RESEARCH STRATEGIES TO FACILITATE PUBLIC PARTICIPATION IN DISCUSSION OF GENETIC TESTING AND BIOBANKING

A summary

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Constructive Conversations/Korero Whakaaetanga
Biotechnologies, dialogue and informed decision-making

Abstract

This paper summarises the development and implementation of the research methodology that was primarily used in Phase One of the *Constructive Conversations/ Korero Whakaaetanga* project – the first eighteen months of work on the project. It outlines the methodology piloted in twenty-five focus groups/ contact groups on genetic testing and biobanking that were facilitated in late 2003 and early 2004. This is followed by a discussion of some issues which emerged as this methodology was developed and employed. A description of the characteristics of the groups who participated in this stage of the project is provided. This is followed by a summary of the strategies used in preliminary analysis of the transcripts of these interviews. Proposed plans for the next stages of the contact group process are outlined, followed by a brief discussion of some issues that have arisen during the year that are relevant to the objective of achieving greater public participation in technological decision making – one of three key objectives of this research programme. This chapter was mainly written by Rosemary Hipkins with some assistance from Rosemary Du Plessis. It draws on a more detailed paper by Rosemary Hipkins (Hipkins, 2004).

Acknowledgements

Contents

1. Introduction

This paper outlines the development and implementation of the research methodology that was primarily used in the first eighteen months of the *Constructive Conversations/ Korero Whakaaetanga* project.[1] It deals specifically with the first of the overall research objectives for this research programme:

> To develop, pilot and evaluate a methodology for facilitating constructive conversations among diverse participants on contentious biotechnology issues in the Aotearoa/New Zealand context. This component is informed by attention to appropriate methodologies for dialogue with Maori.

The section begins with a summary of the methodology piloted in twenty-five focus groups/ contact groups[2] on genetic testing and biobanking that were facilitated in late 2003 and early 2004. This is followed by a discussion of some issues which emerged as this methodology was developed and employed. A description of the characteristics within each contact group is provided. This is followed by a summary of the strategies used in preliminary analysis of the transcripts of these interviews. The outcome of that preliminary analysis can be accessed in other papers available on the Constructive Conversations website.[3] Proposed plans for the next stages of the contact group process are then outlined, followed by a brief discussion of some issues that have arisen during the year that are relevant to the objective of methodological innovation with respect to achieving greater public participation in technological decision making. Where relevant, sub-sections are accompanied by a brief outline of issues that have arisen during the design and piloting process.

Most members of the research team contributed, in varying degrees, to the development of the contact group methodology directed at public participation in discussion of genetic testing and biobanking between April 2003 and December 2003. In late 2003, this research strategy was reviewed and more clearly defined sub teams developed to work on specific aspects of the research objectives. Maori researchers on the project formed a sub team, Te Kopere, to ensure that Kaupapa Maori research principles were applied to the research programme, particularly with respect to the facilitation of contact groups and the analysis of research material that involved Maori participants.[4] A 'Complementary expertise' sub-team was also developed to experiment with the use of another research strategy directed at generating knowledge about the implications of new health biotechnologies (see Goven et al., 2005). At this stage most of the planned contact groups had been carried out, so the opening up of a second experimental process took place after the deliberations reported in this paper. Since March 2004 a 'Participation' sub team has focused on the development of the contact group methodology and the completion of

the first set of contact groups. It is this group that has been largely responsible for analysing interview transcripts and designing the research strategies for the second round of contact groups. (See Time line)

2. Piloting constructive conversations about genetic testing and the storage of genetic information

The research team has been involved in the development and piloting of a "contact group" process that is seen as different in at least one key respect from the related, more familiar "focus group" process. Here we outline what we mean by "contact" groups, and provide brief details of the groups that have been convened to date.

