Academic Research in Member Hospitals and Associated Facilities

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DEVELOPED / UPDATED BY	John Menzies
RESPONSIBILITY OF	Board of Directors
IMPLEMENTATION STRATEGY	Display on Health Roundtable Website
EVALUATION STRATEGY	Review biennially. Next review November 2019.
SUMMARY	This policy describes the application and approval process for academic researchers to access Health Roundtable datasets and the subsequent publication of any research findings.

USE OF HEALTH ROUNDTABLE DATA FOR RESEARCH

1. Background Information

When this policy was initially drafted, the Health Roundtable was not expecting a large number of research requests. As the value of the data base has become more widely known, an increasing number of requests are being received for a variety of research topics. This policy has been updated to assist both applicants and the Board of the Health Roundtable Ltd. in assessing and approving research activities and possible publications.

The Health Roundtable inpatient episode data base is one of the largest non-governmental collections of hospital operational activity in the world, adding over 4.5 million records per year for over 140 major public hospital facilities across Australia and New Zealand. Data are available from 1996 to 2015 for 15 of the member organisations, and for at least five years for almost all other members. The database has a wealth of diagnosis, procedure, and demographic data linked to hospital stays, and provides a mechanism to track episodes of the same patient over time for many member organisations. (However, there are no direct patient or hospital identifiers in the datasets.)

The general intent of providing Health Roundtable data for approved research is to assist in one or more of the goals:-

i. development of a better understanding of issues that will help improve the quality and safety of patient care in member hospitals and health services;
ii. development of products that will help to better analyse hospital data and benchmark hospital service improvements; and
iii. allow collaboration on projects that will improve the general advancement of scientific knowledge about patient disease, patient management and hospital and health service improvement.

Whilst the Health Roundtable will provide its data to approved research projects, all costs associated with the research must be met by the research entity, including costs of the Health Roundtable when it is requested to do elements of the research.

In the event that a product, methodology or technique is developed by a researcher that Health Roundtable could reasonably believe would be a benefit to improve service to the member hospitals that provide the original data, then the researchers must provide a free, non-exclusive license to The Health Roundtable to use the methodologies developed as part of the research. The intent is to enable the Health Roundtable to continue or expand the research to other member organisations or time periods.

Generally, research requests fall into two broad categories. The first type relates to requests involving all, or a substantive part, of aggregated and de-identified Health Roundtable data where there is no requirement to identify any hospital or jurisdiction. The second type relates to specific topics where access to particular parts of Health Roundtable data sets are required.

To assist with the first type of request, the Health Roundtable requires that when members sign up to participate in The Health Roundtable, they will be required to agree to their hospital's de-identified and aggregated data being used for general research purposes that have been approved by the Board of Directors.

2. General principles that must be followed

This policy only applies to research requests from member hospitals and associated hospital facilities.

Extracts from the Health Roundtable database may be made available to researchers who agree to abide by the following requirements:

2.1 All research requests must be supported by the personal member of a Health Roundtable member hospital.

2.2 Prior to any research request being received in writing, researchers should initially discuss the proposed research with the General Manager of the Health Roundtable to ensure it meets the basic criteria of this policy and that the Health Roundtable data set will have the necessary information to complete the research. The discussion will also need to consider if the HRT data needs modification to meet the researcher's methodologies. If data modification is required, the researcher will be provided a quotation for the required work. Funding for this work should be built into the research proposal.

2.3 If the research request is considered appropriate, the applicant must complete an application for request form, (attached as Annex 1), and an agreement on how Health Roundtable may be used for academic research. (Form attached as Annex 2).

2.4 Prior to any approval, research applicants must also sign an agreement that they will abide by the Health Roundtable Honour Code that requires that the data will not be used to the detriment of any member organisation. (Attached as Annex 3).

2.5 Provided data will exclude hospital and jurisdictional identifiers in the dataset to avoid the possibility of disclosure. Only the General Manager of The Health Roundtable will have the ability to decode the information for the benefit of the member organisations.

2.6 Depending upon the type of research product that is produced during, or at the conclusion of the research, the research product(s) will need to be provided to either the General Manager and/or any involved member organisation for comment prior to any submission for external publication or distribution.

2.7 All research products are to be circulated to member organisations for comment prior to any submission for external publication. Any requests by members to remove their data from the analysis must be honoured, and any request by an organisational member to terminate the research project will be forwarded to the Board of Directors for resolution. The Board will consider all submissions regarding the dispute, and will make a final, binding decision regarding the use of Roundtable data in the project.

