

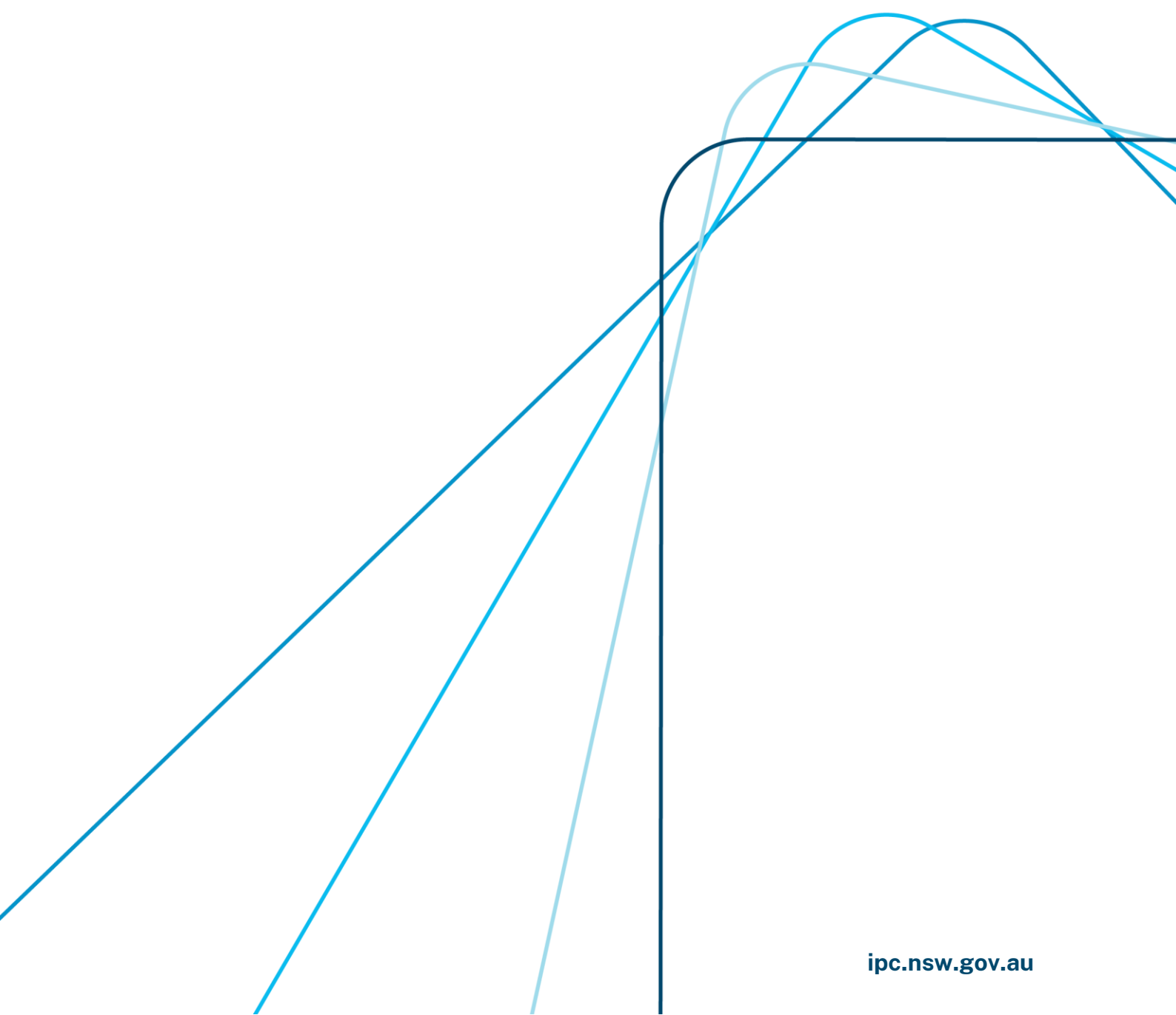


Information and Privacy
Commission NSW

Statutory Guideline on Research – section 27B

Privacy and Personal Information Protection Act 1998

September 2019



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Privacy and Research

Introduction

Under s 27B(e) of the *Privacy and Personal Information Protection Act 1998* (PPIP Act) the NSW Privacy Commissioner may make guidelines for the collection, use and disclosure of personal information for the purpose of research, or the compilation or analysis of statistics.

For the purposes of these guidelines and the accompanying guidance, the term research should be taken to include 'research, or the compilation or analysis of statistics, in the public interest.'

These statutory guidelines are designed to assist agencies subject to the PPIP Act in using the exemption provided by s 27B for research. The Commissioner reminds agencies that most research should be able to be undertaken in full compliance with the PPIP Act without needing to rely on s 27B exemption. The agencies are also encouraged to adopt a 'privacy by design' approach and complete a privacy impact assessment.

