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Appendix 1

This appendix was part of the submitted manuscript and has been peer reviewed.
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Appendix to: Couzos S, Nicholson AK, Hunt JM, et al. Talking About The Smokes: a large-scale, community-based participatory research project. *Med J Aust* 2015; 202 (10 Suppl): S13-S19. doi: 10.5694/mja14.00875.

APPENDIX 1:

FRAMEWORK- Guiding principles for participatory health research [*adapted from source: WHO, 2003]*

IP= Indigenous Peoples

RI= Research Institution

1. Consultation and Approval

1.1 Where IP wish to approach an RI regarding a health need, and there have been no previous contacts or research relationship, community leaders may choose to make a preliminary contact.
1.2 If research institutions initiate research, they should first ascertain if there is an appropriate Indigenous institution to consult. Where Indigenous-controlled structures are in place contact should be made to the local leaders to discuss the possibility of collaboration.
1.3 If the first approach is made by the RI, consultations with the IP concerned over the research ideas and goals should take place *before* a research proposal is drawn up.
1.4 Health research is undertaken only if the proposed research topic and process are compatible with the health priorities and needs of the IP.
1.5 Approval to proceed with the research needs to have been formally obtained by the RI from community leaders, IP representatives, and local community members as appropriate (see also *Consent*).

2. Partnerships and Research Agreements

2.1 Both parties enter into a research relationship as equal partners.
2.2 It may be useful for the parties to jointly prepare a **research agreement**. This helps to ensure that all steps of the research activity are understood, and agreed conditions and responsibilities on each side are clearly spelled out.
2.3 Health **research proposals** should be prepared jointly on the basis of prior consultations between the parties.
2.4 If it is agreed that the interests of both parties can be served by preparing or seeking approval for a joint research proposal, a timeframe and the division of responsibilities can be prepared.
2.5 The goals, objectives, and methods of the research should be agreed between the partners.
2.6 The research process (planning, design, methods, consent forms, data forms, data collection, analysis, interpretation, dissemination and reporting) should be open and collaborative through in-depth consultation with community representatives.
2.7 The RI has the following obligation: to inform the IP if it considers that the research cannot meet its original goals and objectives, and cannot provide the expected benefits to the IP. This contingency should be discussed between the parties as part of the research agreement.
2.8 The IP have an obligation to inform the RI if they decide to withdraw from the research and to facilitate the research activity by all possible means to ensure its anticipated benefits to the community will materialize.

3. Communication

3.1 The lines of authority within the RI must be clarified to the IP. The internal structures and governance processes of the IP must be recognised and respected.
3.2 The IP will select a committee to follow the research and maintain communication with the RI. Ideally, the committee should represent all relevant community-controlled organizations, in order to avoid undue influence, control or coercion by any one group. This committee also facilitates and promotes the research activity.
3.3 Communication on all aspects of the work including progress reports will be regularly maintained.

3.4 At the end of the study, RI representatives will participate in IP community meetings to discuss the results and their implications.

4. Funding

4.1 There should be a joint commitment to fund seeking.
4.2 Where external funding is involved, agreement should be reached in advance on sources that do not conflict with Indigenous interests.
4.3 Where the IP do not possess the resources or capacity to provide infrastructural support or to negotiate independently, RI have an obligation to ensure (together with the national authorities), that the IP are adequately involved, supported and protected in the research.

5. Ethics and Consent

5.1 Health research should respect national and international ethical guidelines on research involving human subjects, and approval for such health research should be obtained from a University ethics committee or other national mechanism as appropriate to the issues involved.
5.2 Ethics committees have been established by Indigenous-controlled ethics organisations. Where they exist, such committees have a say on any ethical issues and approval procedures pertaining to the proposed research.
5.3 Work should not start until the research has been authorized by the national, regional, or local research ethics committee, and any research agreement planned between the parties has been drawn up and signed.
5.4 Health research should conform to the customary laws and ethics of the IP involved including any additional protocols to minimise harm to the collectivity or to individuals.
5.5 It may be necessary to obtain three levels of consent:
    5.5.1 Informed individual consent (preferably in writing) of study participants;
    5.5.2 Consent of recognised representatives of Indigenous peoples through the community's own internal procedures, such as through the creation of a research agreement;
    5.5.3 Consent from an umbrella Indigenous organisation (if it exists) to provide additional collective consent and to ensure that a larger collective is informed and consents to the research.
5.6 The content and format of the informed individual consent form, and the process to be followed in obtaining consent, should be discussed and agreed jointly by the research partners.
5.7 The umbrella Indigenous organisation must demonstrate to the RI that they have the collective consent of the groups or communities concerned (if they are authorised to represent regional or local IP groups or communities).

6. Data

6.1 Issues related to intellectual property rights and benefit -sharing should be discussed fully by the research partners.
6.2 The boundaries of use of any information given by the IP to the RI should be agreed by both parties. For example, a community may restrict discussion on specific topics or limit the number of individuals authorised to speak on certain cultural issues.
6.3 Confidentiality should be ensured through an appropriate data-coding system and by limiting access to the data.
6.4 Prior to publication, both the IP and the RI should have the opportunity to review manuscripts and comment on the interpretation of the data.
6.5 Participants in a joint research activity who have contributed in a significant capacity (e.g. through conceptual work, interpretation of data, writing up of findings) will be associated with the published findings, and either acknowledged in the manuscript or named as co-authors, as appropriate to the contribution made.
6.6 Any data and final reports held by the IP should be in a language and format that can be utilised by them independently of the researchers.
6.7 Where prior agreement designates the IP as the final owner of research data, requests by the RI for further use of the information will be considered and authorized by the IP.

7. Benefits of the Research

7.1 Research institutions have an obligation to ensure that any research jointly undertaken should have clearly identified short-term and long-term health benefits for the IP. This may include arranging for the provision of health care where this is lacking.

7.2 Research institutions must be open about potential economic benefits originating wholly or in part from information obtained from research with the IP with a fair profit-sharing agreement (where relevant).

7.3 The benefits of the research should include:

7.3.1 resources and funding for the training, employment (where appropriate capacities exist), and general capacity-building of community members in all aspects of the research process;

7.3.2 improved health status or services for the research population or prospects of such improvement within a defined period of time through interventions discussed and agreed with the IP.

Adapted from: World Health Organisation. Indigenous peoples and participatory health research. World Health Organisation, Geneva, Switzerland, 2003. http://www.who.int/ethics/indigenous_peoples/en/index1.html (accessed Sept 2014)