

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Awhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 4 February 2009

Members Present

Sharron Cole (Chair)

Alison Douglass

Tere Scotney

Bice Awan

Diane Wepa

- 1 **Apologies:**, Katrina Ings (Katrina will not attend meetings until approximately June 09. Kathy Spencer is acting in Katrina's role but will not be attending meetings. Patricia Logan will continue to represent Katrina), Kevin Morris (expected to be 30 minutes late to meeting)

In attendance: Kevin Morris, Kurutia Seymour (for Miriama Henderson), Patricia Logan (ex officio), [REDACTED] (Secretary).

- 2 **Confirmation of Minutes:**

- 2.1 The Minutes of the meeting 3 December 2008 were confirmed as a correct record.

- 3 **Matters arising:** Nil noted

- 4 **Discussion of conflict of interest for Committee Members and the Secretary**

Bice Awan noted that she knew [REDACTED], one of the supervisors for [REDACTED] research proposal (5.1).

- 5 **Approval of research and data requests**

- 5.1 Describing community participation amongst a small group of New Zealand Children after Traumatic Brain Injury. [REDACTED], AUT. #152

The committee noted:

- The exclusion from the study of those who do not understand or speak English will limit the extent to which findings can be extrapolated to the general population

Status: Approved

- 5.2 Survival following fracture neck of femur – changing patients, population and treatment. [REDACTED] #153

The committee noted the potential usefulness of the research and the importance of the maintenance of confidentiality of the data.

Status: Approved

5.3 Re-submission: Motor cycle Injury Outcomes Study (MINOS). [REDACTED], University of Otago. #149

The committee noted the proposal included a request from the researcher to ACC for the provision of information regarding characteristics of non-participants in the research. While it is recognised that this information is required to check the validity of the sample who do participate in the research, the process is not transparent. A person who declines to participate should also have the opportunity to decline to have information provided by ACC to the researcher.

At the end of the questionnaire there are questions regarding the amount of income and household income received in the last 12 months. People may be reluctant to answer these questions.

On the consent form it is stated that ACC and health services will not know that people have taken part in the study. This is not strictly true as ACC will be providing the data.

It is not clear what “the amount of earnings-related (weekly) compensation paid within 365 days of the accident date” variable, regarding non-participants in Appendix 1b, would add to the research, and it was recommended that this be removed.

It was felt that 15 minutes may not be a realistic timeframe in which to answer the questionnaire and that it may take longer.

Status: Approved subject to the following changes being made and sighted by the Chairs and Bice Awan:

- The information sheet is modified to explain to participants that there are three options: to participate, to not participate but have some non-identifiable information released to the researcher, or to not participate or have any of their information released to the researcher.
- Instead of asking income and household income, ranges of income should be offered with tick boxes. The questionnaire needs to state clearly that people do not need to answer any questions if they do not wish to.
- Change the statement on the consent form – number 3. Remove “ ACC and health services will not know that I have taken part in the study” and replace with “ ACC will provide data but will not keep a copy of this”.
- Remove “amount of earnings-related (weekly) compensation paid within 365 days of the accident date” variable from Appendix 1b.
- The statement in the information sheet, regarding the questionnaire taking approximately 15 minutes to be completed, needs to be reviewed. Has this been tested? If not this should be revised as nearer to 30 minutes.

5.4 Testing a new measure of workability, [REDACTED], AUT, Auckland University. #154

A phone conversation was held with [REDACTED]. The patient information form was noted to be unclear in terms of by whom the patient's notes would be viewed and the necessity of all ACC case notes being passed to a researcher or assessor was unclear.

The consent form to have research information considered in rehabilitation needs to be amended to reassure patients that ownership of the information rests with them and that they can choose who it is released to.

The committee questioned the inclusion of the statement, "I understand the compensation provisions for this study" on the consent form, but were advised by [REDACTED] that this is required for Northern Y Regional Ethics Committee approval.

Status: Approved subject to the following changes being made and sighted by the Chairs:

- The patient information form needs to be more specific about who will see ACC patient case notes and why. This needs to be allied with the 'Procedure for research assessors' in Appendix B.
- The consent form should be amended to re-assure patients that ownership of the information rests with them. Only information that would be beneficial to the claimant would be passed on to ACC with their consent. The Committee requested an example of what sort of beneficial information might be found and passed on.

6 Other Business

None

Meeting closed: 1.10 pm.

Next Meeting: 4 March 2009 11.00- 1.00 Shamrock House, Ground Floor, Rm 3.

Research Ethics Committee



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Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 4 March 2009

Members Present

Sharron Cole (Chair)

Alison Douglass (via phone)

Tere Scotney

Dianne Wepa (via phone)

Kevin Morris

Jackie Fawcett (ex-officio)

Kurutia Seymour (for Miriama Henderson)

██████████ (Secretary).

- 1 Apologies: Bice Awan, Sandie Waddell, Graeme Osborne, ██████████
In attendance: ██████████, Programme Manager.
- 2 Confirmation of Minutes:
 - 2.1 The minutes of the meeting 4 February 2009 were confirmed as a correct record. It was noted that Kevin Morris and Sandie Waddell were members of the committee but had been incorrectly recorded as 'in attendance'.
- 3 Matters arising: ██████████ proposal was considered at the last meeting, 'Testing a new measure of workability' – secretary to follow up on response to committee's suggestions.
- 4 Discussion of conflict of interest for Committee Members and the Secretary
Kevin Morris noted that he was the business owner for the proposal of 5.1 Clients' expectations of elective orthopaedic surgery – pre- and post-op.
- 5 Approval of research and data requests
 - 5.1 Clients' expectations of elective orthopaedic surgery – pre-and post-op. ██████████
UMR Research. #155

██████████, Programme Manager, attended the meeting to discuss the research proposal. The committee noted the value of the research and commented on the quality of the proposal.

Comments were received regarding cultural issues and how Maori expectations of the research would be obtained. It was suggested that an example of culturally appropriate practice would be to offer to have a Maori interviewer or the opportunity to have whanau present at an interview.

It was asked if the Maori and Community Relations Unit had been involved or contacted and it was suggested that it would be appropriate to involve them.

In the letter to clients it was suggested that clients be informed of the options of discussing the research with family and having friends or whanau present to help with the interview.

It was noted that in a retrospective study of this type it would be difficult for clients to remember their expectations of nine months prior. This was acknowledged as a risk but it was explained that the more in depth interviews were aimed to more accurately capture this information.

It was suggested that in the letters to clients that further clarification of the term “expectations” be provided and examples provided.

Status: Approved subject to the following changes being made and sighted by the Chairs

- The Maori and Community Relations Unit have the opportunity to review and comment on the proposal.
- Culturally appropriate practices such as offering a Maori interviewer and the opportunity to have whanau present at the interview should be incorporated into the letter to clients. Also participants should be informed of the options of discussing the research with family and having friends or whanau present to help with the interview.
- Further clarification of the term “expectations” should be provided in the letter to participants and examples given.

5.2 Response to the committee on the use of de-identified data: Motor cycle Injury Outcomes Study (MINOS). [REDACTED], University of Otago. #149

The committee considered [REDACTED] response to the committee’s previous decision regarding de-identified data on non-participants being provided to the researcher after clients declined to participate in the research.

It was noted that under normal circumstances ACC provides de-identified, aggregated data without client consent. However the committee noted that this research proposal differed from the norm. In this case, the potential participants would have been asked for consent to participate in the research project and some of them will have exercised their right to decline.

The committee recognised that the data on non-participants would be of value to the researcher, but was of that view that to provide the de-identified data when someone has been asked to participate in research and has declined risks the integrity of the research and is an encroachment on the person’s autonomy. Under normal research circumstances, a researcher would be unable to get any data about potential participants if they had declined to participate in the research. It was felt that just because ACC clients are a captive audience and their data is available, does not mean it should be provided.

To maintain the integrity of the research and to uphold informed consent principles, a solution was proposed:

ACC will provide a summary table of the whole sample to the researcher for date of birth, sex, ethnicity, location (geographic), total cost of claim to ACC in one year and employment status. This summary table will be provided with the sample for the researcher to use so that by analysing the data of participants and subtracting these from the whole sample, an analysis of the profile of non-participants should be possible.

Status: Approved subject to the proviso of de-identified data being supplied in a summary table for the whole sample.

6 Other Business

- 6.1 Revision to ACC Research Ethics Committee instructions and template to enhance business functions.

Jackie Fawcett, Principal Advisor, Research and Development, explained the addition of an appendix to the guidance for applicants form and minor changes to the template for the purpose of enhancing ACC's business functions.

It was suggested a flow chart may be useful and that contact names be removed in preference for generic email addresses as points of contact.

Meeting closed: 12.00 pm.

Next Meeting: 1 April 2009 11.00- 1.00 Shamrock House, Ground Floor, Rm 3.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 6 May 2009

Members Present

Alison Douglass (chair)

Sharron Cole

Tere Scotney

Bice Awan

Dianne Wepa (via telephone)

Kevin Morris

Graeme Osborne

1 Apologies: [REDACTED] (for Sandie Waddell)

In attendance: Jackie Fawcett, [REDACTED] (Secretary).

2 Confirmation of Minutes:

2.1 The Minutes of the meeting 4 March 2009 were confirmed as a correct record.

3 **Matters arising:** Clients' expectations of elective orthopaedic surgery – pre-and post-op. [REDACTED], UMR Research. #155 – this proposal was considered at the meeting of 4 March 2009 and approved subject to conditions. Amendments were made to the proposal as requested by the Committee and approved by the chairs.

4 Discussion of conflict of interest for Committee Members and the Secretary

No conflicts of interest were noted.