The concept of contact groups

A point of difference initially envisaged between *contact* groups and the more familiar *focus* groups was that people who were "networked" in certain ways would be recruited into focus groups to talk about the implications of new health biotechnologies. This was done on the basis of research suggesting that attitudes to technologies are developed through social processes and social relations. Networks might include social or kinship ties, community organisations, religious groups and so on. People who came to contact group meetings would bring with them views and stories shaped by their interactions with other people and with technologies in their daily lives – and take back from their involvement in these discussions new topics of conversation, and new ways of looking at existing and future interactions with health technologies. New understandings generated in the group discussions might be shared along the same social pathways. We have experimented with this shifting, flexible, two-way flow of ideas and actions as a grassroots level of democratic awareness/ response upon which other layers of participation might be built. The first round of contact group conversations began this process of a two-way flow of ideas, and it is envisaged that this will continue when the same groups are reconvened.

Selecting genetic testing as a conversation topic

Choosing a first conversation topic was an important aspect of the early planning stages. Some health related biotechnologies such as xenotransplantation and embryonic stem cell research were considered, but rejected in favour of a focus on genetic testing and issues relating to biobanking and the storage of genetic information.

There were at least three reasons for this choice. Genetic testing was seen as a topic that might draw a wider base of people into conversations because it was potentially more familiar than the other topics considered. Additionally, a rich base of existing literature prefigured a range of issues that might potentially arise in the conversations. The project

leaders were also mindful that legislation to regulate the use of embryonic stem cells was already in process, and knowledge related to that biotechnology could not be generated in time to inform that process. Rather, a topic that had yet to be addressed by the New Zealand government might generate useful knowledge that **anticipated** the need for future regulation and ethical debate.

The first contact group sessions explored issues related to genetic testing and biobanking; they are further discussed below. The second sessions will report back to participants on issues they collectively raised, then follow up with a more policy-focused discussion. The intention is to engage people in ways that maximise their sense of empowerment and do not just focus on what others, including the government, ought to do. The process will seek to facilitate the flow of conversation about social and political contexts which can maximise the benefits of genetic testing while minimising the risks.

3. The development of the contact group discussion processes

We now report on various aspects of the conversation process that were discussed and piloted by the participation team during the first round of contact groups, including deliberations for creating a comfortable environment in which conversation can flow. Following that, plans for the second round of contact groups are described.

Planning for lively discussion in the first contact group session

This study uses *narrative* materials as a stimulus for discussion in the contact groups. The intention is to open up spaces where participants can give 'storied' accounts of their relationships to the technology under investigation. Either implicitly or explicitly these stories reveal potential or actual impacts on participants' lives and on those of others they care about, and their views of issues and opportunities concerning the wise use of the technology. However, once the decision was made in principle to use this approach, many complex practical considerations followed.

The team initially experimented with the use of short stories about specific disorders that might be implicated in genetic testing – for example Huntington's disease or breast cancer. These stories were accompanied by questions that sought reactions to personal, family, social, and public policy decisions related to each condition. Pilot sessions using these stories were successful in engaging interest and stimulating conversation, whilst also providing participants with some relevant information about the science relating to genetic testing.

Notwithstanding this success, there was a concern that the stories potentially reinforced a hegemonic framing of genetic testing as primarily a scientific/medical/consumer

issue, with a negative focus on the pathological. The ensuing debate identified a range of alternative possible ways of framing materials that included:

• consumerist/individual choice approaches;

• political economy (e.g. ownership of DNA; corporate control);

• health spending/resourcing of health and welfare;

• social identities;

• spirituality;

• scientific or 'expert';

• kinship/family/community;

• regulation and governance.

The focus shifted from the pathological to the use of genetic testing on "well" people, from individual to collective concerns, and from personal "consumption" to wider issues related to the commercialisation of the technology. After considerable debate and exploration of possibilities, the research team settled on the use of three resources intended to stimulate and support small group conversations about genetic testing. In different ways, these resources all used principles of narrative pedagogy as a starting point. Each was structured in a way that we hoped would invite participants to tell stories of their own.