2.8 The Health Roundtable reserves the right to not support the publication or distribution of any research product if it is believed that such publication or distribution may cause potential issues of concern for one or member organisations.

2.9 Any requests by organisational members to remove their data from the analysis must be honoured, and any request by an organisational member to terminate the research project will be forwarded to the Board of Directors for resolution. The Board will consider all submissions regarding the dispute, and will make a final, binding decision regarding the use of Health Roundtable data in the project.

2.10 All research must acknowledge the source of data as The Health Roundtable, and the final versions of the research must be freely available to The Health Roundtable and all member organisations at no cost.

2.11 Researchers must provide a free, non-exclusive license to The Health Roundtable to use the methodologies developed as part of the research to enable The Health Roundtable to continue or expand the research to other member organisations or time periods. A copy of algorithms, computer source code, and step-by-step instructions shall be submitted to The Health Roundtable when the research products are circulated to member organisations prior to submission for external publication.

2.12 Data provided to researchers by The Health Roundtable must be used only for the purpose identified in the research application. No secondary usage is permitted without separate approval.

2.13 All research should be completed within 12 months of receipt of the data. In the event that an extension is required, an extension application must be completed. (Attached as Annex 4).

3. Application process

3.1 To commence the application process an applicant must first discuss the proposed research project with the General Manger to ensure the research is within the parameters required by the Health Roundtable.

3.2 If the proposed research is considered to be appropriate, the applicant must complete and submit the application forms and agreement cited above.

3.3 The application must include information about the ethics and research approval that has been completed at the applicant's employing institution.

3.4 The completed application will either:-

i. be approved by the General Manager if it fully complies with all elements of this policy - in such cases, the General Manager will bring the research to the attention of the Board of the Health Roundtable at its next meeting; or

ii. where the request does not fully meet all policy requirements but is still considered to be of potential importance, the General Manager will table the proposal for consideration at the next Board meeting; or

iii. where the application does not substantially meet the policy requirements, the General Manager will not accept the proposal and advise the applicant that it is not acceptable but the applicant may resubmit a new proposal for consideration if it meets the requirements of this policy.

3.5 Whenever any research proposal is approved, the Health Roundtable will inform its membership of the proposed research at the next appropriate opportunity.

4. Data provision, security and return

4.1 When a research proposal is approved, discussions will occur between the applicant and the Health Roundtable to arrange the transfer of the Health Roundtable data.

4.2 If the data requires modification to meet the requirements of the researcher, as requested in the original proposal, the Health Roundtable will undertake the necessary data preparation. (If necessary, the appropriate data preparation fee will be charged).

4.3 Once the data is transferred, the researcher must maintain the security of the data as outlined in the approved research protocol.

4.4 At the completion of the research period, all data must be returned to the Health Roundtable and any related files or material must be destroyed.

4.5 In the event that the research is not completed within a 12 month period, the applicant may retain the data for further research for a period as defined in an approved research extension.

5. Publication process

5.1 If the researcher wishes to publish any findings or outcome of the research, a copy of the proposed publication and the intended publication site must be provided to the General Manager of the Health Roundtable for consideration.

5.2 The General Manager after reviewing the proposed publication will implement one of the following actions:-

i. If the material fully complies with the expectations of this policy and does not identify any individual member or jurisdiction, the document will be discussed with the President of the Health Roundtable. If both agree the document is suitable for publication, the applicant will be advised of the decision. The General Manager will arrange to advise the full Board of the decision at its next scheduled meeting and all members of the HRT as soon as possible after the Board meeting; or

ii. if the material is reasonable but does not fully comply with the expectations of this policy and/or it is considered that there may be an issue for a particular hospital or jurisdiction, the General Manager will discuss the proposed publication with the President and recommend that each member that may be affected by the publication be given a confidential copy of the proposed publication for consideration. It would then be up to the individual member(s) to decide if they approve the publication or wish that their institution's data is withdrawn. The time period for collection of member opinions will be for a period of sixty days. In the event that a significant number of members are not approving the publication and/or the withdrawal of the institution(s) data would seriously compromise the value of the research, the General Manager will recommend to the President that the research publication not be approved;

iii. if the material does not meet the requirements of this policy, the applicant will be immediately advised of the decision by the General Manager.

5.3 In making a decision not to approve publication of research findings, the Health Roundtable reserves the right to refuse permission without giving a reason.

5.4 In the event of either (ii) or (iii) occurring in 5.2 above, the researcher will be given one opportunity of submitting a complying publication. In the event that a subsequent publication request is received, the process outlined in 5.1 and 5.2 above will again be followed. If the second proposal for publication is rejected in full, the researcher will be advised that the research project is at an end and the procedures in Section 6 below will apply.

