

Community Advisory Committee Meeting 1/2016

Wednesday 16 March 2016

5:00 – 7:00pm

Meeting Notes

1. Welcome & Apologies

Attendees: Judi Walker (Principal co-Investigator Gippsland - interim Chair), Michael Abramson (Principal Investigator), Carolyn Boothman, Glenys Butler, Ruth Churchill, Alda Dunlop, Ian Gibson (Proxy for Kellie O'Callaghan), John Guy, Dale Harriman, Tracie Lund, Tim Owen, Andrew Wood, Wendy Wright

Observers: Matthew Carroll (Investigator), Jill Blackman (Senior Project Manager), Susan Denny (Recruitment and Engagement Coordinator), Melanie Reeves (Project Officer - Meeting Notes)

Apology: Kellie O'Callaghan

Professor Walker welcomed attendees to the meeting and invited them to take a promotional Hazelwood Health Study t-shirt.

2. Declaration of Conflicts of Interest

- The Declaration of Interest Register had been circulated and completed and there were no declared conflicts of interest.

3. Confirmation of minutes from meeting held 2 December 2015 (Attachment 1)

- Unendorsed notes of the meeting held 2 December 2015 were endorsed by the committee and confirmed as a true and accurate summary. CAC meeting minutes from the December meeting onwards are available on the HHS website.

Action: Change status of 2/12/2015 meeting notes on the HHS website from unendorsed to endorsed.

4. Actions arising

- All member organisations had confirmed their nominated representatives would serve on the CAC in 2016. Community members had received invitations to continue (staggered terms of 12 months or 24 months) and all had confirmed their intention to continue, with the exception of Marilyn Mathieson (Sale) who has resigned due to travel commitments.
- Expressions of Interests to fill the Sale vacancy have been received and reviewed. Dr Iain Nicolson from Sale has been invited to join the committee.

Actions arising not covered elsewhere

4.1 Identification of areas for recruitment approach

- Several members had worked with Susan Denny and were thanked for their advice.

4.2 Identification of community champions

- Individual discussions to identify community champions have been very encouraging and resulted in a photo shoot, (photos to be displayed later in the meeting).

5. Study Update (Attachment 2)

- The latest Monthly Status Report was viewed, and the following updates provided.

5.1 ELF Study

- Latrobe City Council has written to almost 4000 eligible candidates, to alert them that the Early Life Follow-up Study (ELF) would be in touch, with the option of opting out if they did not wish to be approached (5 per cent opt rate to date). It was noted that the ELF stream expected to have its first direct mail out to 100 potential participants before Easter.
- Working with Hunter Research in final preparation for the telephone and web based surveys.
- Approvals have been received from Births, Deaths and Marriages and also the Monash Human Research Ethics Committee. Approval processes were briefly discussed, explaining that the stream has been able to work through the complex processes as required.

5.2 Adult Survey and Hazelinks

- After 8 months of negotiations permission has been granted from the Victorian Electoral Commission to access the Electoral Roll for the Adult Study and a formal Agreement will be executed.
- Privacy matrix and signing of confidentiality agreements are underway, in accordance with VEC standard conditions.
- Permission from Medicare for verbal consent to data linkage has not been successful, so this has been dropped from the protocol as requesting a separate consent process was too onerous for participants.
- Decisions from VEC and Medicare have multiple impacts on protocols, consent processes, explanatory statements, recruitment, tracking data base and data transfer etc. Once the Electoral Roll list is received, these and other processes can be actioned and a late April launch is anticipated.

5.3 Community Wellbeing Stream

- Now analysing qualitative data from the first stage. Recurring themes have emerged that will be shared with the community.
- Morwell Neighbourhood House was thanked for the use of the facility and support.
- It appeared to have opened up many avenues for people to express their views and assist in facilitating community dialogue. It was felt that the interactions have produced valuable grass roots raw information and will continue to grow.
- Ideas have been suggested for the next stage of the study, such as mounting an exhibition at the Latrobe Regional Gallery.

5.4 Schools Study

- Disappointing parent consent rate of approx. 15% against a 20 – 40% target.
- Expansion to look at identified and unidentified data including NAPLAN, school entrance questionnaire, attendance rates and other useful patterns.
- Further work for the year to include more discussion with the teachers and staff from the schools, to capture their valuable perspectives.

5.5 Older Persons Stream

- Progressing on target. The recruitment strategy has extended to visiting groups and organisations. The change in approach has produced improved recruitment rates. By Easter around 100 people will have participated in focus groups.
- One on one interviews with Service providers and key personnel underway.
- Policy work is the current focus, so that desktop analysis can commence with a view to producing final report in August.

6. Recruitment and Marketing Issues

A detailed Marketing Strategy is in place and is constantly evolving. External assistance has been engaged from

Wordwise Communications, however committee input is required.

