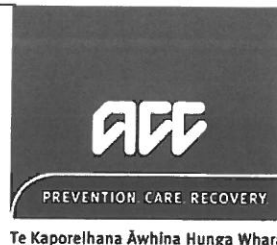


Research Ethics Committee



Minutes of the ACC Research Ethics Committee, 4 February 2009

Members Present

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

- 1 Apologies: [REDACTED] ([REDACTED] will not attend meetings until approximately June 09. [REDACTED] is acting in [REDACTED] role but will not be attending meetings. [REDACTED] will continue to represent [REDACTED]), [REDACTED] (expected to be 30 minutes late to meeting)

In attendance: [REDACTED] (for [REDACTED]), [REDACTED] (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

[REDACTED] 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 [REDACTED]:

- 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 [REDACTED]

Research Ethics Committee



PREVENTION CARE RECOVERY

Te Kaporehanga Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 4 March 2009

Members Present

[REDACTED]

1 Apologies: [REDACTED]

In attendance: [REDACTED], 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 [REDACTED] and [REDACTED] were members of the committee but had been incorrectly recorded as 'in attendance'.

3 Matters arising: [REDACTED] 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

[REDACTED] 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. [REDACTED], UMR Research. #155

[REDACTED], 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.

[REDACTED], 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 [REDACTED]

Research Ethics Committee



PREVENTION CARE RECOVERY

Te Kaporehanga Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 6 May 2009

Members Present

[REDACTED]

1 Apologies: [REDACTED]

In attendance: [REDACTED].

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 [REDACTED]

Research Ethics Committee



PREVENTION CARE RECOVERY

Te Kaporehanga Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 3 June 2009

Members Present

[REDACTED]

1 Apologies: [REDACTED]

In attendance: [REDACTED].

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. [REDACTED] 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. [REDACTED] 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 [REDACTED]

Research Ethics Committee



Minutes of the ACC Research Ethics Committee, 1 July 2009

Members Present



1 Apologies: None

In attendance: [REDACTED] for [REDACTED], [REDACTED], [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. [REDACTED] undertook to find out more from [REDACTED] and report back to members.

Meeting closed: 1.00 pm.

Next Meeting: 5 August 2009 11.00- 1.00 [REDACTED]

Research Ethics Committee



PREVENTION CARE RECOVERY

Te Kaporehanga Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 5 August 2009

Members Present



1 Apologies: [REDACTED]

In attendance: [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.

██████████ 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

██████████ 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, ██████████, Senior Analyst, Market Research, ACC. # 167

██████████, 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, ██████████, Principal Advisor, Research and Development, ACC. # 168

██████████ 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, ██████████, Research Advisor, Research and Development, ACC. # 169

██████████, 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.

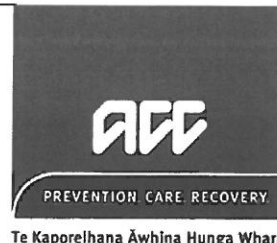
Status: Approved subject to consent forms to be viewed by the Chair and that the Multi-regional Ethics Committee be consulted.

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. ██████████ is no longer with ACC, ██████████ has moved to a new position and ██████████

Research Ethics Committee



Minutes of the ACC Research Ethics Committee, 4 November 2009

Members Present



1 Apologies: [REDACTED]

In attendance: [REDACTED] (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, [REDACTED] 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 [REDACTED] acknowledged that he originally wrote the contract for item 5.3 from [REDACTED]. 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, [REDACTED], 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 [REDACTED]

Research Ethics Committee



PREVENTION CARE RECOVERY

Te Kaporehanga Āwhina Hunga Whara

Minutes of the ACC Research Ethics Committee, 2 December 2009

Members Present



1 Apologies: [REDACTED]

In attendance: [REDACTED] (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 [REDACTED] is the reporting manager of [REDACTED] (Research proposal 5.2)

4.2 [REDACTED] 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

[REDACTED] 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

[REDACTED] 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*, [REDACTED], 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. [REDACTED], 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.

[REDACTED] 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 [REDACTED]