Section 27B exemption clearly anticipates that contravening the collection, use or disclosure principles should not be a first option even where the research is judged to be in the public interest. Agencies should first consider whether the objective could be achieved, as applicable, by direct collection of the information from individuals, by use of de-identified or anonymous information and by obtaining consent. Only if none of these options are available, or practicable, should an agency rely on the exemption.

Background

Section 27B was inserted into the PPIP Act by the Privacy and Personal Information Protection Amendment (Exemptions Consolidation) Act 2015 (No 69) which commenced on 1 January 2016. It replaced the Public Interest Direction on Disclosures of Information by Public Sector Agencies for Research Purposes (the Research Direction), originally made by the Privacy Commissioner in 2000 and renewed by successive Commissioners.

The scope of the s 27B exemption is considerably different from that of the Research Direction, as it does not address the specific circumstances of agencies with a major archives/library/museum function¹, or provide for exemption from the public awareness, access or correction principles in such cases.

Instead, it provides that a public sector agency is not required to comply with the Information Protection Principles (IPPs) relating to collection, use or disclosure of personal information (i.e. ss 8-11 and ss 16-19 of the PPIP Act) subject to certain conditions.

How the statutory guidelines on research relate to other regulations

The statutory guidelines on research under the PPIP Act apply only to research involving personal information. The NSW Privacy Commissioner's Statutory Guidelines on Research issued under

s 64 of the *Health Records and Information Privacy Act 2002* (HRIP Act)² in 2004 cover any research involving health information. Where the proposed research involves both personal and health information, both statutory guidelines should be adhered to.

While the research guidelines under the two acts are similar, there are some differences between them, due to the fact that unlike s 27B of the PPIP Act, the HRIP Act has no research exemption from the *collection* principles.

¹ It is no longer necessary, because of the separate, specific exemption at clause 5 of the *Privacy and Personal Information Protection Regulation 2019*.

² https://www.ipc.nsw.gov.au/sites/default/files/2019-01/statutory_guidelines_on_research.pdf

Public concerns about research

It is important to recognise that there will be many cases in which research will be a normal secondary use of personal information collected for another (typically administrative) purpose, and within the reasonable expectations of the individuals concerned, even if they have not been expressly notified. This is more likely to be the case where there is no intention of the research results identifying individuals or where results are not published.

The Commissioner recognises the wide variety of activities that may be included under the heading of 'research' and 'compilation or analysis of statistics' and previously provided some guidance on what constitutes 'research':

"There are many definitions of research. It can be a systematic investigation to establish facts, principles or knowledge or a study to obtain or confirm knowledge. A defining feature of research is the validity of its results. The knowledge that is generated by research is valid in the sense that what is discovered about the particular facts investigated can be justifiably claimed to be true for all like facts".³

The assessment or program evaluation of the operation of the agency or services provided by the agency are generally not categorised as research as they are deemed to be for lawful purposes directly related to function or activity of the agency.

Concerns which may be held by some individuals about the use of their personal information for research may include:

- intrusive questioning, including concerns both about the questions themselves and about the timing or method (e.g. many people dislike 'cold calls', particularly in the evenings, and doorknocking);
- unexpected and unwelcome access by researchers to 'sensitive' personal information such as racial origins, political opinions or religious beliefs (s 19(1)), whether or not research will lead to publication or other release; and
- the possibility of public disclosure of identifying information in any research results, whether published or through more limited release.

Purpose

These statutory guidelines seek to minimise the administrative burden on public sector agencies making use of s 27B exemption, while ensuring that it is not used when alternatives are readily available – either compliance with the IPPs or steps such as de-identifying information⁴ or obtaining consent⁵.

Part 1 contains the statutory guidelines on research. You must comply with these statutory guidelines if you are seeking to collect, use or disclose personal information relying on s 27B exemption. They are issued under s 36(2)(b) of the PPIP Act for the purposes of s 27B(e).

Part 2 explains some of the issues you need to consider when collecting, using and disclosing personal information for research. It also includes a checklist and examples to help you decide whether you should rely on the s 27B exemption.

³ https://www.ipc.nsw.gov.au/sites/default/files/2019-01/statutory_guidelines_on_research.pdf, p.7.

⁴ There is an extensive body of guidance about de-identification techniques and whether they satisfy requirements of privacy laws. See for example Office of the Australian Information Commissioner, *De-identification and the Privacy Act* <https://www.oaic.gov.au/privacy/guidance-and-advice/de-identification-and-the-privacy-act/>

⁵ NSW Privacy Commissioner's Guidance on Consent – see <https://www.ipc.nsw.gov.au/fact-sheet-consent-and-bundled-consent>

PART 1: Statutory Guidelines on Research

1. Application of statutory guidelines

- 1.1 These statutory guidelines define the scope and applicability of the exemption provided by s 27B in the PPIP Act for collection, use and disclosure of personal information for research. They apply to public sector agencies subject to the PPIP Act.