5 Approval of research and data requests

5.1 The economic costs of Inflicted Traumatic Brain Injury (“Shaken Baby Syndrome”) in New Zealand, [REDACTED], Starship Children’s Health, Auckland District Health Board. #156

In a telephone conversation with the Committee, [REDACTED] clarified that the request was for economic information relating to ACC claims for Inflicted Traumatic Brain Injury. The Northern Y Ethics Committee approval was obtained by the researcher for sharing information outside Auckland DHB and was previously approved under their fast-track procedure as low risk – this approval expires on 20 May 2009 but an extension to the approval has been submitted.

Status: Approved subject to the following:

- Further discussion is held with [REDACTED], Manager, National Serious Injury Service, to advise ACC of the specific data fields that will be delivered by ACC.
- A confidentiality agreement is signed by the researcher.
- Prior to publication ACC has the opportunity to comment and review the report to ensure accuracy in terms of the use of ACC data.

- Confirmation of the extension of Northern Y Ethics Committee approval, once received, should be forwarded to ACC.

5.2 School of Dentistry research Project, [REDACTED], School of Dentistry, University of Otago. #157.

Status: Approved with confirmation from the researcher that treatments received will be included in the study to improve the depth and quality of the information.

5.3 A longitudinal study of Dental Injury Treatment, [REDACTED], Dental Policy and Clinical Advisor, ACC. #159.

This study is longitudinal and the Committee sought further information regarding the ownership of the project to ensure the sustainability of the study.

Status: Deferred with the invitation to resubmit the proposal once the methodology and design have been further developed, including establishing the ongoing commitment required for a ten year study.

5.4 Supported Employment/Supported Living Evaluation, [REDACTED], Colmar Brunton Ltd. # 158

[REDACTED], Researcher, [REDACTED], Researcher and [REDACTED], ACC Programme Manager attended the meeting to discuss the research proposal. There was extensive discussion of the validity of the Success Case Method as a tool and the need for transparency in presenting the purpose of the research to participants.

Status: Approved subject to the following changes (to be given final approval by the Committee)

- Confirmation that Success Case Method (SCM) has been used previously in a health setting and if it has not, participants should be informed of this fact.
- The recruitment letter and information sheet should explain the purpose of Supported Living and Supported Employment Programmes and the proposed evaluation now planned.
- Clarification is required to inform participants that the evaluation is about the role that the programme has played in achieving/not achieving their goals. This is to ensure that clients do not interpret the evaluation as being about the clients as either successes or failures. If the researchers do not intend to inform the participants of the success/failure method of evaluation then there ought to be ethical justification for withholding this information.
- The information sheet needs to clarify the basis for approaching employers and explain what information will be obtained from them.
- A protocol to manage people who are unable to give informed consent should be developed.
- Participants should be informed that a Maori/pacific interviewer will be available.
- The consent form should be changed to read “My participation in this study will have no bearing on any current or future dealings I may have with ACC”

- On the information sheet under “what is the research for?” – change “ACC has set for them” to ACC has set with them”.

6 Other Business

6.1 Research/Data request monitoring forms.

The Committee reviewed the forms. It was suggested that the number of outstanding monitoring forms be reviewed for the next Committee meeting.

6.2 Six monthly Ethics Committee report to the Executive Leadership Team (ELT)

The Committee reviewed the draft of the proposed 6 monthly report to ELT. It was suggested that a section be added regarding the Committee’s review and revision of the ethics application form which was completed at the end of 2008 with the comment that the new form appeared to be producing applications of higher quality.

It was proposed that the Committee consider building a portfolio of examples of good practice in response to ethical issues.

The Committee also agreed that they would appreciate feedback from the ELT.

Meeting closed: 1.10 pm.

Next Meeting: 3 June 2009 11.00- 1.00 Shamrock House, Ground Floor, Rm 3.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 3 June 2009

Members Present

Sharron Cole (chair)

Kevin Morris

Alison Douglass

Tere Scotney

Bice Awan

Dianne Wepa (via telephone)

1 Apologies: Jackie Fawcett, Miriama Henderson

In attendance: Patricia Logan, [REDACTED] (Secretary).

2 Confirmation of Minutes:

The Minutes of the meeting 6 May 2009 were confirmed as a correct record.

3 Matters arising:

3.1 Supported Employment/Supported Living Evaluation, [REDACTED], Colmar Brunton Ltd. # 158. This proposal was considered at the meeting of 6 May 2009 and approved subject to conditions. Amendments were made to the proposal as requested by the Committee and these were viewed by the committee. Further recommendations were made to the researchers and the final amendments made by the researchers have been viewed by the committee.

3.2 Six monthly Ethics Committee report to the Executive Leadership Team (ELT). The draft was reviewed at the last meeting on 6 May 2009. A copy of the final report was circulated to members prior to this meeting. Patricia Logan noted that the Committee's request for feedback was removed from the report.

4 Discussion of conflict of interest for Committee Members and the Secretary

No conflicts of interest were noted. Kevin Morris noted that he had been consulted in the preparation of the proposal, 5.4 [REDACTED], University of Auckland.

5 Approval of research and data requests

5.1 Recognising emotions after brain injury, [REDACTED], Massey University. #160.

The meeting was attended by [REDACTED] and [REDACTED].

The committee noted that the research proposal had approval from the Central Regional Ethics Committee. The researcher clarified the research process and issues of competence, harm and consent. [REDACTED] explained that all participants in the research (including controls) would be offered the successful intervention, if the research identifies that one treatment is beneficial to participants. It was suggested that in the information sheet, for family members, the

term “whanau” be used to acknowledge that those with brain injuries are not necessarily cared for by just one person. The researchers agreed.

Status: **Approved in principle:**

- Because the proposal has not been finalised with ACC further discussion needs to be held between the researcher and ACC regarding resource commitment and administrative facilitation for the proposal.
- Once processes within ACC are established these must be sighted by the Committee at its next meeting.
- A covering letter to be sent to case managers to inform them of the research proposal and requesting their assistance should be sighted by the committee at the next meeting.

5.2 Work place organisation and return to work: an exploratory study. [REDACTED], University of Otago. #161

This study has requested an amendment of the ethical approval given to the POIS study from the Multi-regional Ethics Committee.

The committee noted several issues regarding the information sheet and letter which required clarification and amendment.

Status: **Approved subject to revision of the information sheet, letter and questionnaire:**

- On page 8 of the questionnaire under ‘Approaching employers’, the statement, “We are NOT going to contact your employer in this study but are simply asking for your opinion on approaching employers”, should be placed at the top of the page so that this statement is clearly visible.
- The information sheet should start by thanking people for their participation in the POIS study and thus present a more welcoming opening.
- “Sensible to New Zealand workers” in paragraph 2, should be replaced with “relevant within the NZ context”.
- It must be clearly stated that this is an independent study and that participation will not affect participant’s ACC cover, for example, “Your participation is completely voluntary. Whether you decide to take part or not has no effect on the status of your claim or your relationship with ACC”.
- The option of having whanau present for the interview should be offered.
- With regard to the development of questions that would be culturally appropriate to Maori, the committee would like to see further information to support this area that is of potential interest to the researchers.
- The sentence “To the best of our knowledge, there are no risks to you taking part” should be revised.

5.3 Disabled by Illness or Injury: carers study. [REDACTED], University of Otago. #162

This research proposal has Multi-region Ethics Committee approval.

The committee noted that carers are often children and this largely invisible group is not captured in research. The research proposal assumes that there is one carer for an injured person where there may be several carers or “whanau” care and it was suggested that this latter term be used in the information sheet and consent forms. The information sheet also needs to acknowledge the independence of the research. A relevant study was noted and it was suggested that this reference be forwarded to the researchers.

Status: Approved subject to the following changes:

- The information sheet and consent form should be amended to include the term and concept of “whanau”.
 - The information sheet must clearly state that the study is independent and that participation will not affect ACC cover, for example, “Your participation is completely voluntary. Whether you decide to take part or not has no effect on the status of your claim or your relationship with ACC”.
- 5.4 The self-reported approach of individual medical practitioners assessing insurance claims for health and accident cover: six anonymised semi-structured interviews. [REDACTED], University of Auckland. #163

The committee felt that the information sheet required a more tactful introduction. Because of the small number of participants in the study the importance of anonymisation of data and ensuring the confidentiality of sensitive feedback is paramount.

Status: Approved subject to information sheet being viewed by Chairs.

6 Other Business

Meeting closed: 1.10 pm.

Next Meeting: 1 July 2009 11.00- 1.00 Shamrock House, Ground Floor, Rm 3.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 1 July 2009

Members Present

Alison Douglass (chair)
Sharron Cole
Bice Awan
Graeme Osborne

Tere Scotney
Dianne Wepa
Kevin Morris
Sandie Waddell

1 Apologies: None

In attendance: Patricia Logan for Kathy Spencer, Jackie Fawcett, [REDACTED]
(Secretary).

2 Confirmation of Minutes:

The Minutes of the meeting 3 June 2009 were confirmed as a correct record.

3 Matters arising:

3.1 Disabled by illness or injury: carers study. [REDACTED], University of Otago. #162. This proposal was considered at the meeting of 3 June 2009 and approved subject to conditions. Amendments were made to the proposal as requested by the Committee and these were viewed by the two chairs. A final recommendation was made by the Chairs for clarification on the information sheet.

3.2 Work place organisation and return to work: an exploratory study. [REDACTED], University of Otago. #161. The amendments were viewed by the committee and final approval was given.

3.3 The self-reported approach of individual medical practitioners assessing insurance claims for health and accident cover: six anonymised semi-structured interviews. [REDACTED], University of Auckland. #163. The amendments were viewed by the committee and final approval was given.

3.4 [REDACTED]. #160. Because of the limited pool of seriously injured patients who can potentially participate in research, this project is still under discussion in terms of business support and allocation of resources.

