



Aboriginal and Torres Strait
Islander health practice
Chinese medicine
Chiropractic
Dental
Medical
Medical radiation practice
Nursing and Midwifery
Occupational therapy
Optometry
Osteopathy
Pharmacy
Physiotherapy
Podiatry
Psychology

July 2013

National Registration and Accreditation Scheme Data Access and Research Policy

Approved by the Agency Management Committee on 30 August 2013

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Introduction

With the establishment of the National Registration and Accreditation Scheme (the National Scheme) in July 2010, for the first time comprehensive national data is being collected across all areas of responsibility of the Australian Health Practitioner Regulation Agency (AHPRA) and the National Boards. It is now possible to produce accurate reports, for example, on the number of health practitioners registered in each profession in Australia. This data clearly has registration, workforce planning, demographic, and commercial and research value, but the National Law imposes strict limits on its use.

An increasing number of data access and research requests are being received by AHPRA and National Boards for access to information, some of which is not publicly available.

To manage such requests the National Boards and AHPRA have established a framework and governance arrangements for responding to these requests, which are described in the *National Registration and Accreditation Scheme – Data access and research policy*. Notwithstanding the proposed policy, AHPRA will not release protected information that identifies individual practitioners.

Background

The National Scheme has established National Boards responsible for regulating 14 health professions under the Health Practitioner Regulation National Law (the National Law), as in force in each state and territory.

The objectives of the National Scheme are to protect the public by ensuring that only suitable and qualified practitioners are registered and to increase the flexibility, responsiveness, sustainability and mobility of the Australian health workforce.

Under the National Law, AHPRA, in conjunction with the National Boards, must keep up-to-date and publicly accessible national registers of registered health practitioners for each health profession. Collectively, these are known as the national register.

The primary purpose of the national register is to strengthen public health and safety by enabling the public to access information about registered health practitioners. AHPRA and the National Boards also use the information to inform decision-making within the National Scheme. In addition, the registration data in the register is an important statistical resource that is used to inform health workforce planning by governments, and to inform research and analysis undertaken by institutions and individuals. AHPRA and the National Boards regularly publish statistical profiles for each profession, including the Annual Report.

The Australian Institute of Health and Welfare (AIHW) is the custodian of the official national health workforce data source, the National Health Workforce Dataset (NHWDS), which encompasses core registration data from AHPRA and data collected in the annual Health Workforce Survey. AHPRA has specific agreements with Health Workforce Australia (HWA) and the Australian Institute of Health and Welfare in relation to release of registration and survey data.

AHPRA cannot release data from the National Health Workforce Dataset. Access to this data should be sought directly from the Australian Institute of Health and Welfare. Increasingly, aggregated data from this dataset is also available to the public by Health Workforce Australia through the National Statistical Resource.

National Boards and AHPRA hold significant amounts of other data which are not part of the public register, most of which is considered to be protected information. This applies to all information that is available to AHPRA as a result of the exercise of functions under the National Law. Data concerning regulatory matters affecting NSW practitioners can also be held by NSW Health Professional Councils. A separate application may need to be made to the relevant NSW Council.

Any access to such information is governed by the National Law and is strictly controlled by the Data Access and Research Committee. Any proposal for access to data needs to comply with the requirements of the National Law, including the privacy protections applicable to personal information and the duty of confidentiality relating to protected information.

Protected information can only be disclosed under specific circumstances. The National Law makes specific provision for data disclosure in certain circumstances, for instance for government workforce planning purposes, disclosure to governments and to other regulators. The National Law also contains a number of provisions about access to data which is not publicly available.

For example, disclosure of protected information does not breach the duty of confidentiality in section 216 of the National Law if the disclosure is in a form that does not identify the identity of the person. This means that the need to ensure confidentiality is paramount, particularly where unit record files are provided for the purposes of research or statistical analysis. Such data can be extremely valuable to researchers and can help to shed light on important questions relevant to the health and care of Australians. A decision about whether to provide access to unit record files therefore requires a careful consideration of risks and benefits.

To guide this process, AHPRA and the National Boards have developed the Data Access and Research Policy which establishes a framework and governance arrangements for access to data and involvement in research, and provides the basis for a consistent approach to these issues across the National Scheme.