6. Procedures at the end of the research period.

6.1 All data sets irrespective of whether they have been modified or not will be returned by the most appropriate secure means to the General Manager.

6.2 Any data extracts or reports prepared by the researcher will either be destroyed or given to the Health Roundtable for destruction.

6.3 In the event that a product(s) methodology or technique has been developed that has value to the member hospitals or the Health Roundtable that provided the relevant data, the researcher must provide a free, non-exclusive license to The Health Roundtable to use the methodologies developed as part of the research. The intent is to enable the Health Roundtable to continue or expand the research to other member organisations or time periods.

7. Ongoing collaboration and development of research products

7.1 In the event that at the end of the research period, further collaboration between the researcher and the Health Roundtable would be of mutual benefit, both parties will in good faith enter into discussions to plan further activities.

7.2 Any proposed agreements that arise from 7.1 above, will be discussed at the next Board of Directors meeting where a decision will be made about the proposed further collaboration.

REVISION AND APPROVAL HISTORY

Date	Rev No	Author and approval
22 Sept 2006	1	David Dean – Approved Board Meeting #34 September 2006
May 2011	2	Updated to reflect larger dataset available
September 2012	3	Updated with change of address of Health Roundtable
19 November 2015	4	Updated – John Menzies, David Dean. Approved at Board of Directors meeting.
25 November 2016	4	Approved at Board of Directors meeting #87 25 November 2016
24 November 2017	4	Adopted at Board Meeting #92 24 November 2017

Annex 1.

APPLICATION TO USE HEALTH ROUNDTABLE DATA FOR ACADEMIC RESEARCH

(Please provide a project proposal covering the following topics, clearly numbering and labelling each section in the order listed. Please limit the size of the proposal to a maximum of 5 pages.)

1. PROJECT TITLE:	< Insert title >		
2. INVESTIGATORS:	List names, affiliations, email addresses, and phone contact details of all individuals who will participate in the project and have access to the data. Indicate who will be the principal researcher.		
3. SPECIFIC AIMS / HYPOTHESES:	What specific hypotheses are to be tested with this research?		
4. ESTIMATED DURATION OF THE STUDY:	Provide a timeline for the analysis and development of the preliminary draft to be circulated for comment.		
5. BACKGROUND:	Describe other research projects that have been conducted on this topic and provide bibliographical references		
6. RESEARCH DESIGN AND METHODS:	How do you propose to conduct the research? List the software applications and/or software languages to be used.		
7. ETHICS / RESEARCH APPROVAL	Please indicate the name of the ethics/research committee that has given approval for this research. Attach a copy of approval letter. If no ethics approval has been given at this stage, Question 11 must be completed.		
8. ROUNDTABLE DATA REQUESTED	Please indicate the data elements required, specifying the number and type of facilities, countries, financial years, etc.		
9. FUNDING	Who is funding the research project? Indicate the total amount of funding received for this project.		
10. DATA SECURITY	What measures will be taken to ensure the security of the data provided to you?		
11. APPROVALS	Has the organisation with whom you are affiliated approved this research project? If so, please provide the name, email address, and telephone contact details of the person who has given this approval.		
Printed Name of applicant		Work Telephone	
Signature		Fax	

Date		Mobile	
Email Address			
12. Approval by the Hospitals HRT Personal Member (usually the CEO)	Print Name :-…… Signature: …… Date: ……/……/…….		

Annex 2.

AGREEMENT ON HOW HEALTH ROUNDTABLE DATA MAY BE USED FOR ACADEMIC RESEARCH

(Please make separate copies and ensure that all investigators listed in the application provide a signed agreement).