4 Discussion of conflict of interest for Committee Members and the Secretary

No conflicts of interest were noted.

5 Approval of research and data requests

5.1 Supply of ongoing database for the long-term evaluation of the modified Tai Chi Programme, [REDACTED], UMR. #164

The previous short evaluation was approved by the committee in February 2008. The evaluation reported evidence that Tai Chi reduces falls and was of benefit to clients.

██████████ spoke to the committee via telephone. It was clarified that this research project is completely separate from the first project and new patients will be recruited for this proposal and clients from the previous project are not involved. This evaluation aims to recruit a larger sample to increase statistical power and provide longer term evidence. The assessment form has been modified.

It was noted that Regional ethics committee approval had expired and that a new application should be made in light of the fact that the evaluation is intending to recruit new participants.

The committee questioned the uniform delivery of the programme nationwide – this responsibility lies with ACC who control the delivery of the programme in the field, whereas UMR are evaluating the data. ACC internal issues with regard to the delivery of the programme need to be addressed. There was no report on the rate of participation from the previous evaluation or analysis of those who declined to participate. The committee questioned the representativeness and validity of the findings if this was not done.

Status: Proposal to be re-submitted with the following points addressed:

- To what extent can this research be justified to increase the statistical power of the original research findings? What does ACC hope to gain from the findings?
- There is an assumption that this evaluation can be delivered nationally in a uniform way. How will this be addressed by a range of providers in different settings?
- More information is required regarding the previous evaluation particularly regarding the process of informed consent. Was there a high rate of consent to participate in the research and if not, what were the reasons identified?
- The committee agreed that this proposal would need further multiregional ethics committee approval

5.2 Post operative visual loss in New Zealand in the last fifteen years, ██████████, Canterbury District Health Board. #165

It was noted that the previous consultation with ACC in relation to this project had happened some considerable time ago and there had been no recent consultation between ACC and the researchers. The number of claims involving visual loss after surgery is anticipated to be very small and the researchers may be unaware of the limited amount of medical information held by ACC. It was suggested that further consultation with ACC would be beneficial. ██████████, Acting Team Manager, Treatment Injury Centre, was suggested as a point of contact.

The information being requested by the researchers is potentially identifiable and the committee agreed that the proposal would need multiregional ethics approval.

Status: Deferred until the next meeting to allow further consultation with ACC on the potential viability of the research proposal

5.3 Examining the causes of drowning and water related injuries in the context of the relevance of swimming ability and acquisition of water skills, [REDACTED], PricewaterhouseCoopers. #166

The committee acknowledged that they were looking at the proposal without the benefit of the literature review, but questioned the assumption of the ability or lack of ability to swim as the only causal link relevant to reducing rates of drowning.

As the research is relevant to ACC's business the committee wondered if a more collaborative approach between WSNZ, PricewaterhouseCoopers and ACC would be appropriate. There was concern about a commercial entity (PricewaterhouseCoopers) doing research on behalf of an NGO (WSNZ) in order to provide a business case to establish a programme. As the information could be potentially identifiable it was queried as to whether the findings would be externally reviewed and published ensuring public accountability.

It was noted that all the variables requested by the researchers from ACC were available from the Drownbase database except the 'cost of the claim'.

Status: To be re-submitted after the following matters have been addressed:

- There is currently not enough information in the proposal to know how the data will be used and how the results will be publicly disseminated. The committee require assurance regarding the independence of the research and the experience and skills of the researcher.
- As external requests for data can be facilitated by having an internal point of contact within ACC the researchers should be advised to contact [REDACTED], Manager, NZ Injury Prevention Strategy, within ACC
- As the committee was working without the benefit of the findings of the literature review, they request further information regarding the rationale for the research.
- There is a lack of clarity around the research question and methodology and an assumption of the research findings. ACC would expect the opportunity to review any findings before publication, as part of the standard data supply agreement ACC has with outside researchers.

6 Other Business

6.1 Letter to members of advisory committees by ACC

External members of the committee had recently received a letter from ACC outlining the new standardisation of meeting fees across advisory committees. Patricia Logan undertook to find out more from Kathy Spencer and report back to members.

Meeting closed: 1.00 pm.

Next Meeting: 5 August 2009 11.00- 1.00 Shamrock House, Ground Floor, Rm 3.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 5 August 2009

Members Present

Alison Douglass (chair)
Bice Awan
Graeme Osborne

Tere Scotney
Dianne Wepa

1 Apologies: Sharron Cole, Kevin Morris

In attendance: Jackie Fawcett, [REDACTED] (Secretary).

2 Confirmation of Minutes:

The Minutes of the meeting 1 July 2009 were confirmed as a correct record.

3 Matters arising:

3.1 Supply of ongoing database for the long-term evaluation of the modified Tai Chi Programme, [REDACTED] UMR. #164

This proposal was considered at the meeting of 1 July 2009 and requested to be re-submitted with a number of points addressed. A letter from [REDACTED] UMR has been received and reviewed by the committee. [REDACTED], Programme Manger, Injury Prevention attended the meeting to answer further questions.

[REDACTED] clarified that this research will provide enough numbers to enable a comparison with ACC falls claim data to understand the effectiveness of the programme. The numbers of claimants who declined to be part of the earlier study was small – there was a greater issue with providers not returning feedback forms. UMR have submitted an application to the Multi-region Ethics Committee

Status: Approved subject to Multi – region Ethics Committee approval. UMR letter to be resent with “draft” removed.

3.2 Examining the causes of drowning and water related injuries in the context of the relevance of swimming ability and acquisition of water skills, [REDACTED], PricewaterhouseCoopers. #166

This proposal was considered at the meeting of 1 July 2009 and was requested to be re-submitted after a number of matters were addressed. [REDACTED] attended the meeting and submitted further written information which was not read by the committee at the time.

[REDACTED] has been consulted by [REDACTED] and was reported to be supportive of the proposal but no written confirmation of this was provided. It was clarified that no literature review had yet been done and that the researcher still held data from a previous research project approved by the committee in December 2008.

Jackie Fawcett agreed to further discuss committee requirements with the researcher regarding publication and dissemination.

Status: Proposal to be re-submitted

4 Discussion of conflict of interest for Committee Members and the Secretary

Jackie Fawcett is involved in proposal 5.2 and did not participate in discussion of this proposal.

5 Approval of research and data requests

5.1 STePS Trial: Consumer Satisfaction, [REDACTED], Senior Analyst, Market Research, ACC. # 167

[REDACTED], Advisor, Service Planning and Design attended the meeting. The statistic validity of the number of clients included, feedback of results to participants and the type of data to be collected was discussed and clarified.

Status: Approved

5.2 Misattribution of work-related claims to the Earner's Account: A client survey, Jackie Fawcett, Principal Advisor, Research and Development, ACC. # 168

[REDACTED] from Colmar Brunton attended the meeting. The committee queried the line of questioning over motivation for cost shifting and whether it implies fraud. The researcher emphasised that this was only one line of questioning and indirect. Rapport with the client would be built up over the interview before more sensitive questions would be asked. The committee queried the title on the letter and suggested it be changed to "ACC Research – client survey"

Status: Approved subject to title change to letter.

5.2 Better@Work evaluation and client satisfaction survey, [REDACTED], Research Advisor, Research and Development, ACC. # 169

[REDACTED], Research Advisor, attended the meeting. The committee discussed the role of GPs in maintaining clients in the work place and their role as patient advocate. The committee felt that there should be assurance of confidentiality for all stakeholders. With regard to access to the clinical provider medical record, the consent forms need to be appropriate for all involved. It was recommended that the Multi-regional Ethics Committee be consulted.

Status: Approved subject to consent forms to be viewed by the Chair and that the Multi-regional Ethics Committee be consulted.

6 Other Business

6.1 Ethics Committee membership

The membership of the committee has undergone recent changes with the establishment or disestablishment of positions within ACC. Sandie Waddell is no longer with ACC, Patricia Logan has moved to a new position and Miriama

Henderson is unable to attend. To ensure that representation of ACC members meets the requirements of the Committee's Terms of Reference, it was acknowledged that there is a need to engage with a representative from Operations and possibly another general manager.

Meeting closed: 1.20 pm.

Next Meeting: 2 September 2009 11.00- 1.00 Shamrock House, Ground Floor, Rm 3.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 4 November 2009

Members Present

Sharron Cole (chair)
Alison Douglass
Bice Awan

Tere Scotney
Dianne Wepa
Miriam Henderson

██████████ (for Kevin Morris)

1 Apologies: Kevin Morris

In attendance: ██████████, ██████████ (Secretary).

2 Confirmation of Minutes:

The Minutes of the meeting 5 August 2009 were confirmed as a correct record.

3 Matters arising:

3.1 In September the committee considered, via email, ██████████ research proposal, 'Examining the causes of drowning and water related injuries in the context of the relevance of swimming ability and acquisition of water skills'. The committee considered that the results of the study should be made public no matter how ACC data was used and that the publication should not be limited to a selected or limited number of stakeholders but be promptly and publicly available.

There has been no response from the researcher to the letter from the committee dated 14 September. Follow up email to the researcher on 28 October did not elicit a response. The committee suggested further follow before the meeting in December

3.2 Due to the attrition of members of the committee over the last few months it was suggested that committee membership be an agenda item for the next meeting. It was also noted that where internal ACC committee members are unable to attend a meeting, a person should be nominated to attend in their absence. If members were unable to attend it was also possible that they submit comments in writing.

4 Conflict of interest declarations

4.1 ██████████ acknowledged that he originally wrote the contract for item 5.3 from ██████████. However this did not exclude him from discussion of the item.