Purpose and scope of the Data access and research policy

This policy establishes the data and research governance framework for the National Scheme and provides guidance to individuals, agencies and researchers about and how requests for de-identified data access and research will be considered. This policy relates only to data that is not already part of the National Health Workforce Dataset.

Third party access to official data must be carefully considered in the light of statutory obligations and any risks associated with disclosure. The purpose of this policy is to maximise the benefits that data access can bring, whilst managing any risks to registrant privacy.

Privacy

National Boards are permitted to release health practitioner data, subject to the provisions of various sections of the National Law, including: section 215 (via Freedom of Information), section 217 (supporting government workforce planning), section 218 (supporting information management and communication), section 219 (disclosure to government entities), section 220 (protect patient safety), section 221 (disclosure to registration authorities), and section 225 (publish the National Register).

Section 213 of the National Law applies the *Privacy Act 1988* (Cwlth) to the National Boards and AHPRA. AHPRA also has a Privacy Policy published at www.ahpra.gov.au. Section 216 creates a duty of confidentiality not to disclose information obtained through exercising functions under the National Law, unless an exception applies.

Access to a full copy of the public register pursuant to section 228 of the National Law may be provided consistent with the AHPRA privacy policy. Section 228 of the National Law provides for a release of a copy of the National Register “only if the Agency is satisfied it would be in the public interest to do so”.

Public interest

The decision-making considerations in the *National Registration and Accreditation Scheme – Data access and research policy* include that the proposed research or data disclosure must be in the public interest. This means there will be a potential benefit to the public (at large) from the disclosure of the information. The public interest must be discernible and not too remote or tenuous. The public interest is not served by promoting the interests of a particular health profession. However, the public interest may be served by improving the safety and quality of, or access to, health care. Steps for applying the test include:

- a) Is the requested information available from another source (e.g. the AIHW, HWA or a professional association)?
- b) Does the benefit contribute to the objectives and guiding principles of National Boards and AHPRA?

The public interest test is met only when requests relate to:

- research,
- educational,
- where a request falls within the regulatory functions of a National Board (for example for Continuing Professional Development).

What is included in the policy

The policy covers data access and research requests from institutions and individuals in accordance with the National Law, to:

- a) access material or use de-identified data held by National Boards and/or AHPRA, which is not publicly available, for research, statistical or other purposes, in the public interest (including use of the national register as a sampling frame)
- b) obtain the support, endorsement, sponsorship of, or collaboration in research by a National Board or AHPRA
- c) access a copy of the public register, pursuant to section 228 of the National Law, or to correspond with practitioners through AHPRA. Such requests are only approved where it would be in the public interest.

Exclusions from the policy

The policy does not cover the following:

- the disclosure of protected information to other entities explicitly provided for under the National Law, including the provision of data to Commonwealth, State and Territory entities,
- disclosure of data for commercial purposes. Data will not be disclosed for commercial purposes except in exceptional circumstances subject to approval by the AHPRA CEO and relevant Board Chair(s), taking into account all applicable legislative requirements,
- use of material or registration data by National Board members or AHPRA staff in presentations, seminars, analysis or written papers about the work of the National Boards, AHPRA or the National Scheme, which is part of ordinary business and is not covered by this policy,
- media queries, which are often dealt with through referral to published sources of information,
- freedom of information requests,
- access to the National Health Workforce Dataset (NHWDS), for which the Australian Institute of Health and Welfare is the custodian,
- access to the National Statistical Resource or the Workforce Survey data, for which Health Workforce Australia is the owner.

Simple and complex requests

The *National Registration and Accreditation – Data access and research policy* outlines the National Boards and AHPRA data and research governance arrangements and procedures for the efficient and effective responses to data requests or research proposals.

The policy provides for two pathways:

1. The **streamlined pathway**, for simple requests which:
 - a) do not involve research or any ethical issues,
 - b) do not involve significant resource implications, e.g. where the data is readily available from a report that is already regularly run,
 - c) do not include the provision of unit record data,

- d) are clearly related to the regulatory functions of a National Board or AHPRA and do not present any risks associated with disclosure.

