GUIDELINES FOR THE DISSEMINATION OF FINDINGS TO THE COMMUNITY FROM THE LONG TERM HAZELWOOD HEALTH STUDY

Preamble

In February 2014, a bushfire spread into the Morwell open-cut brown coal mine adjacent to the Hazelwood power station in the Latrobe Valley which burned for approximately 45 days. Surrounding communities were shrouded in smoke, in particular the town of Morwell which is located a few hundred metres from the mine. As authorities struggled to put out the fire, nearby communities became increasingly concerned about perceived health risks of exposure to the smoke, particulate matter and gaseous emissions from the burning coal.

The smoke event galvanised the community leading to the establishment of advocacy groups and a petition signed by over 25,000 people calling for a long term health study of the smoke impacts. One of the recommendations from a round of community consultations by the Victorian Department of Health was for the Victorian Government to establish a long-term health study and a Tender process began in July 2014. The Victorian Government's Hazelwood Mine Fire Inquiry, which first reported in August 2014 reinforced the need for the long-term study and the importance of community involvement in the study.

A consortium of researchers led by Monash University were the successful tenderers and the long term health study – the Hazelwood Health Study (HHS), with six research streams, began in November 2014.

Since its inception, the HHS has intended to feedback key health findings to the Latrobe Valley community. Evaluation of possible information delivery approaches, and the timing of messages, has been undertaken with the aim of developing an optimal framework for the dissemination of study findings to the community in ways which are both meaningful and appropriate to the target audience.

In 2015 the Government re-opened the Inquiry to address continuing community health concerns. During this renewed inquiry, issues were raised regarding the long-term health study, including, in Recommendation 6, a request to the state to "establish a process whereby key health information obtained through the study about the health status of the population and the effects from the Hazelwood mine fire is provided to study participants, the community, local health practitioners and the Latrobe Valley Health Assembly". This recommendation supports the process which was already under evaluation by the HHS Team.

Purpose

The purpose of this document is to provide guidelines for the dissemination of the study's findings to the community. It has been developed in consultation with the HHS Community Advisory Committee and the Clinical Reference Group.

The Guidelines include:

- A diagram of the scope of the Hazelwood Health Study (illustrated using the first three years of the study)

- Explanations of the terms *dissemination, knowledge translation*, and *the community*, emphasising the need to tailor research findings to the community and other identified audiences

- a set of guiding principles for the dissemination of the study's findings to the community

- clear attribution of roles and responsibilities, and

- attachments with further information about dissemination techniques and tools.

HHS Research Streams (Years 1 – 3)

Explanations

Dissemination is a term meaning communication or a flow of information from a source. Dissemination is an active concept where the information is tailored or targeted for an intended and identified audience.

Dissemination goes well beyond simply making research available through the traditional vehicles of scientific journal publication and academic conference presentations. It involves a process of extracting the main messages or key implications derived from research results and communicating them to study participants, the wider community and targeted groups of decision makers and other stakeholders in a way that encourages them to factor the research implications into their work.

Knowledge Translation is understood as a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound applications of knowledge to improve health, provide more effective health services and products and strengthen healthcare systems.

The emphasis of knowledge translation is to ensure the community, especially those who have participated in the research, advocates, health providers, policy makers and the researcher community, are aware of, can access, and are able to use health research findings especially to inform decision making. Differences among audiences make it imperative to know when and how to utilise various modes of dissemination for health research.

The simple dictionary definition of *the community* ranges from a group of people who live in the same area to society at large. For the purposes of these Guidelines *the community* encompasses residents of the Latrobe Valley and Sale, and the wider Gippsland region, including but not limited to study participants, local healthcare practitioners and organisations, local government entities and a wide range of groups and individuals bound by a common interest in the impact of the 2014 Hazelwood mine fire.

Guiding Principles for the dissemination of HHS's findings to the community

1. **Principles of Effectiveness**
   - release findings in a timely way to avoid potential release via other sources
   - release findings when available not at the end of the study
   - resource dissemination strategies appropriately
   - be prepared to pay attention to comments about effectiveness of dissemination strategies
   - provide options for access to more detailed/technical information
   - monitor and evaluate the effectiveness of the dissemination process

2. **Principles of Inclusion**
   - build on the community's diversity and individual's differences
   - eliminate barriers to access study findings
   - utilise a variety of media

3. **Principles of Clarity**
   - transparency in terms of purpose and communication
   - transparency about how findings will be used
   - present findings in ways that are simple and easy to understand
   - present findings in the context of the entire study over time