5 Approval of research and data requests

5.1 NZ snow safety ski binding standards, education and testing project, ██████████ ██████████ e, AUT. # 170

The committee recalled previous research in this area by the same researcher. This was 'ACC Critical Review of Ski Binding standards and related research: Data analysis from Mountain Safety Council data and ACC data' – a research proposal that was submitted

in October 2007. The aim of that critical review was to gain a comprehensive understanding of the impact that the implementation of international standards relating to ski binding settings and adjustment had on the occurrence/prevention of knee injuries in alpine skiing. Analysis of injury trends by the researchers was to compare and contrast use for an analysis of knee injuries in relation to snow sports in New Zealand with international trends. This study was approved by the committee.

The committee wished to understand if any ethical issues arose during the last research and how they were managed and felt that they needed more information on previous work in this area to provide context to the current research. Security of the data in terms of storage and disposal at the end of the research were not addressed in the proposal and the committee expected that the research would not identify any individuals in publishing the research.

Status: Approved subject to the above matters being addressed and to be viewed by the Chairs.

5.2 Adult outcomes of Childhood TBI, [REDACTED], University of Canterbury.
171

The committee requested further information regarding the following:

It was queried whether the current proposal had been modified after submission to the Upper South B Regional Ethics Committee and if so, how and in what manner. Final approval from the Upper South B Regional Committee was also requested. The Upper South committee letter refers to DHB information but does not mention ACC data – was this included in the ethics application to that committee?

More information was required regarding storage of data and what will happen to the data after the research is completed.

More information is required in the research proposal regarding how these clients will be identified and the process agreed with ACC to contact potential research subjects.

There was inconsistency in that the proposal mentioned a 3 hour assessment and the information sheet to participants stated a 2 hour assessment.

Did the proposal intend to inform participants that the results of the study would be forwarded to them?

Status: Defer and resubmit

5.3 Data to drive the serious non-fatal work-related injury indicators – request for variation in the use of ACC data, [REDACTED], IPRU, Otago.
140

After clarification of a number of terms and protocols for publishing the committee agreed to approve the proposal.

Status: Approved

5.4 Exploring the relationships between self reported Physical Activity level, Fatigue and Return to Work following Mild Traumatic Brain Injury, [REDACTED], AUT. #172

The committee felt that the letter to potential participants should include the purpose for the research, even though this is covered in the information sheet.

The questionnaire required some modification in terms of layout with more white space and clearer instructions. Ethnicity should also be captured. The date of injury should clearly state the injury for which they are attending the concussion clinic. The term 'occupation' is misleading and 'employment status' should be used. The questionnaire should also be piloted.

The data specification should include timeframes, age to be greater than 17 and current attendance at a concussion clinic.

It was suggested that a copy of the letter to the researcher (a Master's student) should also be copied to the supervisor [REDACTED], so that she is also aware of the points made.

In light of the number of research proposal originating from AUT under the supervision of [REDACTED], the committee felt it would be useful to meet with her to discuss the ethics, protocols and processes where ACC clients are involved.

Status: Approved subject to the above matters being addressed and to be viewed by the Chairs.

6 Other business

Meeting closed: 1.20 pm.

Next Meeting: 2 December 2009 11.00- 1.00 Shamrock House, Ground Floor, Rm 3.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 2 December 2009

Members Present

Sharron Cole (chair)
[REDACTED] (For Kathy Spencer)
Kevin Morris

Tere Scotney
Dianne Wepa

1 Apologies: Alison Douglass, Bice Awan and Miriama Henderson

In attendance: Jackie Fawcett, Grant Pittams (ex-officios), [REDACTED]
(Secretary).

2 Confirmation of Minutes:

The Minutes of the meeting 4 November 2009 were confirmed as a correct record.

3 Matters arising:

3.1 NZ snow safety ski binding standards, education and testing project, [REDACTED] [REDACTED], AUT. #170

The committee requested further information from the researcher and this proposal was approved by delegation prior to the meeting.

3.2 Exploring the relationships between self reported physical activity level, fatigue and return to work following mild traumatic brain injury, [REDACTED], AUT. #172

The response to the committee's request for changes has been forwarded by the researcher. To be viewed by the Chairs before final approval.

4 Conflict of interest declarations

4.1 Kevin Morris is the reporting manager of [REDACTED] (Research proposal 5.2)

4.2 Grant Pittams is the reporting manager of [REDACTED] (Research proposal 5.5)

5 Approval of research and data requests

5.1 Resubmission - Adult Outcomes of TBI, [REDACTED], University of Canterbury. #171.

The committee discussed the possibility that some potential participants may not have had contact with ACC for some time, or may not even know that they had a head injury as a child. Therefore any initial letter from ACC to potential participants would need to clearly explain the research.

- The committee wanted to see a draft of the ACC letter to potential participants.

- Approval should be subject to approval from the Upper South B Regional Ethics Committee.
- Participants in the research should receive a summary of the findings without having to request the information.

Status: Approved subject to the above matters being addressed

- 5.2 A study into why ACC Clients have not completed their dental implants with crowns, [REDACTED], ACC. #174

Kevin Morris provided background information on the research proposal. The committee noted that the letter to participants needed to be more open and direct about the purpose of the research and also reassure participants that their entitlement will not be affected whether they participate or not.

Status: Approved subject to two changes above and letter to be viewed by Chair.

- 5.3 How accurate are surgeons at predicting RTW following Anterior Cruciate Ligament (ACL) Repair? [REDACTED], ACC. # 173

Normally audit as part of an employee's job role would not come before the ethics committee, but in this case the member of staff is doing the audit as part of a thesis.

Status: Approved

- 5.4 Unintentional or Accidental Strangulation or Hanging, [REDACTED], Auckland DHB. #175

This data request to ACC only captured 16 instances in the data. The other sources of information being used by the researcher may pick up the deaths (coronial data) but there were 9 non-fatal cases. As the information is potentially identifiable the committee agreed that this should be explained to the researcher with the hope that these cases can be picked up in other data. The committee also noted that a number of other causes of strangulation, for example, cot bars or being caught up in a buggy were not represented in the ACC data.

Status: R&D to further discuss the potential to obtain data from other sources and explain the small amount of identifiable data on ACC database.

- 5.5 Market Research Review – Pre-testing and ongoing Market Research Programme application, [REDACTED] ACC. #176

[REDACTED] attended the meeting. The committee clarified with the researcher that external agents who are contracted to ACC are not “third parties” as the risks of confidentiality are covered in the contract with the agent. Therefore the release of personal details, for example, names, to those contracted to ACC does not require committee approval. Where there is a need to release clinical details to an agent, this matter should be referred back to the committee for guidance.

The standard exclusions were confirmed by the committee and it was clarified that treatment injury claims were excluded while going through the decision process but once the claim was accepted by ACC, they were no longer excluded.

6 Other business

6.1 Monitoring forms

The following research project monitoring forms were reviewed by the committee: # 123, 125, 130, 135, 136, 137, 141, 142, 145, 146 and 147. No issues were identified except in monitoring form #147.

#147 – The mechanisms and types of non-motor vehicle injuries to pedestrians in the transport system and indicated infrastructural implications, ██████████, Opus International consultants - it was noted on the monitoring form that there had been a small number of complaints about the manner of the interviewer approach. ██████████ Manager of R&D agreed to follow up on the method of interviewer selection, the nature of the complaints and how they were managed.

6.2 Research Ethics Committee application template for 2010

The committee agreed that under '3. Background' the instructions should include the statement: "Include any previous research undertaken in this area and the outcomes of the research".

The font will be changed to Arial 11.

The dates for 2010 will be set for the first Wednesday of the month with the first meeting being held in February 2010.

6.3 Half yearly report to ELT

The half yearly report to ELT is due on 14 December. Issues to be identified in the report are:

1. The commercial use of research findings – this relates to the research proposal put forward by PricewaterhouseCoopers earlier in the year.
2. Planned review of the ACC Research Ethics Committee

6.4 The future structure and operation of the ACC Research Ethics Committee.

Jackie Fawcett discussed the planned review of the Research Ethics Committee and outlined the issues to be addressed

Until the review is finalised at the end of February 2010, the committee will continue with the same interim membership.

Meeting closed: 1.45 pm.

Next Meeting: 3 February 2010, 11.00- 1.00 Shamrock House, Ground Floor, Rm 3.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 3 March 2010

Members Present

Alison Douglass (chair)
Grant Pittams (For Kathy Spencer)
Kevin Morris
Zeeman Van Der Merwe

Tere Scotney
Dianne Wepa
Bice Awan
Miriam Henderson

In attendance: [REDACTED]

1 Apologies

Apologies were received from Sharron Cole, Patricia Logan, Dianne Wepa and [REDACTED].

2. Confirmation of Minutes

Minutes of the meeting held on 2 December 2009 were confirmed as a correct record.

3 Matters arising

3.1 Goals and self-regulation skills in brain injury rehabilitation: an RCT, [REDACTED], Auckland University. # 151

Expansion of the recruitment process for this study was granted by the Regional Ethics committee for the use of a recruitment pamphlet and poster to be distributed to ACC Branch Managers in the Auckland and Hamilton offices.

This amendment to the protocol was approved by the Chair on 15 December.

3.2 The mechanisms and types of non-motor vehicle injuries to pedestrians in the transport system and indicated infrastructural implications, [REDACTED], Opus International Consultants. #147

The Ethic Data Monitoring form was viewed at the last meeting by the committee. It was noted that there had been a complaint about one of the interviewers. The committee requested further information regarding the nature and management of the complaint.

There were two issues:

- (1) A GP who was contacted by [REDACTED] team had not received a letter from ACC asking for permission to pass her details to the researchers. Her main concern was that the same could happen to patients. The action taken was that researchers modified their approach by checking that people had received a letter from ACC before proceeding.
- (2) Another complaint was received from the mother of a 14 year old boy whose details had been passed to Opus without her consent. It turned out that the father (the parents were separated) had already given consent and the matter was resolved.