The AHPRA CEO has delegated decisions in relation to these requests to the DARC or its nominee.

2. The **standard pathway** applies for all other requests.

Complex requests for release of non-publicly available data for profession-specific research will not be approved without the endorsement of the relevant National Board.

All requests are managed on a cost-recovery basis.

Data Access and Research Committee (DARC)

The Data Access and Research Committee (DARC) has been established to consider requests for de-identified data access and/or research that are received by National Boards and AHPRA. Its role is to make recommendations to the AHPRA CEO for final approval, in consultation with relevant boards.

The DARC is a committee of the Forum of National Board Chairs (which includes all Chairs of National Boards). It will consider all requests for de-identified data for research participation in accordance with the provisions of the National Law and *Privacy Act 1988* (Cwlth).

The DARC standing membership consists of:

- two National Board members, including at least one with expertise in research and one community member,
- one member of the Agency Management Committee,
- the Director of National Board Services, AHPRA,
- the Director of Business Improvement and Innovation, AHPRA (or their nominee), and
- General Counsel, AHPRA.

Where applications are received relating to particular professions, the relevant National Board Chair(s) or nominee(s) may be invited to participate in the discussion at the DARC meeting. The DARC will determine when a profession-specific representative is required in addition to the relevant National Board Chair or their nominee. Invited members do not form part of the standing membership.

Quarterly cycle

Data access and research requests made to AHPRA and/or National Boards will be considered by the DARC on a quarterly basis.

Application documents and relevant information will be published on the AHPRA website under a dedicated data access and research request section, along with detailed advice to stakeholders about the application process and key dates.

