- Endothelial function (as a marker of early vascular disease).
- Inflammatory markers, such as C-Reactive Protein (CRP)

The Clinical stream will recruit participants from those who completed the Adult Survey. The delay in the Adult Survey closure may delay the commencement of the Clinical stream, which was projected to commence recruitment in the 2nd quarter of 2017.

In the Project Plan it was projected that the Clinical Stream would require approximately 300 participants from each of Morwell and Sale for respiratory testing, and the same again for cardiovascular testing. It was proposed that, for cardiovascular testing, older people would be over sampled with and without pre-existing cardiovascular disease and/or diabetes. For respiratory testing, participants with a history of asthma would be over sampled, as would asymptomatic non-smokers. The actual numbers of Adult Survey participants meeting these criteria are not yet known and will be determined after the Adult Survey data has been cleaned.

4.8 Exposure Assessment

CSIRO Oceans & Atmosphere Flagship were subcontracted to conduct an in-depth analysis of existing air quality datasets in order to:

- Identify key pollutants relevant to health impacts;
- statistically analyse differences in pollutant concentrations measured at Morwell during smoke-impacted and non-smoke impacted periods (e.g. background ambient air quality in the Latrobe Valley);
- compare pollutant concentrations measured at Morwell to other urban sites within Australia and assess of the impact of Morwell fire on ambient air quality.
- Provide exposure fields for $PM_{2.5}$across Morwell and the greater Latrobe Valley.

CSIRO has completed these works.

In May 2015, CSIRO completed a report which made preliminary estimates of how far the mine fire smoke travelled in the air, and how often it passed over different towns within the Latrobe Valley and the broader Gippsland region for the duration of the fire.

In May 2016, CSIRO completed a report describing the air quality during the Hazelwood mine fire based upon measurements made by various organisations. Pollutants measured include particles smaller than 2.5 µm ($PM_{2.5}$) and smaller than 10 µm (PM_{10}), carbon monoxide (CO), ozone (O_3), nitrogen dioxide (NO_2), sulphur dioxide (SO_2), volatile organic compounds (VOCs) (e.g. benzene and formaldehyde), polycyclic aromatic hydrocarbons (PAHs) (e.g. benzo(a)pyrene), dioxins and metals.

In December 2016, CSIRO submitted a report, and provided the associated data fields, for modelling which provides hourly air exposure estimates for the entire smoke effected area in the Latrobe Valley, distinguishing between exposure from the Morwell fire and other air pollution sources. The modelled data are integral to the Adult Survey and ELF streams which aim to estimate each participant's cumulative exposure to air pollutants by linking the model to geocoded locations where participants spent time during the mine fire.

An example of the information provided by CSIRO, showing hourly averaged observed and modelled concentrations of $PM_{2.5}$ and CO in the southern region of Morwell, is shown in Figure 12.

Summaries, of the above-mentioned reports, are available at hazelwoodhealthstudy.org.au/air-quality-assessment/

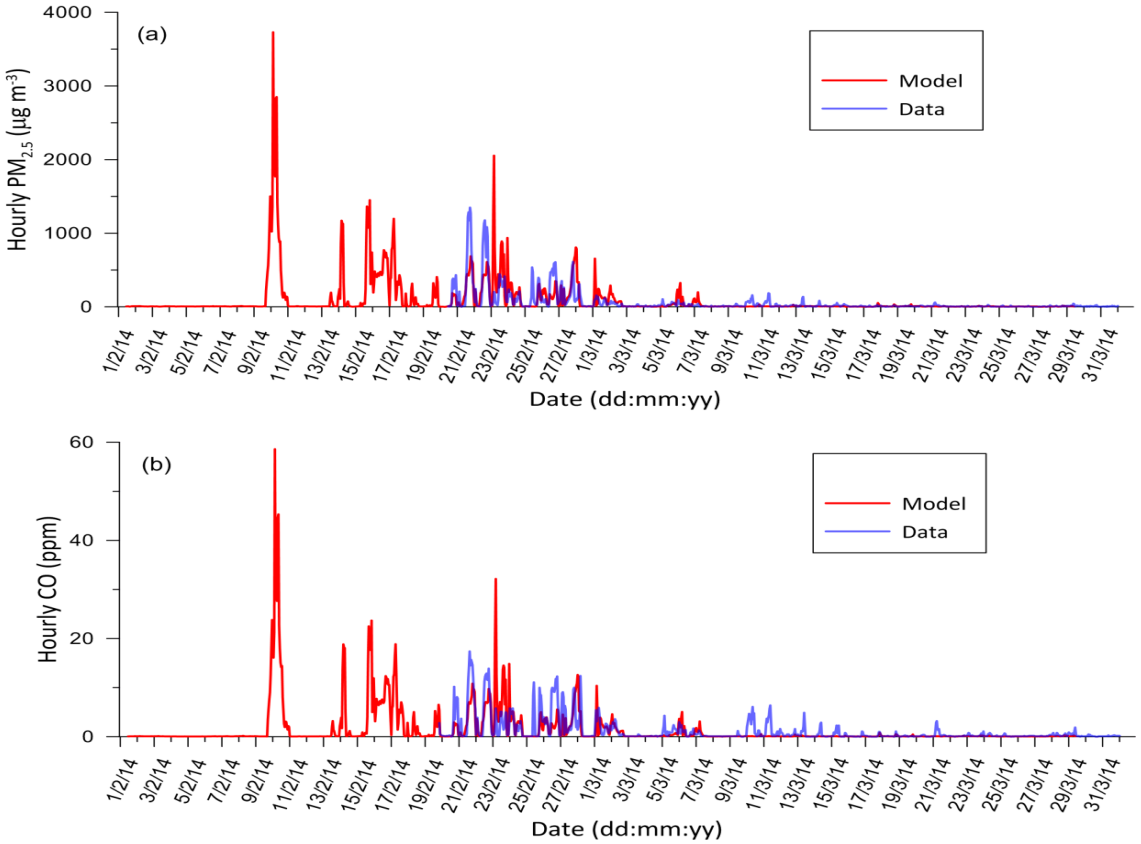


Figure 12 Time series of hourly-averaged observed and modelled concentrations of (a) $PM_{2.5}$ and (b) CO in southern Morwell.

Version History

Version Number	Date Approved	Approved By	Brief Description
1.0	19 March 2017	Senior Project Manager	Submitted to DHHS
1.0	11 April 2017	Principal Project Officer, Strategic Projects & Regulatory Policy Team DHHS	Approval received from DHHS
1.1	13 April 2017	Senior Project Manager	Table 10 re-inserted as it had previously dropped out. Table of Contents updated. Version History table added.