Failure to comply with statutory guidelines constitutes a breach of the PPIP Act

- 1.2 A public sector agency proposing to collect, use or disclose personal information for the purposes of research and relying on the s 27B exemption must comply with these statutory guidelines. Failure to comply with these statutory guidelines constitutes a breach of the IPPs and the PPIP Act.

Prerequisites to applying the statutory guidelines

- 1.3 (a) It must be **reasonably necessary** to collect, use or disclose personal information for the purpose of research; and
- (b) It must be unreasonable or impracticable to collect the information **directly from the individual** to whom the information relates; and
- (c) in the case of use or disclosure of the information – either:
- i. the relevant purpose of research cannot be achieved by the use or disclosure of **de-identified** information and it is impracticable for the agency to seek the **consent** from the individual(s) to use or disclose their personal information, or
 - ii. reasonable steps are taken to de-identify the information; and
- (d) where the information could reasonably be expected to identify individuals – the information is not published in a **publicly available publication**.

Conditions for agencies seeking to collect, use or disclose

- 1.4 Where an agency seeks to rely on these statutory guidelines to lawfully collect, use or disclose personal information it must:
- (a) Be satisfied that the research has been approved by either:
 - i. Human Research Ethics Committee (HREC) for research involving humans; or
 - ii. professional market or social research agency; or, if neither is applicable
 - iii. the NSW Privacy Commissioner.
 - (b) Be satisfied that the granting of approval by one of those bodies satisfied the conditions in these statutory guidelines; and
 - (c) Comply with other duties imposed upon it by these statutory guidelines.
- 1.5 A public sector agency making use of the s 27B research exemption must document:
- (a) the public interest in the research;
 - (b) the reasons why it cannot *either* comply with one or more of the IPPs or take the preferred steps of de-identification or obtaining consent; and
 - (c) what steps, if any, it will take to ensure that privacy risk to individuals is minimised.
- 1.6 A public sector agency must maintain records of any decision to use the s 27B exemption, and make those records available to the Privacy Commissioner on request.

Agencies being asked to use or disclose personal information may decline to do so

- 1.7 Unless it is expressly mandated by law, no holder of personal information is under any obligation to provide that information to a third party for the purposes of research. A public sector agency or other researcher seeking personal information from another agency cannot use its compliance with research guidelines, or reliance on the s 27B exemption, as a reason to insist on access to personal information.

2. Procedure to be followed in the collection, use or disclosure of personal information pursuant to section 27B

Collection, use or disclosure

- 2.1 Where an agency proposes to collect, use or disclose personal information under the s 27B exemption, the steps that should be followed will depend on whether the proposed research is subject to approval by a HREC in a case of all research involving humans, subject to professional market and social research standards or the NSW Privacy Commissioner's approval.

Human Research Ethics Committee

- 2.2 Where an agency proposes to collect, use or disclose personal information under the s 27B exemption for research involving humans, the research proposal must be submitted to be ethically and scientifically reviewed and approved by a HREC in accordance with the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research (2007).⁶
- 2.3 Where a public sector agency submits research to a HREC for approval, the agency should keep a record of its written proposal and any communications with the HREC throughout the approval process.
- 2.4 The agency will be subject to any conditions placed on the research by the HREC, including compliance with the obligations set out in the Australian Code for the Responsible Conduct of Research.⁷
- 2.5 A HREC must only give approval for the collection, use or disclosure of personal information for the purpose of research where it is satisfied that the public interest in the proposed research activity substantially outweighs the public interest in the protection of privacy.
- 2.6 Detailed guidance for preparing a proposal to a HREC and HRECs obligations are found in the Statutory Guidelines on Research issued under the HRIP Act.

Professional Market and Social Research

- 2.7 If the proposed research is in the nature of market or social research, then the public sector agency should seek approval from a professional market or social research organisation. The public sector agency is encouraged to use the services of a contractor, which is a member of the Association of Market and Social Research Organisations (AMSRO). All AMSRO members adhere to the Privacy (Market and Social Research) Code 2014 (Privacy Code).⁸ The Privacy Code, registered by the Commonwealth Privacy Commissioner under the *Privacy Act 1988* (Cth) defines market and social research, and sets out how the Australian Privacy Principles are to be applied and complied with by

⁶ National Statement on Ethical Conduct in Human Research (2007) updated July 2018 – see <https://www.nhmrc.gov.au/guidelines-publications/e72>

⁷ The Australian Code for the Responsible Conduct of Research (2007) was published in 2007 and is currently under review – see <https://www.nhmrc.gov.au/guidelines-publications/r39>

⁸ AMSRO, 2014 (approved by the Australian Privacy Commissioner) – see <https://www.amsro.com.au/member-services/privacy/privacy-market-and-social-research-code-2014/>

AMSRO members in relation to the collection, retention, use, disclosure and destruction of personal information in market and social research.