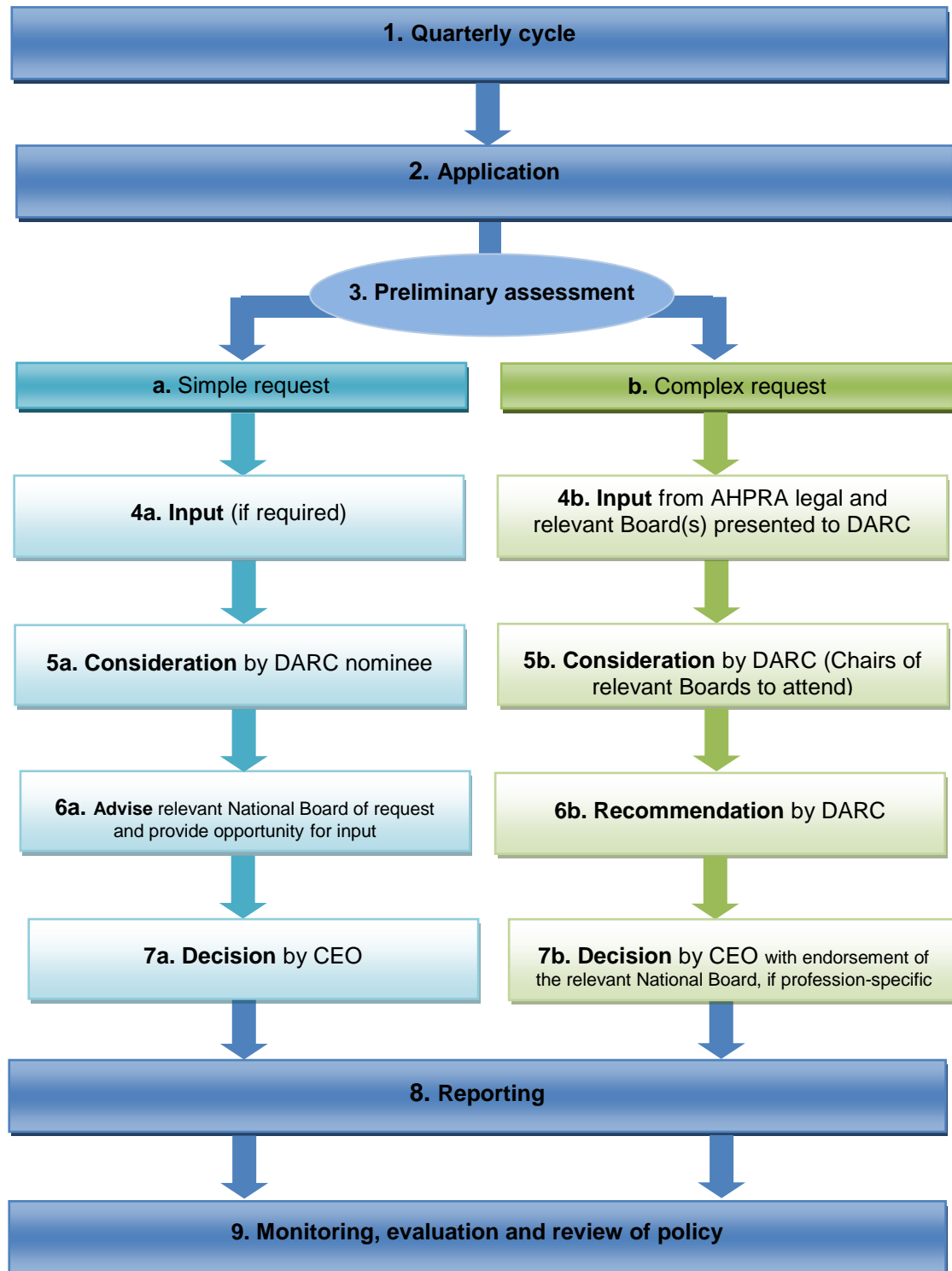
Application

Applicants should complete the initial checklist to ensure that their request falls within the scope of this policy. If it does, the applicant should then complete the application form which will collect more detailed information on the aims, method, ethics approval, etc, of their request. If the request relates to data held by the Australian Institute of Health and Welfare or Health Workforce Australia the applicant will be referred to those agencies.

The checklist and application form can be found on the AHPRA website www.ahpra.gov.au.

Process

The data and research policy and request process is as follows.



Consideration

The DARC Secretariat will make a preliminary assessment of applications as they come in (during the quarterly cycle). Applications that are received between the quarterly DARC cycle will be considered at the following quarterly meeting.

Complex requests that involve particular professions and/or National Board(s) will be referred to Boards via a paper drafted for their endorsement, taking into account any legal and operational advice. The Board's endorsement will be provided to the subsequent DARC meeting. A recommendation from the DARC and the relevant National Board's endorsement will go to the AHPRA CEO for final approval.

Relevant considerations

In considering requests under this policy, the DARC will consider the objectives and guiding principles of the National Law as well as the regulatory responsibilities of the National Boards and government entities, other relevant legislative provisions and the public interest. Careful consideration will be given to weighing the risks and benefits associated with each application.

The DARC will take into account a range of considerations including, but not limited to the following:

- Is the requested information available from another source?
- Is disclosure explicitly provided for under the National Law?
- To what extent is the request consistent with the objectives and guiding principles of National Board and AHPRA?
- Will disclosure meet the duty of confidentiality?
- Will disclosure be in accordance with the *Privacy Act 1988* (Cwlth) and AHPRA's Privacy Policy?
- The risks associated with the release of data
- The extent to which the request meets the public interest test
- The rigour and validity of the proposed project and methodology
- The sensitivity of the information to be accessed, including any cultural sensitivities
- The steps taken by the applicant to ensure compliance with the 'Procedures for Data Access and Research Requests' under Section 95 of the *Privacy Act 1988* (Cwlth): privacy and medical research (March 2000)
- Whether approval has been granted for the research project by a Human Research Ethics Committee (HREC) established in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (updated 2009), including ethical considerations specific to participants (e.g. Aboriginal and Torres Strait Islander peoples). HREC approval will be necessary where required by the NHMRC guidelines¹.
- The level of data quality required and possible resource and/or operational implications of any data extraction and quality assurance, noting that data is provided on a cost-recovery basis.
- Any potential conflicts of interest and whether these can be effectively managed
- Where communication with practitioners is sought, the cumulative impact on registrants
- Alignment with the research priorities periodically identified for the National Registration and Accreditation Scheme

Recommendations

After all previous steps in the process have been successfully completed, the DARC will make its recommendation to the AHPRA CEO for final approval, with a copy to all relevant National Boards.