6.1 Adult Survey flyers

- Photo shoots in Morwell and Sale have taken place to promote the adult survey included members of the research team, Community Advisory Committee members and recognisable key community members.
- Flyers to go out to all households in Morwell and parts of Sale providing a brief overview of the study and alerting residents that they may receive an information pack in the mail over the coming weeks.
- The DL sized flyer is also a fridge magnet and will include a photo to remind people of the study.
- The CAC provided advice on selection of photos and presentation and selection of local mailing house for distribution.
- Distribution will be strategic and staggered, mindful of the Latrobe City Council's recent health surveys and to prevent overlap or confusion.

Action: Researchers and Recruitment and Engagement Coordinator to finalise design the flyers. Names of individuals to be acknowledged.

6.2 Adult Survey launch

- Adult Survey to be promoted alongside other local community events to best maximise exposure, over next 6 months.
- Promoting at local events and interaction with local media to commence from mid-April.
- The social media strategy was discussed. Members advised for care to be exercised with social media used for advertising statements and encouraging participation in the Adult Survey.

Action: CAC members to advise any local events for promotion of Adult Survey.

6.3 Reimbursements

- The issue of reimbursement for time spent completing the survey was discussed.
- It was felt that reimbursement would encourage participation, whilst acknowledging that some members of the public would willingly participate regardless of reimbursement.
- The Committee agreed that reimbursement opportunities should be targeted at locally based businesses and relate to a wide range of goods and services.
- The existing Latrobe Valley gift card and Wellington Shire eVoucher were explained, both of which are redeemable from a wide range of local businesses. The committee was supportive of their use in the study.

7. Process for release of study findings to the community

- An appropriate process to be developed for dissemination of study findings as the study progresses, with the extent of the role of the CAC in that process to be defined with time. Underpinning principles to be developed to guide the process.
- CAC advice was received including:
 - Study results to be released to the local community in a timely manner to avoid potential release of findings via other sources. Delays in the release of findings may prompt people to question the transparency of the study.
 - The study has a responsibility to be aware of public sensitivities, as responses to findings may be varied - positive, upsetting or negative.
 - If people are particularly anxious or concerned, opportunity for discussion and some form of immediate support to be offered from relevant organisations and/ or medical / health professionals, as appropriate.
 - Providing a list of expected questions may reassure those who are hesitant to ask questions openly.
 - The Clinical Reference Group to play a major role in the process of identifying what the significance of findings might be and their impact on the community. Specialists to be on hand for instances where data results are found to be detrimental to health.
 - Individual briefing with affected community members before any public media release.

- Information to be presented in a simple, open and easy to understand way, without charts, graphs and medical jargon. However access to more detailed information should also be an option for those who wish. Question and answer sessions could follow to address concerns.
- Expert advice to be sought to look at frequency, format and level of information disseminated. A regular easy to read newsletter in addition to a website has been successful in other projects. Short plain language videos have also proved effective.
- Findings to be released at different stages according to the research activity. This may boost recruitment along the way, by generating ongoing interest and trust in the study.
- Community networking and local talk back radio (with the release of the inquiry recommendations) were given as examples of ways to increase the levels of community engagement.

8. Mine Fire Inquiry Vol 3 Report and Recommendations

- Potential impacts on the HHS of the Inquiry's Recommendations 3 - 6 were discussed recognising that the whole of government response to Volume 3 recommendations had not yet been released.

9. CAC Independent Chair: Options Paper

- It was agreed at the December 2015 meeting, that the interim Chair (Principal Co-Investigator – Gippsland) step aside to enable the committee to appoint an independent Chair.
- The options presented in the paper were discussed in the context of the recommendation from the Mine Fire Inquiry (Vol 3) and alternatives suggested, such as internal/ external candidates, a rotating Chair, short versus long term solution etc.
- The committee resolved to appoint a Chair to serve until the end of November 2017 (end of initial funding contract) and specified that the Chair be 'independent of' Monash, the research team and government representatives.
- A consensus was reached that it would be in the committee's best interests if the Chair was elected from the CAC community members, nominated by any member of the committee.
- HHS Principal Investigator, HHS Principal Co-Investigator (Gippsland) and the Chief Health Officer to be Ex Officio members of the CAC.
- Members called for volunteers from the organisational representatives on the CAC to form a sub-committee to refine the position description and implement an election process.

Action: Sub-committee volunteers Dale Harriman and Wendy Wright to work with the Interim Chair to develop process for election of the independent Chair.

10. Other business

- Concerns were raised over how to explain to particular Sale residents why they may not necessarily be selected for recruitment to the Adult study.
- Current recruitment work to include this as a priority (with assistance from Lynne Smith, Wordwise Communications), by ensuring that study information is clear and addresses questions such as this in its literature with sensitivity.

11. 2016 Meeting Dates

15 June
14 September
23 November

Meeting closed at 7:10 pm