1. Each group began with the telling of an oral story about a hypothetical dilemma confronting new parents who had been asked to consent to the genetic profiling of their newborn baby. Participants were asked to discuss whether they inclined to take the side of the mother or the father, who were presented as having different viewpoints on what they should do. All the contact groups were presented with this story and discussed their responses to the viewpoints of both the hypothetical parents.

2. One of two paper-based stimuli was a mock advertisement for a personal, privately funded, direct-to-consumer genetic testing service. Participants were shown the advertisement, and invited to discuss their reactions, questions and concerns. Some groups used this attractive, realistic-looking resource to discuss issues relating to the provision of predictive genetic testing by private providers.

3. The other paper-based resource was a mock brochure about a hypothetical project to set up a NZ Biobank[5] for the purpose of collecting genetic and other health-related information on a population basis. Again the resource was realistic (and indeed, some groups initially thought this was a genuine pamphlet). Some groups used this material in their discussions.

These stimulus materials and the information for facilitators related to their use are available on the Constructive Conversations/Korero Whakaaetanga website – www.conversations.canterbury.ac.nz/overview/meetings.htm.

While the hypothetical story about genetic profiling was the first resource used in every contact group meeting, in many of the meetings, only one set of the two paper-based stimulus materials was used. This was usually chosen to reflect the direction of the unfolding conversation. In a few cases, all three stimuli were used. Conversations typically lasted for about two hours.

Creating a comfortable environment for conversation

The research team began with a shared intention to use processes derived from tikanga Maori to generate a comfortable atmosphere and good discussion in the contact groups. This intention developed out of the use of tikanga processes in research team meetings and discussion of the value of Maori strategies for facilitating talk. It was also inspired by the team's shared reading of Joan Metge's book *Korero Tahi: Talking Together* (2001). There was much discussion of the best means by which to implement this strategy.

Processes that could be used included a formal welcome, or whakatau. This included a whakatauki (Maori proverb), and a karakia where that was appropriate, followed by tea, coffee or a shared meal with time for informal chat. Each discussion then began with a structured mihimihi, followed by the presentation of the stimulus materials by facilitators and a more conventional group discussion in the focus group tradition. Each meeting was to finish with participants expressing their reflections on the meeting via a structured poroporoaki process, with the project whakatauki used as a formal farewell.

The research team decided in principle to use these processes strategically, adapting them to the cultural preferences of particular contact groups. The emphasis was to be on making each group feel comfortable and welcomed, so that good conversation could flow.

Interesting issues

One issue of concern to some of the researchers was whether participants would need access to factual material about genetic testing during the actual conversations. In anticipation of this need, some mock "Frequently Asked Questions" sheets were designed. Researchers had these to hand, should the need to use them arise in the flow of the conversation. There is a tension in this type of research between collecting *views* and collecting knowledge formed as a result of deeply embedded personal experiences and engagement with issues. This links directly to questions about the role public conversations

such as these should play in *educating* people about topics such as genetic testing. Those who were concerned that the group conversation should support the (scientific) education of participants were more likely to use the mock "frequently answered questions" than those who did not. Some facilitators used the FAQ sheets to inform themselves about aspects of the technologies discussed and inserted components of the information in the sheets when they seemed relevant. Others tended to use the sheets only when explicit questions were asked by group members. Analysis is currently being done on the relationship between the conversations in the contact groups and differences in the ways in which facilitators used the interview kit and its associated FAQ sheets.

Some of the research team hold a strong view that *informed* comments are more productive outcomes from this type of research. In this view there is a danger that comments that are seen to represent real but misinformed concerns provide material that can be used by policy makers as a means of reassuring people rather than actually addressing the issues raised. Others in the team believe equally strongly that pro and anti genetic testing views should kept in a complex play of meanings, and that tipping the balance towards informing rather than eliciting views could prematurely consolidate discussion, thereby masking nuances or indirect insights that might arise in the conversation. We have as yet found no clear-cut means of resolving this dilemma, nor have we as a whole team inclined to one view over the other at this point.