4. **Principles of Respect**
   - work in partnership with the community
   - use dissemination tools and techniques that are acceptable to the community
   - hear what people say
   - make best use of research data
   - make available opportunities for discussion of findings
   - take public sensitivities into account
   - identify pathways for immediate support (medical or otherwise)
   - provide briefings for affected community members before any public media release

Dissemination Roles and Responsibilities

1. **The role of HHS research stream teams is to:**
   - advise the Project Steering Committee when research stream findings/outcomes become available
   - advise the Project Steering Committee about the nature of the findings/outcomes
   - make suggestion about appropriate dissemination tools and techniques, formats and target audiences, and
   - provide spokespersons.

2. **The role of the HHS Project Steering Committee (PSC) is to**
   - ensure the research stream teams provide appropriate advice and peer review about research findings, target audiences and dissemination activities
   - advise the Community Advisory Committee when this information is available, and
   - ensure these dissemination Guidelines are followed.

3. **The role of the HHS Clinical Reference Group (CRG) is to**
   - identify the significance of the findings and their potential impact on the community, and
   - provide expert advice regarding the format and level of information provided.

4. **The role of the HHS Community Advisory Committee (CAC) is to**
   - receive advice from the HHS PSC and CRG on the nature of research findings
   - provide advice as to appropriate audiences, dissemination tools, techniques and formats
   - receive appropriate advice as to when information is to be disseminated; and
   - participate in dissemination activities.

Linked documents

   - HHS Publications Policy
   - DHHS Contract Committee Release of Project Findings (Project Intellectual Property)
   - HHS Community and Stakeholder Engagement Plan
   - HHS Governance document

References

Canadian Foundation for Healthcare Improvement www.cfhi_fcass.ca accessed 12/06/2016

Primary Health Care Research & Information Service http://www.phcris.org.au accessed 30/05/2016

Rural Health Research Gateway www.ruralhealthresearch.org/pdf/rural-health-research-dissemination-toolkit.pdf accessed 12/06/2016

Attachments to these Guidelines

1. Dissemination Tools and Techniques

- Policy Brief
  - Offers research findings and evidence informed policy options in a synthesised, neutral and user-friendly format to a non-specialised audience. The World Health Organization states that "policy briefs improve the chances that policy makers will read, consider, and apply the contents of research summaries when reaching policy decisions".

- Fact sheet / Newsletter
  - One to two page document that provides basic information and important facts in lay language on a specific topic or issue. They are particularly useful when disseminating information to an audience with very little time and outside of the discipline.

- Full Report / Working paper
  - Technical paper that makes a practical contribution to a field of study or area of research. Papers may also include preliminary results of research that has yet to be tailored for publication in a professional journal. It provides an opportunity to publish results quickly especially when the topic is currently receiving significant attention. Working papers will provide significant background to the topic and justification for the study.

- Journal publication
  - Peer-reviewed scientific journal articles are an important resource in the research community and speak to a study's credibility, but they do not meet the needs of users who prefer timely, easily accessible and jargon free information. Journals look for innovative and original research that will either impact patient care or add to the specialised field of the study.

- Chartbook
  - A comprehensive report that presents the most complete data available on a particular topic. Majority of the document will be tables and figures with very little narrative or discussion. The purpose of a chartbook is to illustrate all that is known about a given topic based solely on the most recent available data.

- Powerpoint presentation
  - An effective way to support research, visualise a complicated concept and share research findings with a large audience. It provides visual support for the information being discussed – slides do not contain the narrative.

- Poster presentation
  - Efficiently communicates concepts and data to an audience using a combination of text and visuals. Posters allow the authors to network and speak with viewers, promote the findings and facilitate exchange of ideas. Often forms part of a scientific conference.

- <u>Infographic</u>
  - Information graphics are visual explanations of data, information or knowledge. A well-developed infographic is an excellent tool for clearly and immediately explaining complex data. It may be a standalone one page flyer, be presentation as a slide in a larger presentation, provide summation in a report or be printed as a large poster for display.

2. Examples of ways to disseminate HHS findings

- Community/stakeholder briefings
- Community forums
- Presentations to community groups
- HHS web site
- Press releases and media interviews
- Newspaper articles
- Social media (Twitter, Facebook)
- Study participant briefings
- Individual participant briefings
- Professional/provider briefings
- Masterclasses
- Policy briefings
- Conferences
- Exhibit (displays)