Disclosure of de-identified data and/or involvement in research will usually require AHPRA entering a formal agreement, including on the Board's behalf. De-identified data requests and research proposals will only be agreed to where they meet the *National Registration and Accreditation Scheme – Data Access and Research Policy*, on the advice of the DARC. Unit record files may need to be 'confidentialised' to ensure that individuals cannot be identified.

¹ See www.nhmrc.gov.au

Possible recommendations

AHPRA and National Boards will **not** provide the postal addresses or email details of registrants in response to data or research requests.

Section 225(b) of the National Law requires that only the suburb and postcode of a practitioner's nominated principal place of practice be listed in the National Public Register. Given this limitation, copies of the public register are unlikely to be useful to those seeking information to contact practitioners, such as for surveys.

To protect the contact details of practitioners, the following data access options may be available, depending on the DARC's (and relevant Board(s)) decision and recommendation:

- a copy of the National Register without contact details - fees apply,
- AHPRA may communicate directly with practitioners to opt-in to further participation - fees and Board approval applies,
- the Board may agree to circulate information to all registered practitioners, using secure distribution options such as through publication of a hyperlink to survey in a Board newsletter or Communiqué,
- supporting, endorsing, sponsoring, funding or otherwise collaborating in a research proposal - subject to an appropriate legal agreement identifying the terms and conditions, and/or
- providing de-identified data under secure and contracted arrangements.

Decision

The final decision on all simple data and research requests is made by the AHPRA CEO on advice from the DARC, taking into account the views of the relevant National Board(s). Complex requests for release of non-publicly available data for profession-specific research will not be approved without the endorsement of the relevant National Board.

Reporting

AHPRA will maintain a register of requests for data and participation in research, and recommendations made by the DARC. To provide transparency of decision-making, foster innovation among applicants and promote the practice of evidence-based policy, information from this register, including information about the applicant, will be published on AHPRA's website. Once the research is complete, applicants will be expected to provide a summary of the outcomes of the research and publication information, for publication.

A summary of all requests will be included in AHPRA's Annual Report.

Monitoring, evaluation and review

The DARC will be responsible for the monitoring and evaluation of this policy. The policy will be reviewed within three years.

Effective date: 30 August 2013

Next review date: 30 August 2016

Associated documentation

- This policy has drawn on the Medical Council of New South Wales *Draft Policy on Data Access and Use for Research* (2011) and the Council's work is acknowledged and appreciated.
- *Manual of the National Boards and their Committees*, AHPRA.
- *Conflict of Interest Guidelines*, AHPRA.
- *Privacy Statement and Privacy Policy* AHPRA
- *Memorandum of Understanding between Health Workforce Australia and the Australian Health Practitioner Regulation Agency and the Australian Institute of Health and Welfare in relation to sharing information, and exchanging data, on Australian health practitioners*. This MOU can be accessed at www.ahpra.gov.au/Legislation-and-Publications/Memoranda-of-Understanding
- *Submissions received* during the targeted consultation on the interim policy as circulated to key stakeholders in April 2012
- Research policies and related guidelines (e.g. Queensland Nursing Council – *Research grants policy* 2009/2010, St Vincent's Hospital (Melbourne) – *Research Endowment Fund Guidelines* (2011), NSW Psychologists Registration Board – *Guidelines for Applicants* (2003), the *Research Governance Toolkit for Victorian Public Hospitals and VMIA Insured Medical Research Institutes* – Victorian Managed Insurance Authority (April 2010)

References

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Medical Council of New South Wales (2011), Draft Policy on Data Access and Use for Research.

National Health and Medical Research Council (2005), *Australian Code on the Responsible Conduct of Research*. Available at: www.nhmrc.gov.au/guidelines/publications/r39 (accessed 4 April 2012).

National Health and Medical Research Council (2005), *National Statement on Ethical Conduct in Human Research*. Available at: www.nhmrc.gov.au/guidelines/publications/e72 (accessed 4 April 2012).

National Health and Medical Research Council (2000) Guidelines under Section 95 of the Privacy Act 1988: privacy and medical research (sets out procedures that Human Research Ethics Committees and researchers must follow when personal information is disclosed from a Commonwealth agency for medical research purposes).