A related tension concerns the manner in which the materials designed to promote conversation can potentially "frame" what is discussed in ways that might bias the data gathered. In some respects this is a sub-set of the tension in striking an inform/elicit balance, because designing materials to potentially "cover" a range of possible framings becomes a contested issue.

For some, the use of tikanga processes was an important part of the experimental aspect of the conversations. Some of the team, both Maori and Pakeha, commented on the empowering nature of establishing a space to start via the use of the whakatauki, the karakia and the encouragement of participants to stand for their personal mihimihi. Others, again both Maori and Pakeha, found this aspect more problematic, and thought it was not necessarily helpful for creating a supportive environment in which conversation could flourish. One resolution proposed was to accommodate the intention of tikanga processes by using an "anthropological approach", asking each group what would work best as a process for them before proceeding.[6]

4. Outline of groups convened

Contact groups were mainly conducted between October 2003 and May 2004. An additional group was conducted in September 2004. Meetings took place in Dunedin,

Christchurch, Kaikoura, Wellington, Hamilton, Auckland, Hawke's Bay, and in Taranaki. Twenty-five groups were facilitated. Sixteen of these groups were drawn from the general population and predominantly included people of Pakeha descent. Some members of these groups were Maori or people of other ethnicities. Nine groups were conducted with members of Maori specific organisations.

While women were not specifically targeted for inclusion in the study, two focus groups were drawn from women only organisations and one of the groups was drawn from an organisation providing support for young mothers. The inclusion of these focus groups in the study, combined with other factors to produce a majority of female participants. Overall, 162 people participated in the first round of contact groups, 41 men and 121 women.

General descriptions of each group have been generated for use when referencing findings from the study. These descriptions have been used to compile the following summary, but as they are shown here are still provisional. Ongoing discussion is occurring with groups about the specific words they would like used to refer to their contact group in publications that use material from the group meetings.

Health focused groups – 6 groups

Health support group 1 (January 04) 9 participants, 4 men, 5 women
Health support group 2 (February 04) 5 participants, 1 man, 4 women
Health support group 3 (Maori) (December, 03) 5 participants, 1 man, 4 women
Iwi community health service (December 03) 5 participants, 1 man, 4 women
Rongoa health providers (December 03) 4 women
Primary care/Public health group (March 03) 4 female participants

Professional/job focused groups – 5 groups

Business and professional group 1 (April 04) 13 female participants
Business and professional group 2 (April 04) 5 participants, 3 men, 1 woman
Scientists group 1 (May 04) 3 women
Scientists group 2 (February 04) 4 participants, 3 women, 1 man
Lawyers group (Maori) (March 04) 3 participants, 1 man, 2 women

Religious/spiritual groups – 3 groups

Religious organisation 1 (February 04) 8 participants, 4 men, 4 women
Religious organisation 2 (November 03) 4 participants, 3 men, 1 woman
Religious organisation 3 (Maori participants) (December 03) 6 participants, 1 man, 5 women

Community organisations – 7 groups

Community group 1 (December 03) 9 participants, 1 man, 8 women
Community group 2 (March 04) 9 woman participants
Community group 3 (March 04) 8 woman participants
Adult education group 1 (older adults) (October 03) 8 participants, 4 men, 4 women
Adult education group 2 (young adults – Maori) (November 03) 10 participants, 1 man, 9 women
Maori community organisation (December 03) 6 women participants
Iwi community organisation (September 04) 7 participants, 3 men, 4 women

Personal/family networks/identities (youth, older adults, gay/lesbian) – 4 groups

Friendship network 1 (young adults) (December 03) 7 participants, 6 men, 1 woman
Friendship network 2 (mid career adults) (December 03) 9 participants, 2 men, 7 women
High school students group (December 03) 5 women
Rural whanau (October 03) 6 participants, 2 men, 4 women