3.3 A Study into why ACC clients have not completed their dental implants with crowns, [REDACTED], ACC. # 174

This study was approved at the last meeting subject to changes to the letter to potential participants. The amended letter was viewed by the Chair and approved.

- 3.4 Unintentional or Accidental Strangulation or Hanging, [REDACTED]
[REDACTED] Auckland DHB. #175
This data request to ACC only captured 16 instances. As the information is potentially identifiable the committee agreed that this should be explained to the researcher with the hope that these cases can be picked up in other data. The committee also noted that a number of other causes of strangulation, for example, cot bars or being caught up in a buggy were not represented in the ACC data.
After discussion with the researchers a revised search strategy was identified and this produced over 150 results. Given the increased number of cases and reassurance about how the data will be used and approval from the Chair the report was released to the researchers.
- 3.5 Adult outcomes of TBI, [REDACTED], University of Canterbury. # 171
At the December meeting the committee noted that some potential participants may not have had contact with ACC for some time or may not know that they had a head injury as a child. Therefore any letter from ACC to potential participants would need to clearly explain the research. The committee wanted to see the draft letter to potential participants and approval from the Regional Ethics Committee.
The Upper South Ethics Committee has provisionally approved the proposal with the ACC letter being sent out with the information sheet attached.
The Committee noted that ACC has an obligation to its clients to protect them from being over researched and therefore those clients with a serious injury may only be approached and asked to participate in research once during a year. Consequently the data received from ACC will have TBI clients already withheld for ACC research purposes and therefore the data received by the researcher will be a subset of the total pool of TBI clients
The information sheet was approved subject to:
- The sheet should start by informing clients why they have been approached and that they may have had a head injury previously.
 - The information sheet should inform clients that their ACC entitlements will not be affected by participation in the study.
 - The researchers should consult with Research Services regarding the available pool of ACC TBI clients and how this may effect the study.

4 Conflict of interest declarations

None.

5 Approval of research and data requests – for approval

- 5.1 Assessment of pituitary function in children who sustained traumatic brain injury (TBI) in infancy, [REDACTED], University of Auckland. #177
The Committee considered this to be a worthwhile project, but raised the following issues:
- Is there a treatment available for this condition? Outcomes of the research need to address expectations
 - The second letter needs to be in lay person's language.
 - The Committee would also like to see the initial letter that was sent out.
 - The 'opt in' letter needs to contain a contact point for researchers.
 - There is a need to look at the \$20 for costs. This may not be sufficient for people out of town.
 - Amend the Information Sheet under the heading 'What are the potential benefits and risks?' last paragraph to read ".....appropriate treatment which will improve their health *at the Starship*" to avoid any confusion.

- Information on application of the numbing cream on the appointment letter is inconsistent with that on the information sheet for the child as to who applies it.

5.2 Anatomical based errors in clinical practice, [REDACTED], University of Otago. #178

The committee considered that access to all the information held in the treatment injury database was too wide a field of personal information without obtaining individual consent from claimants. The provision of ACC data is restricted to information required for the research purpose only.

The Committee fully supported the utility of the research and supported an alternative way forward. The definition of anatomical error may need to be more closely defined to help narrow down the data required. Would summarisation of the files be appropriate?

The Committee recommended that [REDACTED] work further with [REDACTED], Team Manager, and [REDACTED], Clinical Analyst, Treatment Injury Centre, to refine the data search and resubmit a further application to the committee.

5.3 Brain Injury outcomes New Zealand In the Community (BIONIC), [REDACTED] University of Auckland. #179

The committee discussed issues regarding ACC's obligation to its clients to protect them from being over researched and therefore those clients with a serious injury may only be approached to participate in research once during a year. As a consequence, the data received from ACC will have TBI clients already withheld for ACC research purposes and therefore the data received will be a subset of the total pool of TBI clients.

The number of READ codes suggested to identify potentially eligible cases of TBI for the study was extensive and will result in an extremely large number of cases being identified.

It recommended that the researchers liaise with Research Services regarding these two matters and then report back to the committee on the implications to their research, before final approval can be given.

5.4 School of Dentistry Research Project, [REDACTED], University of Otago. #180

This proposal uses the same data that has been used in the past. There is no individual consent required. [REDACTED] is to be thanked for his paper published in respect to previous work.
Proposal approved.

5.5 Research into the Maori experience of ACC, Researcher to be confirmed, Department of Labour. #181

[REDACTED] attended the meeting and apologised for the incomplete documentation. The committee considered that it would be useful for the research proposal to include a literature review and review of previous research to inform the methodology chosen.

While acknowledging the need for the stocktake to be independent of ACC, the committee suggested that data already held by ACC could be utilised and if these data

sources were sufficient further research would not be required. It was suggested that further discussion with Grant Pittams, Research Manager, would be useful to identify available data.

If appropriate data was unavailable the committee would require a resubmission providing further information regarding the investigator, information sheets, information about the recruitment process, community consultation and engagement plans.

The Committee acknowledged the tight timescale for the project and expressed agreement in doing its utmost to assist in a timely manner to view any further submission.

6 Other Business

6.1 Review of the ACC Research Ethics Committee update

The review of SP&R included looking at the function of various committees to see that they align with the strategic directions of ACC. A review team consisting of Grant Pittams, [REDACTED], and two senior evaluators, was asked by Dr White to look at how the Ethics Committee is operating, the process for applications, privacy, data and Research Group support and also its relationship to the R&D Committee. They are also looking at other organisations' structures against the ACC model. The Review Committee has now reached the point of doing qualitative interviews and Grant Pittams enquired, on behalf of the Review Committee, how the Ethics Committee members would like to be interviewed. The majority of the Ethics Committee opted for face-to-face interviews and also requested that Grant Pittams send them out a copy of the current Terms of Reference.

6.2 The Chair suggested that a letter of thanks should be sent to Jackie Fawcett for her work on behalf of the Committee.

Next meeting: Wednesday 7 April .

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 7 April 2010

Members Present

Sharron Cole (Chair)
Grant Pittams (For Kathy Spencer)
Kevin Morris
Zeeman Van Der Merwe
Tere Scotney

Dianne Wepa
Bice Awan
Miriam Henderson
Patricia Logan

In attendance: [REDACTED], [REDACTED]

1 Apologies

Apologies were received from Alison Douglass and [REDACTED].

2. Confirmation of Minutes

Minutes of the meeting held on 3 March 2010 were confirmed as a correct record.
Tere Scotney/Grant Pittams.

3 Matters arising

3.1 Adult outcomes of TBI, [REDACTED], University of Canterbury # 171

[REDACTED] has acknowledged that the remaining small sub-set of the sample left after ACC has removed its own requirements, may not be enough for a true representative sample. The information sheet has been amended and the Committee gave final approval to the research proposal

3.2 Assessment of Pituitary Function following Traumatic brain Injury in Early Childhood, [REDACTED] Liggins Institute #177

The researchers have decided to use ADHB sources to try and contact potential study participants but have requested that their request remain open should they need to return to ACC.

3.3 Traumatic Brain Injury Burden in New Zealand: a population based incidence and outcomes study (BIONIC), [REDACTED], AUT. #179

[REDACTED] originally requested an extensive number of read codes which would have resulted in ACC having to send out 12,000 letters. However, after discussions with [REDACTED], he expressed an intention of re-submitting a request for a smaller number. ACC is awaiting her formal reply.

3.4 Letter of thanks was sent to Jackie Fawcett.

4 Conflict of interest declarations

Grant Pittams declared a conflict of interest regarding the Treatment Injury Market research application.

5 Approval of research and data requests – for approval

5.1 Supported Activities Service Evaluation, [REDACTED], PS Services. #183 [REDACTED] joined the meeting.

This is a qualitative study and is part of a larger evaluation programme and information collected will be used in conjunction with that collected by other people.

- The Committee expressed concern over whether twelve case studies would be enough to evaluate the service. However the case studies also include, as well as the client, providers, family, carers, providers and other involved organisations which should increase the number of interviews to 50-60 people which should be enough to draw out common themes. The Committee also expressed concern that with the limited number of case studies, care would have to be taken to ensure that participants were not able to be identified and also that Maori and Pacific island people are included in the study. The regions chosen do contain a high proportion of Maori and Pacific island people.
- Timeline is very tight.
- It was suggested that the language used in the information sheet should be simplified because it is being sent to clients with moderate to severe brain injuries and these people may have difficulties with the language. The modified information sheet should be sent to the Chair for approval.
- Extreme care should be exercised when disseminating the outcome reports to protect the privacy of the participants as the sample is so small. Released reports should be at executive summary level or top line reports, not case study level. Participants should be provided with feedback or an executive summary of the findings of the evaluation.

The proposal was approved subject to these matters being addressed and the information sheet being viewed by the Chair.

5.2 **Feasibility of a national study of workers' exposures to health and safety risks,** [REDACTED], IPRU, University of Otago. #184

The Committee noted that consent was initially obtained from participants up to 2005, with no time constraint placed on the duration of the consent. It is unclear what the clients' understanding was at that time. However, because the study intends to use the data for the same purposes as it was collected, the consent obtained at that time is still valid.

Also, given that they are still using the same data obtained when the original consent was given, and that there was an undertaking given at that time to destroy the data after 5 years, the Committee would still expect this undertaking to be honoured which now imposes a considerable time limitation.

The Committee noted that the Multi-region Ethics Committee approval was given in October 2009 for the project to start in October and would therefore have expected to see an application to the ACC Research Ethics Committee sooner.

The Committee approved the research proposal.

