National Kaitiaki Group Application to access Māori data from the NCSP Register

Please submit your application at the start of the month to be on time for the next NKG meeting.

Quarterly meetings (kanohi ki te kanohi)

- mid October
- mid February
- mid May
- mid August
- mid November

Monthly meetings

The NKG have monthly meetings in between the quarterly meetings.

Date Application Submitted

Full title of the study

Lay summary of the study (no more than 250 words). In particular think about the benefits of the study for Māori women.

Applicant Details		
Name		
Title		
Organisation		
Address		
Phone		
Email		

Details of an additional person we can contact to verify details regarding your data request

Name & Title		
Phone/email		

Check list		
1.	Is access to the data permitted under section 112J of the Part 4A of the Health Act 1956? (If not, then the National Kaitiaki Group has no jurisdiction)	
http://www.legislation.govt.nz/act/public/1956/0065/latest/DLM307905.html?search=qs_act%40bill%40regul ation%40deemedreg_NCSP_resel_25_h&p=1		
2.	Is the information protected information for the purposes of the definition in regulation 2 (1) in the Health (Cervical Screening (Kaitiaki)) Regulations ie,	
	(a) is the information on or from the NCSP Register; and	
	(b) does it identify the woman or women to whom the information relates as being Māori	
http://www.legislation.govt.nz/regulation/public/1995/0029/latest/DLM198873.html		
3.	Have you attached a copy your Health & Disability Ethics Committee application and feedback on your application if this is available?	
4.	Have you attached evidence of Māori engagement	
5.	Have you attached a Māori data management plan	

Applications are forwarded to:

Email - ncsp@health.govt.nz

SUBJECT TITLE: Attention National Kaitiaki Group

1. Summary of the study in no more than two pages (This can be provided separately as a word document, or outlined below).

The summary must include:

- The purpose / intent of the study
- An outline of the study protocol
- How the results of the study will be used
- How the results of the study will be disseminated?

<u>Please attach</u> a copy of the approved Ethics Committee proposal, and their feedback if it is available.

2. Provide any evidence you have of engagement with Maori

3. Why do you and / or your organisation want access to Māori women's data on the NCSP Register?

4. What data are you requesting? (may include elements / fields, as appropriate)

5.	ln a	accordance with the Health (Cervical Screening (Kaitiaki)) Regulations clause 5 (3):
	a)	Explain your understanding of te whare tangata
	b)	How will Māori women's data (a taonga) be protected in a culturally appropriate way?
		Attach a Maori data management plan . (<u>https://data.govt.nz/manage-data/data-ethics/nga-</u> tikanga-paihere/).
	c)	Publications: all publications resulting from the use of the Māori women's data is to be submitted to the National Kaitiaki Group for: • unconditional approval to publish
		• impose conditions (such as the requirement to seek further approval from the Group before publishing the results of the research, in order to ensure that any such publication is consistent with the considerations in clause 5(3)).

NOTE:

In approving this data request for research, as a condition of approval the National Kaitiaki Group will ask applicants to report annually on progress with their research, and also provide a final summary report.

Information for applicants

The role of the National Kaitiaki Group is to consider applications, under The Health (Cervical Screening (Kaitiaki)) Regulations 1995, for approval to disclose, use, or publish 'protected information' being information that is on or from the NCSP Register and that identifies the woman to women to whom the information relates as being Māori, and to grant approval for such disclosure, use or publication in appropriate cases.

In making their decision the group considers:

- The principle of the sanctity of Te Whare Tangata
- The need for culturally-appropriate protection for the taonga of protected information
- The need to ensure that protected information is used for the benefit of Māori women

The applicant may find using the list of resources below and/or engaging with kaumātua, kuia, person or persons knowledgeable in tikanga Māori helpful if they are experiencing difficulties answering questions.

Resources to assist

A brief narrative on Māori women and the National Cervical Screening Programme https://www.moh.govt.nz/notebook/nbbooks.nsf/0/988B28DF5C86944B4C2565D70018B69E/\$file/whaitia.pdf

Ngā Tikanga Paihere https://data.govt.nz/manage-data/data-ethics/nga-tikanga-paihere/

Health (Cervical Screening (Kaitiaki)) Regulations 1995 http://www.legislation.govt.nz/regulation/public/1995/0029/latest/DLM198873.html

Part 4A of the Health Act, 1956 <u>http://www.legislation.govt.nz/act/public/1956/0065/latest/DLM307750.html?search=qs_act%40bill%40regulation%</u> 40deemedreg_NCSP_resel_25_h&p=1

Further information

Identifiable data relating to Māori women cannot be extracted from the NCSP-Register until approval is obtained from the National Kaitiaki Group.

The group meets as required up to four times a year.

The process of extracting Māori women's data from the NCSP-Register can take the NSU up to six weeks from the date of approval. Applicants should take this into account if they have reporting requirements.

It is an offence under regulation 11 of the Regulations for any person(s) that contravenes or fails to comply with the conditions imposed on the requested data.