Interesting issues

Some of the team's researchers considered that the idea of "networked" groups was not sufficiently clearly elaborated so that a shared understanding was held by all in the team from the outset. This created two types of interesting issues for further consideration and ongoing work. The first concerns selection of groups for participation in the research. For some, the process of identification of a wide range of potential categories of networked people who might be recruited was seen as implicitly selecting groups for inclusion in the study on the basis of demographic coverage (ensuring a range of ages, ethnicities, occupations etc.). With the benefit of hindsight, some researchers felt we should have begun with an analysis of different ways people were actually interacting in their communities/networks with a range of new health technologies and based selection on differences in those factors. A second related issue is that such an analysis might have informed modifications to the conversation materials used, such that participants would continue the conversations initiated in the contact group sessions. These are issues that will be further explored in the second round of conversations.

5. Data gathering aspects of the contact groups

With the consent of participants, conversations were taped from the mihimihi stage onward. These tapes were subsequently transcribed. Wherever possible one researcher acted as an observer and took notes to aid the transcription process. Consent forms were signed during the informal introductions and some demographic data was also collected.

All participants were ultimately assigned pseudonyms to protect privacy. The transcriptions have provided the data that is currently being analysed to build knowledge of social, cultural, ethical and spiritual implications of genetic testing.

The sixteen transcripts drawn from general population meetings have been coded using NVivo, and analytic memos have been prepared relating to key issues and concepts. These reports are a resource used in further work, such as preparation of a feedback report for participants, reporting on themes emerging within the groups, and the writing of academic papers. The nine Maori-specific groups have been analysed through group processes within Te Kopere. Discourse analysis is being used to develop academic papers relating to the social, cultural and ethical implications of genetic testing and biobanking. This work is currently in process.

6. Planning for follow up sessions with contact groups

There has been considerable discussion about ways in which participation in the contact group process could help people feel more empowered to be proactive when addressing perceived impacts of health related technologies on their lives. As a beginning point for addressing this question in the context of the second session, the group decided we should devise an effective means informing participants about what was said in the first round of sessions across the different contact groups. Individuals could then see how their views and experiences fitted in with the overall range of positions reported. At the same time, it was realised this 'reporting back' stage would potentially provoke a fresh round of conversation and story telling that would add another, perhaps more nuanced layer, to the data already collected. The Participation Team decided to provide a detailed feedback document that organised material from the first round of contact groups around key questions raised by participants (see 'Talking about genetic testing – Information for participants', www.conversations.canterbury.ac.nz/). To prompt discussion of this material they have settled on the use of 'issue diagrams' (a conversation strategy borrowed from the use of 'concept cartoons' in science education) as the means of reporting back in a way that prompts further discussion, whist minimising reading demand. The issue diagrams involve the identification of a key question, for example 'Why do genetic tests?' and the presentation of a range of possible answers to this question based on discussion in the contact groups.

Discussion of selected issue diagrams will be followed by consideration of policy orientated questions. This component of the second round will explore the 'aspirational' question of how we can maximise the benefits of genetic testing and the storage of genetic information while minimising the risks. While some structured questions will be used as discussion prompts, it is intended that this conversation be as open as possible,

be future focused, challenge participants to consider personal as well as public obligations and responsibilities, and take place in small groups. Just as in the first round it was anticipated that some participants might need information about genetic testing, we anticipate that participants in the second round may need access to information about agencies involved in policy making. Resource material on the policy making process and relevant government agencies, advisory groups/committees and other organisations will be available to research participants.

At the outset of the project, two meetings with each contact group were envisaged. The first meeting aimed to familiarise people with the topic chosen for discussion and to gather their responses to materials that were intended to stimulate discussion of issues associated with this topic. The second meeting was intended to move participants towards a consideration of actions they might take, or wish to see others take, in response to the issues raised. At the time of writing this paper, plans for this second meeting of each group are being finalised and conversation support materials prepared. Some group members will then be invited to participate in small-group workshops with scientists, policy makers and others with specific expertise relating to genetic testing and biobanking. The full research team is currently discussing strategies for these workshops which will be held in mid 2005.