5.3 **Treatment Injury Service Delivery Monitoring,** [REDACTED], Research New Zealand. #182

This is part of the Customer Satisfaction suite of surveys that ACC has undertaken over a number of years. This application seeks approval for this survey to be done every year for the next three years. The survey is needed to meet KPI measures. The committee approved the proposal and suggested that the FAQ Sheet needs to include information on the purpose of the survey and also should note, for the client's benefit, that ACC will not know that the client has participated in the survey.

5.4 **Re-submission – Anatomical based errors in clinical practice,** [REDACTED], University of Otago. #178

The method of data collection has now been modified to provide a de-identified dataset for initial analysis and then ACC will provide the relevant claim records (e.g. operation notes, relevant clinic letters, etc) for those claims specifically requested. The committee approved the revised application.

6 Other Business

- 6.1** Review of the ACC Research Ethics Committee update by Grant Pittams. The Committee was thanked for participating in the interviews which are now coming to an end. Other government departments have also been consulted (Justice, Police etc) as well as people external to ACC. Focus groups are now being held with staff. Currently there is a strong consensus of opinion around the value that the Ethics Committee provides in terms of risk management. The results of the consultation will be discussed with the CEO in approximately three weeks time and then a paper will be prepared for ELT with a recommendation scheduled for the end of May.

Next meeting: Wednesday 5 May 2010.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 5 May 2010

Members Present

Alison Douglass (Chair)
Grant Pittams (For Kathy Spencer)
Zeeman Van Der Merwe
Tere Scotney

Bice Awan
Miriam Henderson
Patricia Logan

In attendance: [REDACTED], [REDACTED]

1 Apologies

Apologies were received from Sharron Cole, Kevin Morris, Dianne Wepa and [REDACTED].

2. Confirmation of Minutes

Minutes of the meeting held on 7 April 2010 were confirmed with two minor amendments.

3 Matters arising

3.1 Adult outcomes of TBI, [REDACTED], University of Canterbury # 171

The information sheet was approved by the Chair.

3.2 Brain Injury outcomes New Zealand In the Community (BIONIC), [REDACTED], University of Auckland. #179

The researchers are still working alongside ACC Senior Research Advisors, on prioritising and refining the number of codes to be requested.

4 Conflict of interest declarations

Zeeman van der Merwe is the sponsor for the application from [REDACTED] for advice and approval to develop comprehensive business rules and protocols for the regular on-going ACC-MOH data linkage for research and service design purposes.

5 Approval of research and data requests

5.1 Advice and approval to develop comprehensive business rules and protocols for the regular ongoing ACC – MOH data linkage for Research and Service Design purposes, [REDACTED], ACC, #185

[REDACTED] attended the meeting. The Ethics Committee raised the following issues for clarification and further development:

- The need for a clear diagrammatic explanation of the process whereby Acc client information moves from being identifiable data to being non-identifiable

- information through the data linkage process. The diagram should included delineation of responsibility at each stage of the process.
- The proposal needs to be set within a legal framework to include the ACC Act, section 289 and the Privacy Act to provide a mandate for the data linkage and explain how the administrative data could be utilised. Examples would be helpful. Both ACC and MOH collect information for a purpose but the joint purpose needs to be clarified. [REDACTED] to supply a set of protocol examples on how the data will be used.
 - There is a need for further clarification of the dichotomy between privacy, which is legally governed, as opposed to confidentiality, which is a relationship based concept. The meaning of confidentiality in statistical terms could be further explained.
 - It was unclear what consent clients currently give for the use of their health information on the ACC 45 form and a need to be certain that information is used in accordance with the purpose for which it was collected and that the individual's data is protected.
 - It was suggested that the development of the business rules be a separate step after the establishment of principles and protocols.
 - It was noted that there may be concerns raised by the Consumer Outlook Group (COG) around who will have access to the database, and it was suggested that this proposal should also be presented to COG for comment.
 - Early involvement of the Office of the Privacy Commission was recommended.

5.2 **Integrated Rehabilitation service – Traumatic Brain Injury (IRS-TBI) Service Trial Evaluation: Client Experiences, [REDACTED] UMR Research Limited, #186**

The meeting was attended by [REDACTED] UMR) and [REDACTED] (ACC Research Services).

It was explained to the Committee that the proposal was part of a suite of research being done by ACC and the proposal was the only part that involving direct contact with the clients.

The Committee noted a lack of consistency in some of the documentation, for example, some documents mentioned that the client's employer may be contacted but in others this information was absent. The use of the phrase, "From this list of clients you have been identified as a potential participant in the study", appeared impersonal and it was suggested this could be rephrased in a softer manner. The Committee wanted the information sheets to state that withdrawal from the research at any stage would result in any information that had been collected being destroyed immediately.

The proposal was approved by the Committee.

6 **Other Business**

6.1 Review of the ACC Research Ethics Committee update by [REDACTED] and Grant Pittams.

The Committee was thanked for participating in the interviews.

The next steps after completion of the analysis would be discussion with Kathy Spencer, General Manager of Policy & Governance, and Dr Jan White, Chief Executive Officer. A paper will go to ELT by 27 May 2010.

Next meeting: Wednesday 2 June 2010.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 7 July 2010

Members Present

Alison Douglass (Chair)
Grant Pittams (For Kathy Spencer)
Zeeman Van Der Merwe
Tere Scotney

Bice Awan
Kevin Morris
Patricia Logan

In attendance: [REDACTED], [REDACTED]

1 Apologies

Apologies were received from Sharron Cole, Miriama Henderson, Dianne Wepa.

2. Confirmation of Minutes

Minutes of the meeting held on 5 May 2010 were confirmed.

3 Matters arising

3.1 Brain Injury outcomes New Zealand In the Community (BIONIC), [REDACTED], University of Auckland. #179

The researchers have now reduced the number of read codes to be used which will lessen the impact on ACC, but will still yield approx 6,000 clients for the research.

[REDACTED] was requested to circulate the letter sent to the client to the committee for information.

4 Conflict of interest declarations

None.

5 Approval of research and data requests

5.1 Integrated Rehabilitation service – Traumatic Brain Injury (IRS-TBI) Service Trial Evaluation: Client Experiences [REDACTED] UMR Research Limited, #186 – Amendment to research protocol

Approval was sought for a modification to the proposal approved by the Committee at the June meeting.

In order to be able to interpret the research findings in a meaningful way, it was felt necessary to expand the sample group to better understand the experience of clients receiving rehabilitation under the *Active Rehabilitation* service. It is proposed to interview 16 *Active Rehabilitation* clients, taking the total sample for the client experience part of this evaluation from 18 to 34. The goal is not to directly compare the two services, but rather to have a clearer understanding of the client experience in each service.

The Committee agreed that the information sheet and consent forms should be amended to inform the business-as-usual clients in Canterbury/Otago that the research was part of a wider study being undertaken in Auckland.

Approved on condition that the amended information sheet and letters be forwarded to the Chairs for approval.

5.2 **Anatomical-based errors in clinical practice, [REDACTED] University of Otago, #178 – Amendment to research protocol**

[REDACTED] Clinical Analyst, Treatment Injury, attended the meeting.

Approval was sought to extend the research to include data for a period of six months, that is, the last six months of 2009. The focus of the project is now specifically on iatrogenic nerve injury. 113 nerve injuries were noted in the first six months of data and it is expected that an additional six months data will add greater statistical power to the research. [REDACTED] is aiming to publish the results in international medical journals.

Approved.

6 Other Business

6.1 Monitoring Forms

Only 50% of the monitoring forms that were sent out have been returned. [REDACTED] to send out reminder emails, with a copy to the researcher's institutional office, reminding them that monitoring was a condition of the original approval being granted.

The monitoring form received from [REDACTED] included a request for an extension in time for final data analysis. The Committee requested that [REDACTED] submit a formal request for this extension to include clarification its intended use its utility to ACC.

6.1 Review of the ACC Research Ethics Committee

Grant Pittams gave an account of ELT's reaction to the review findings as circulated to the Committee. The ELT response to the report acknowledged the importance of an independent Chair and external membership in mitigating organisational risk and that the external committee members played an important role for ACC. The ELT resolved the following:

- (a) **Agree** that the Research Ethics Committee be a standing committee of the Leadership Group with a reporting line via the General Manager Governance Policy and Research.
- (b) **Agree** the number of external appointees may be reduced to 2-3
- (c) **Agree** that the chair of the committee will be an external appointee
- (d) **Agree** that an external member will represent the requirements of Maori
- (e) **Note** that the terms of reference and supporting processes will be amended to ensure flexibility and streamline the committees operations.

The Committee discussed the findings and recommendations from the review.

The next meeting for August 2010 was planned to be conducted with the Committee as it currently exists.

Next meeting: Wednesday 4 August 2010.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 4 August 2010

Members Present

Sharron Cole (Chair)
Alison Douglass
Grant Pittams
Dianne Wepa (via telephone)

Kevin Morris
Zeeman Van Der Merwe
Tere Scotney

In attendance: [REDACTED]

1 Apologies

Apologies were received from Bice Awan, Miriama Henderson, Patricia Logan.

2. Confirmation of Minutes

Minutes of the meeting held on 7 July 2010 were confirmed.

3 Matters arising

3.1 Brain Injury outcomes New Zealand In the Community (BIONIC [REDACTED] [REDACTED] University of Auckland. #179

The letter was received and viewed by the committee

4 Conflict of interest declarations

None.

5 Approval of research and data requests

5.1 Exploring relationships between self-reported Physical Activity Level, fatigue and Return to work following Mild Traumatic Brain Injury, [REDACTED], University of Auckland, #172 – amendment to methodology

The Committee appreciated the researcher coming back to the committee for advice about a proposed change and for taking the issue seriously. This also reflected good supervision by [REDACTED]

Approved.