PROJECT TITLE:	<Insert title>		
If granted access to Health Roundtable data for the above research project, I personally agree that:	1. I will not conduct analysis of the data which could be used to the detriment of any member organisation of The Health Roundtable. 2. I will retain the coded identity of organisations as provided by The Health Roundtable, and will remove specific organisations from the analysis on request. 3. I will submit the research products of my analysis to The Health Roundtable General Manager for circulation to the Board of Directors and/or member organisations for comment prior to any submission for external publication. 4. I agree to abide by the decision of the Board of Directors of The Health Roundtable if any member organisation of The Health Roundtable lodges a concern about the analysis or interpretation of the data within 60 days of circulation of the research products. 5. I agree to acknowledge the source of data as The Health Roundtable Ltd, and to make the final versions of the research freely available to all member organisations at no cost to them or to The Health Roundtable. 6. I agree to provide a free, non-exclusive license to The Health Roundtable to use the methodologies developed as part of the research to enable the Health Roundtable to continue or expand the research to other member organisations or time periods. 7. I agree to provide a copy of algorithms, computer source code, and step-by-step instructions to The Health Roundtable General Manager when the research products are circulated to member organisations prior to submission for external publication. 8. I agree to use data provided by The Health Roundtable only for the purpose identified in this research application. I accept that no secondary usage is permitted without separate approval. 9. Unless Health Roundtable approval has been given for an extension, I agree to complete the research within 12 months of receipt of the data or to destroy all copies of the data received. 10. I agree to protect the security of the data entrusted to me by The Health Roundtable. 11. I agree to pay the direct costs incurred by The Health Roundtable in extracting the requested data, if requested. I understand that I will be provided an estimate of these costs in advance.		
Printed Name		Work Telephone	
Signature		Fax	
Date		Mobile	
Email Address			

Annex 3.

Confidentiality agreement to be signed by Research Applicants.

CONFIDENTIALITY and HONOUR CODE AGREEMENT

BETWEEN

Researcher < Name to be inserted >
AND
THE HEALTH ROUNDTABLE LIMITED

This form is to be completed by any researcher who will be working on the provided data.

A) Commitment to the Health Roundtable Honour Code

If the research application is approved by The Health Roundtable, I commit my organisation and all engaged researchers to abide by the Health Roundtable Honour Code:

- *No participant shall criticise the performance of member hospitals, or use any of the information to the detriment of a member.*
- *No external distribution of data or conclusions based on Health Roundtable workshops or data is made without the consent of the Board of Directors and each participating hospital.*

I understand that any breach of these principles may result in the termination of my organisation's research approval by the Health Roundtable and the immediate return of all data provided for research purposes and forfeiture of any relevant fees paid to prepare the data before transmission to the research team.

B) Specific Confidentiality Requirements

In return for its access to the data and any materials produced by, The Health Roundtable, the Researcher agrees:

1. *That the data provided by The Health Roundtable shall be treated as confidential and shall not be divulged to any third party whatsoever without prior written consent of The Health Roundtable, both during the life of this agreement and after its termination.*

2. *That any materials marked as confidential, and electronic data however stored, made or supplied by The Health Roundtable which are in the possession of the Researcher shall be returned to The Health Roundtable (or destroyed if so directed) upon termination of the Agreement.*

This Agreement applies to all material already supplied to the Researcher by The Health Roundtable Limited as well as all subsequent material.

……..	……	……/ ……../ 201 .
Printed Name of Researcher	*Printed Name of Witness*	*Date of signing.*
……..	……	
Signature of the Researcher	*Signature of Witness*	

Annex 4.

APPLICATION TO EXTEND THE TIME FOR A PREVIOUSLY APPROVED RESEARCH PROJECT

(Please provide a project proposal covering the following topics, clearly numbering and labelling each section in the order listed. Please limit the size of the proposal to a maximum of 5 pages. If no change from the original approved request, please state '*no change*'.)

1. APPROVED PROJECT TITLE:	<Insert title>		
2. INVESTIGATORS:	List names, affiliations, email addresses, and phone contact details of all individuals who will participate in the project and have access to the data. Indicate who will be the principal researcher. If no change from the original request, state 'no change from original request'.		
3. SPECIFIC AIMS / HYPOTHESES:	What specific hypotheses are to be tested with this research? If no change from the original request, state no change from original request.		
4. REASON FOR REQUESTED TIME EXTENSION:	Provide an explanation of why a time extension is required and the new estimated date for completion.		
5. RESEARCH DESIGN AND METHODS:	If a change from the additional research design is proposed, please describe the new methodology. If no change, state 'no change from original request'.		
7. ETHICS / RESEARCH APPROVAL	Please indicate if any ethics / research body has made any comment about this research since commencement or if any entity / individual has expressed concerns about the research since commencement. If yes, please attach any relevant documentation		
8. ROUNDTABLE DATA REQUESTED	Please indicate if any additional data elements are required. If yes, please specify the number and type of facilities, countries, financial years, etc.		
9. FUNDING	Who is funding the extension of the research project? Indicate the total amount of additional funding received for this project.		
10. DATA SECURITY	Will data security continue to be maintained to the same high level as occurred during the current phase of the research?		
11. PRESENTATIONS TO DATE	Has there been any presentation of the research data to date? If yes, please advise of any relevant comments that may be of relevance in the consideration of this request.		
Printed Name of applicant		Work Telephone	

Signature		Fax	
Date		Mobile	
Email Address			