7. References

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Footnotes

[1] Discussion of another approach to generating knowledge about the social, cultural, ethical and spiritual implications of genetic testing and the storage of genetic information is discussed by Joanna Goven, Fiona Cram and Jane Gilbert in their paper on 'Eliciting complementary expertise in genetic testing in Aotearoa New Zealand' (Goven et al., 2004). The case for this alternative methodology developed out of the experience of developing and piloting the focus group methodology discussed in this chapter.

[2] For reasons that will be outlined later in this paper, focus groups in this study are referred to as 'contact groups'.

[3] See 'The social, cultural, ethical and spiritual implications of genetic testing and the storage of genetic information – Preliminary findings' (Du Plessis et al., 2004) and 'Talking about genetic testing' (Participation Sub-team, 2005).

[4] See Cram at al. (2004) for a discussion of the development of parallel processes within the Constructive Conversations/Korero Whakaaetanga research team and other 'parallel process' research strategies on teams including Maori and Tauiwi researchers.

[5] See Contact Group Materials, Phase One, October 2003, www.conversations.canterbury.ac.nz/.

[6] See Tipene-Matua, B. et al. (2004) 'Old ways of having new conversations: Using tikanga Maori based research methods to discuss genetic testing', a paper about incorporating tikanga based processes into the Constructive Conversations/Korero Whakaaetanga project produced by members of the Te Kopere research team.

Timeline

2002

August – October

Preliminary discussions consolidate as a formal proposal that is accepted by FRST in January 2003

2003

February   Whole team meets in person for first time

March   Preparation of materials for first contact group sessions begins

May   Contract with FRST signed

Materials for first contact groups still being debated

June   Draft materials undergo first pilot with New Zealand Council for Educational Research group

July   Human Ethics Committee (University of Canterbury) approval obtained for piloting of revised contact group processes and materials

Draft materials and tikanga process trialled within research team

Pilot session for first contact group process carried out

August   Team meets to discuss issues from piloting of processes and materials and to work on shape of materials to be used in first contact groups. Discussion continues throughout the month

September   Trials of revised materials carried out

October   Human Ethics Committee approval for finalised materials received

November   First contact groups begin (and carry on through into December)

December   Whole team meeting in Christchurch – discussion of contact group methodology and its implementation. Formation of Te Kopere sub-group for separate analysis of Maori transcripts debated and confirmed. Discussion of 'Complementary expertise' as a parallel research strategy.

2004

February   Paper on the establishment of a parallel process for Te Kopere team released for discussion within team

First round contact groups continue to be convened

Data analysis from first round begins

March	Reorganisation of project team into "Participation" and "Complementary Expertise" sub-teams takes place
	Further first round contact groups are facilitated
May	Methodological review of first round begins within the Participation team
	Data analysis from first round is ongoing
August	Emergent findings from Te Kopere groups shared with wider team and compared with findings from other contact groups
	Work on methodological overview paper begins
	Data analysis of contact group transcripts is ongoing
September	Materials and approaches for second session with first contact groups debated. Feedback document for contact groups is drafted and circulated to team members for comment.
October	Resource preparation for second sessions begins (in particular written summaries of first round contact group discussions and 'concept cartoons' for sharing preliminary findings with participants)
November	Policy-focused aspect of second session debated and resource preparation begins. Documents are prepared outlining key actors in the development of policy in the fields of genetic testing and the storage of genetic information. Summary documents are prepared on the policy making process. Application to Human Ethics Committee, University of Canterbury for the second round of contact groups is approved.
December	*Talking Genetic Testing* documented completed. It summarises responses of research participants and is developed for use in reconvened focus groups and workshops in 2005. (Available at www.conversations.canterbury.ac.nz)
	Final versions of documents are prepared that summarise the research strategies used in the first round of contact groups, the key findings from the group meetings and the complementary expertise methodology. (Available at www.conversations.canterbury.ac.nz)
	Materials and processes for second round of contact groups are finalised.

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