5.2 Factors affecting artificial eye wear, [REDACTED], University of Auckland, #188

An enquiry to the ACC data warehouse confirmed that there is no definitive way of coding a loss of an eye. Although there were a few READ codes that came close, the best method of identifying loss of an eye was to use those claims that have had a payment of a prosthetic eye, of which there were 346 claims. They could also be identified from the accident description but this would be a time consuming process. In going back to 1974 there was a risk of attempting to contact a deceased person

The Committee queried whether the nine national prosthetic eye centres might be a better source of research subjects.

It was decided that in respect of deceased persons, they should be removed from the data as far as possible on the 346 claims.

Approved by the co-Chairs subject to the following to be viewed by them:

- The information sheet should make provision for those who may be vision impaired or have 2 artificial eyes
- Where people are invited to participate they should have the option of having a friend/support person present. Further information should be provided about the physical examination and if any discomfort is to be expected.
- "characteristics" on the first page of the information sheet should be changed to "demographics"
- The initial letter and information sheet to be sent from ACC should explain ACC's role in the identification of potential subjects.
- A standard statement regarding a person's right to complain under the Code of Health and Disability Consumers' Rights should be included should any harm occur. The intended physical testing of participants means this research is a clinical trial and as such requires approval by an accredited ethics committee.
- There should be a standard statement on the information sheet to inform potential participants that their coverage and entitlement of ACC will not be effect whether or not they choose to participate in the study

5.3 Study of 750 clients who have attended rehabilitation clinics over the past 3 years with chronic low back pain, [REDACTED], TBI Health, #187

The committee discussed the data matching of TBI Health with ACC data and expressed concern that the consent form

- did not actually extend to consenting to data matching of ACC and TBI health data
- stated that health information would be used "ONLY to the extent necessary for the services we provide". While this consent would cover treatment it did not cover research

It was unclear how the results would be disseminated to the public domain and the proposal did not guarantee publication. The results could be used solely for business promotion.

This application was declined but the researchers were invited to resubmit the application with the decision of the Central Division of the National Ethics Committee.

5.4 Testing a new measure of workability, [REDACTED], University of Auckland, #154 – request for project extension

The Committee appreciated the full response from the research about the reasons for the request for the extension.

Approved.

5.5 **MSD evaluation of Active Case Management of New Work Tests, [REDACTED], MSD, #189**

The meeting was attended by [REDACTED] (lead researcher), [REDACTED] (Manager, Social Outcomes Team) and [REDACTED] (statistician). MSD does not have its own Ethics Committee and hence MSD requested that ACC consider and offer advice. The Committee clarified that they could not approve the proposal but only provide advice. Although there was no obligation to follow the advice provided by the ACC Ethics Committee it was expected that the advice would be given serious consideration.

Discussion focussed on two main issues from the proposal: the methodology and informing clients.

Methodology:

The methodology was clarified by the researchers – Those people receiving the DHB with a child over six years of age will be subject to a work test and will be required to accept a 'suitable job offer. The research is an evaluation of the case management of the law not the law itself and will look at service usage, the frequency of contact between case managers and clients to see how the law is working in practice. The active case management will be over 3 months for 4,500 clients.

A random sample of those on the DPB will be selected evenly across work and income offices and lists provided to the offices of those selected. For clients who have not been selected there is an opt in but no opt out for those randomly selected.

Measures of outcomes from the intervention: leaving benefit, employment, doing better financially; proxies for income such as subsidies for children receiving extra childcare, changes in accommodation supplement; child outcomes such as neglect, abuse, domestic violence notifications, children receiving benefits later; youth justice data, for example, youth supervision orders; educational outcomes of children, for example truancy, school retention, evidence of student loans later on.

The Committee noted:

There will be a staged implementation of the new law because there are not enough resources and therefore some people will be denied an intervention that could benefit them.

The research needs to set out the perceived harms and risks that may be encountered have not been described. In not telling or informing clients about the research there is a risk of potential health impacts, for example suicide. Need to set out anticipated harms and benefits of active case management.

If research shows intervention to be having a deleterious effect what can the researchers do about it? Will the study results affect policy – is the research intended for refinement of policy or process?

The research needs to ensure that the thoroughness of the methodology to measure outcomes will impact on the validity of the results. Need to ensure that results are sound and statistically strong. There are many confounders for the evidence. Employment may be associated with an outcome such as less domestic violence

notifications but employment cannot be deemed to have caused less domestic violence.

Informing clients about the evaluation:

Informing of clients about the research and recruitment method should be open and clearly explain that not all clients have been recruited initially due to a lack of resources. There was no voluntary participation for those randomly selected. The researchers should use the opportunity in the letter to all clients and the media release to communicate that MSD are constrained by resources and it will be a phased approach. Those initial selected clients that are case managed will be evaluated.

Are clients clear about their consent for the use of their information for research purposes? Need to be upfront from the beginning and provide letter and information sheet for all clients.

There was concern expressed by the committee that if the results of the evaluation were unfavourable and the trial was found to have little or no impact that the results might not be disseminated. MSD could offer no guarantee of this and the committee expressed that openness should be apparent.

It was noted that there is a qualitative strand of research planned alongside this quantitative study looking at case manager interaction with clients, but not of clients' perceptions. The committee noted that the qualitative stream of the study will have separate important ethical issues that will need to be considered

6 Other Business

6.1 Review of the ACC Research Ethics Committee update

Next meeting: Wednesday 1 September 2010.

Research Ethics Committee



PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 1 September 2010

Members Present

Alison Douglass (Chair)
Sharron Cole
Grant Pittams

Zeeman Van Der Merwe
Miriam Henderson

In attendance: [REDACTED]

1 Apologies

Apologies were received from [REDACTED].

2. Confirmation of Minutes

Minutes of the meeting held on 4 August were amended and confirmed.

3. Matters arising

3.1 Factors affecting artificial eye wear, [REDACTED], University of Auckland, #188

It was confirmed that the Health and Disabilities Multi Regional Ethics Committee had approved this project but a copy of the approval has not been viewed by the Committee. Therefore it was not clear whether the Health and Disability Ethics Committee had considered the research to be a clinical trial. If it was deemed a clinical trial with the possibility of physical harm, the information sheet would need to have an appropriate statement regarding cover from ACC in the event of injury.

The Committee required changes to the information form to change the statement about the Health and Disability consumer's rights to state that participants had a right to complain under the Code. Under 'Complications the Committee required "incidental findings" to be changed to "such findings". The information sheet and letter should include a statement about the ACC Research Ethics Committee and Health and Disabilities Multi Regional ethics Committee approval for the research

4 Conflict of interest declarations

Zeeman Van Der Merwe declared his involvement in 5.3 Advice and approval to develop comprehensive business rules and protocols for the regular ongoing ACC-MOH data linkage for research and service design purposes.

5 Approval of research and data requests

5.1 Home Injury Prevention Intervention Study, [REDACTED], Health Research Council, University of Otago. #190

The Committee noted the importance of the research about home injuries. However they also noted the confusing nature of the application and requested further clarification on the following:

1. The present research study needs to be linked to the previous research to explain the context further and provision of the outcomes from the research thus far would be helpful.
2. The Committee noted that an application had been sent to the Central Ethics Committee and that the Committee had requested changes to the protocol. The Committee noted the researcher response to the Central Committee dated 17 June 2009 but wanted to view what the Central Committee had said and how the researchers had altered their protocol in response to that Committee's decision. The ACC Committee requested to see a copy of all the correspondence between the researchers and the Central Ethics Committee.
3. The Committee noted that given the identifiable nature of the data there would need to be informed consent for the release of this information and requested further information around the process and documentation for this.
4. The Committee requested that information sheets, consent forms and letters to be used in the research be provided to the Committee.

It was suggested that these matters be clarified and the researcher invited to attend at the next Committee meeting to address these matters.

5.2 Brain Injury outcomes New Zealand In the Community (BIONIC), [REDACTED], University of Auckland. #179

[REDACTED] Senior Research Advisor attended the meeting. Thus far 949 out of the planned 5,888 letters had been sent out to potential participants of the study. Twelve complaints to the researchers had been received from the parents or guardians of children, concerned that ACC had asked the researchers to investigate them as possible perpetrators of child abuse. The complainants had refused to participate in the research.

The Committee appreciated that this matter was brought before them and requested that a memo be sent to the Committee addressing the following:

- The background to the research and the complaints
- The potential harm to parents or children from the letter
- The reasoning for not contacting the 949 potential participants further
- The changes to the letter to address the complaint and how the letter will be trialled.
- If the research uncovers child abuse how will the researchers deal with this – a clear process needs to be put in place.

The memo is to be sent to all members of the Committee for comment before the next scheduled meeting.

5.3 Advice and approval to develop comprehensive business rules and protocols for the regular ongoing ACC-MOH data linkage for research and service design purposes, [REDACTED] ACC, #185

[REDACTED] attended the meeting to provide an update of the research proposal progress and in response to the Committee's recommendations provided in June.

The Committee discussed the adequacy of the ACC 45 and ACC 167 consent forms currently used by ACC when individual data is used for this type of research. The Privacy Impact Assessment Report is planned to address this matter.

It was noted by the Committee that it is useful to have examples to assist in illustrating concepts particularly in understanding the identification and anonymising of data throughout the linkage process. This will be provided in the Privacy Impact Assessment Report and [REDACTED] intends to keep the Ethics Committee informed of progress with this project.

6 Other Business

6.1 ACC Research Ethics Committee Terms of Reference

In light of the conversation regarding the management of complaints about research, it was agreed that this issue should be addressed in the Terms of Reference. Grant Pittams agreed to make some amendments to the TOR and distribute these to the Committee prior to the next meeting.

6.2 Acknowledgement of members leaving the Committee

The Committee wished to acknowledge the valuable contributions of Bice Awan, Tere Scotney and Dianne Wepa and agreed that a letter expressing appreciation and thanks from the Committee should be sent to them.

6.3 Appointment of new member to the Committee

Grant Pittams announced the appointment of [REDACTED], from the Ministry of Health, to the Committee as the representative for Maori interests

Next meeting: Wednesday 6 October 2010.

Research Ethics Committee



Te Kaporeihana Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 6 October 2010

Members Present

Sharron Cole (Chair)

Zeeman Van Der Merwe
Miriam Henderson

In attendance: [REDACTED] for Grant Pittams and [REDACTED]

1 Apologies

Apologies were received from Alison Douglass and Grant Pittams.

2. Confirmation of Minutes

Minutes of the meeting held on 1 September were amended and confirmed.

3. Matters arising

- 3.1 Brain Injury Outcomes New Zealand in the Community (BIONIC), [REDACTED] #179 – amendments to letters to potential participants following complaints. The researchers submitted a revised letter and plan to manage the issue. This was viewed by the committee and approved by the Co-Chair (Alison Douglass). The researchers will provide a brief interim report after they have trialled the first revised 50 letters to parents. The decision was ratified by the Committee
- 3.2 Appointment of new member to the Committee – [REDACTED] from MOH will not now be joining the committee as representative for Maori interests and the position is yet to be filled. Sharron Cole suggested contacting [REDACTED] from Te Pūmanawa Hauora about a possible representative for the Committee.

4 Conflict of interest declarations

None declared.

5 Approval of research and data requests

- 5.1 Home Injury Prevention Intervention Study, [REDACTED], Health Research Council, University of Otago. #190

[REDACTED] attended the meeting.

The Committee raised two issues:

It was queried whether there would be interim analysis planned and what would happen if causation of injury from hazards in the home became obvious. It was queried as to whether there were any stopping mechanisms in place so that people in the control group would not continue to be exposed to risk for an indeterminate period. [REDACTED] confirmed that there would be interim analysis and the research would stop if such causation was verified by robust data.

The Committee queried whether any hazards identified in the homes of the control group would be pointed out to participants to avoid leaving them exposed to dangerous risks. ██████ confirmed that assessment of the control group homes would follow a standardised procedure and any dangers discovered would be pointed out to the participants. However it was up to the participant to remediate any dangers.

It was noted that ACC is not funding this study.

The proposal was approved.

5.2 Factors affecting artificial eye wear, ██████, University of Auckland. #188

The Committee noted that the Central Regional Ethics Committee had approved the research as a clinical trial and therefore participants injured as a result of treatment received in this trial will be eligible to be considered for compensation in respect of those injuries under the ACC scheme. The committee agreed that this should be stated on the information sheet.

Although the information sheet had been approved by the Central Regional Ethics Committee, the ACC Committee were surprised by this and noted the complex and technical language used which they considered inappropriate for lay people. It was suggested that the title and purpose of the study be up front and the names of the researchers only at the end of the sheet.

The study was approved.

6 Other Business

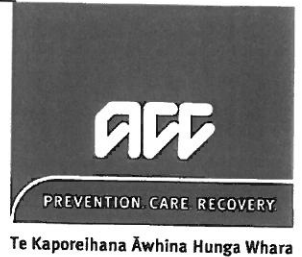
6.1 ACC Research Ethics Committee Terms of Reference

The Terms of Reference were discussed in light of the minor changes. The committee were happy with the Terms of Reference with the proviso that Alison Douglass (Co-Chair) have the opportunity to comment.

6.2 The Committee meetings for next year, 2011, will continue to be held on the first Wednesday of the month. There will be no meeting in January

Next meeting: Wednesday 3 November 2010.

Research Ethics Committee



Minutes of the ACC Research Ethics Committee, 3 November 2010

Members Present

Alison Douglass (Chair)
Sharron Cole

Zeeman Van Der Merwe
Miriama Henderson
Grant Pittams

In attendance: [REDACTED] (Secretary)

1 Apologies

No apologies were received.

2. Confirmation of Minutes

Minutes of the meeting held on 6 October were confirmed.

3. Matters arising

None

4 Conflict of interest declarations

None declared.

5 Approval of research and data requests

5.1 A population based study of falls after stroke, [REDACTED], University of Auckland. #191

It was noted that the information supplied on the information sheet did not match the research proposal in terms of declaring which ACC data will be accessed by the researchers. The research proposal states that information on gender and ethnicity will be accessed but this is not included on the information sheet and therefore any potential participant would not be fully informed about what they were consenting to.

The committee did not like the use of the word "burden" in relation to persons who had suffered a stroke and also agreed that the sentence, "any concerns regarding the nature of this project should be notified in the first....." should be simplified to, "if you have any concerns please contact.....".

The Committee noted that the study is based on the assumption that all costs from a fall will be recorded in ACC data. However some falls may not be reported to ACC and the cost of the injury may fall on the family who care for the individual rather than be attributed to ACC. Therefore the ACC data will potentially under estimate the prevalence and cost of falls.

The research proposal did not cover how the researchers would manage the issue of informed consent where a potential participant was significantly cognitively impaired and the Committee expected a protocol to be in place for this scenario.

The Committee also requested to see a copy of the approval from the Northern Regional Ethics Committee.

The proposal was approved subject to the above matters being addressed.

5.2 **Approval to undertake telephone survey to understand the purpose of a traffic journey resulting in an ACC motor vehicle traffic crash (MVTC) injury claim, [REDACTED], ACC. #192**

The Committee noted that the purpose of the research was not openly explained in either the letter or the "Frequently asked questions" sheet for potential participants. It was suggested that, although complex to explain in full, a sentence or statement should be added to explain the purpose of the research which would be to assist ACC to allocate claims in terms of funding decisions.

The Committee felt that it was important that those conducting the telephone interviews should be prepared for informed questions from the public about ACC accounts and apportioning of claims and be able to answer any queries correctly and appropriately.

It was also suggested that the term road traffic "crashes" be replaced by road traffic "accidents" to sound less dramatic.

The study was approved subject to the above matters being addressed.

5.3 **Proposed pilot of a pain screening questionnaire and decision tool – Committee advice**

Information on this proposed pilot was circulated to the committee prior to the meeting and in view of the committee's email comments was placed on the agenda for consideration by the Committee. It was explained that this pilot is in the early stages of design and the Committee's guidance was being sought at an early stage.

The Committee are expecting a paper with firmer ideas about the proposal and addressing the ethical issues. However it was advised that pre-testing of the questionnaires and decision tool would be advisable and that the results of this should be presented to the Committee

6 Other Business

6.1 ACC Research Ethics Committee Terms of Reference

The Terms of Reference were discussed in light of Alison Douglass' additional comments. Grant will amend the TOR and once agreed by the Committee, these will be signed off by Kathy Spencer, General Manager, Governance, Policy and Research.

6.2 Membership of the Ethics Committee

Grant suggested that Maori interest in research could be represented by [REDACTED], Chief Advisor, Maori and that another external member be considered to increase the membership of the Committee and in order to ensure a quorum at meetings.

Next meeting: Wednesday 1 December 2010.

Research Ethics Committee



Minutes of the ACC Research Ethics Committee 1 December 2010

Members Present

Sharron Cole (Chair)

Zeeman Van Der Merwe

Grant Pittams

In attendance: [REDACTED] (Secretary)

1 Apologies

Alison Douglass, Miriama Henderson.

2. Confirmation of Minutes

Minutes of the meeting held on 3 November 2010 were confirmed.

3. Matters arising

3.1 Grant Pittams reported that one of the respondents contacted for "Factors affecting Artificial Eyewear", a study by [REDACTED] had phoned to complain about [REDACTED] and also had been contacted for an ACC satisfaction survey. The list of the sample of clients supplied to [REDACTED] will be forwarded to Zeeman Van Der Merwe to check that all those included on the list are flagged so that they cannot be contacted for other research purposes.

3.2 The finalised Terms of Reference for the ACC Research Ethics Committee were distributed to members.

3.3 Grant Pittams announced that [REDACTED] Chief Advisor, Maori, ACC, will act in the role of representing the interests of Maori for the Committee in the New Year. Also in the New Year ACC will begin the formal process of selecting an additional external member

4 Conflict of interest declarations

Grant Pittams declared his involvement in the proposal to be considered at the meeting.

5 Approval of research and data requests

5.1 ACC Branch Pain Screening Tool Pilot. #193

[REDACTED], Programme Manager and [REDACTED] Rehabilitation Practice Advisor, attended the meeting.

With regard to the questionnaires being administered by non-clinical case managers, it was emphasised that the questionnaire is one factor that will be used to assess clients for potential pain intervention. They will also be using flags, the information held on a client's file, GP information and interaction with the client and family to

inform decisions. The case managers will also be utilising the advice and assistance of Branch Medical Advisors and Branch Advisors, Psychology to make decisions.

The Committee suggested that the demographics of clients who complete the questionnaire be collected so as to understand the representativeness of the sample and for which groups the questionnaire may be unacceptable.

It was clarified that where a client declines to take part in the pilot, and the usual case management in that Branch is for a questionnaire to be used, the client will be assured that their questionnaire will not be used in the pilot.

The Committee requested that the information sheet be amended to include contact details for [REDACTED] should clients want more information about the pilot and that information be added to explain that the questionnaires are commonly used in New Zealand and validated in Australia. It was also requested that the information sheet state that the pilot has ACC Research Ethics Committee approval.

The proposal was approved subject to the above matters being addressed.

6 Other Business

No other business.

Next meeting: Wednesday 2 February 2011.