- 2.8 A public sector agency will be subject to any conditions placed on the research by an AMSRO member, including compliance with the obligations set out in the Privacy Code and the AMSRS Code of Professional Behaviour.⁹
- 2.9 A public sector agency engaging a professional market or social research entity to undertake research should document all details of the engagement and what steps it has taken to ensure that privacy risk to individuals is minimised, for the purposes of the documentation required by these guidelines.

Other research

- 2.10 If the proposed research does not involve humans, or, market or social research (i.e. it would not be appropriate to seek approval from a HREC or a professional market or social research organisation), a public sector agency should submit a proposal to the NSW Privacy Commissioner.
- 2.11 The proposal will need to identify the public interest in the research and the reasons why the agency cannot either comply with one or more of the IPPs or take the preferred steps of de-identification or obtaining consent. To comply with the statutory guidelines, the agency will also need to document what steps, if any, it will take to ensure that privacy risk to individuals is minimised. These steps could include, for example, restrictions on access to research data and findings.

Collection, use and disclosure of sensitive information for research purposes

- 2.12 Public sector agencies taking advantage of the s 27B exemption should take into account the sensitivity of the personal information involved. Almost any personal information can be sensitive in particular contexts, but it should generally be obvious when the research subjects perceive proposed research as particularly sensitive.
- 2.13 Sensitive information includes the categories of information protected by s 19(1), i.e. personal information relating to an individual's ethnic or racial origin, political opinions, religious or philosophical beliefs, trade union membership, or sexual activities.
- 2.14 Where proposed research involves the collection, use or disclosure of sensitive information, public sector agencies should apply very strict criteria before deciding that they need to use s 27B research exemption. The public interest in the research needs to be particularly strong to outweigh the privacy interests of the individuals concerned. Where sensitive information is involved, the records that a public sector agency is required to keep under these guidelines should make specific reference to the justification for the use of the s 27B exemption for this information.

⁹ AMSRS Professional Standards – see <http://www.amsrs.com.au/professional-standards/standards>

PART 2: Guidance on Collecting, Using and Disclosing Personal Information for Research

1.1 When can an agency collect, use or disclose personal information for research?

This checklist can help you decide when you can collect, use and disclose personal information for research, and whether you need to comply with the s 27B and the statutory guidelines on research in Part 1. The checklist assumes that: the information you are proposing to collect, use or disclose is 'personal information' – that is, information capable of identifying an individual by itself, or, in combination with other information reasonably available and that:

- the information you are proposing to use or disclose is not 'health information' as defined in the HRIP Act; and
- you are covered by the PPIP Act.

A flowchart version is available at **Appendix A**.

Collection of personal information

1. Is the research a lawful purpose that is directly related to the agency's function and the collection of information is reasonably necessary for that purpose?

Yes	☐	Go to question 2.
No	☐	Go to question 9.

2. Is the information collected by lawful means?

Yes	☐	Go to question 3.
No	☐	Go to question 9.

Best practice tip: agencies need to be mindful of unlawful collection methods, such as unauthorised covert surveillance or telecommunications interception.

3. Is it possible to collect the information directly from the individual or an authorised representative?

Yes	☐	You can collect personal information for research, provided you fulfil the requirements of IPPs 1-4. You do not need to rely on the s 27B exemption and comply with the statutory guidelines on research.
No	☐	Go to question 4.

Use and disclosure of personal information

4. Could the purpose of the research be served by using or disclosing de-identified information?

Yes	☐	You should use or disclose de-identified information only. If you de-identify the information then you do not need to read any further, and you do not need to rely on the s 27B exemption and comply with the statutory guidelines on research.
No	☐	Go to question 5.

5. Are you proposing to use or disclose personal information with the consent of the individual(s) concerned?

Yes	☐	You can use or disclose personal information relying on s 17(a), or, the exemption in s 26(2) if the consent is express.
No	☐	Go to question 6.

Best practice tip: Wherever possible, you should seek express consent of the person. Use or disclosure authorised by the person is almost always to be preferred, as opposed, to relying on one of the other exemptions, provided the consent is current, voluntary and informed. It is important that the person does not feel pressured to participate.

6. Is the information related to an individual's ethnic or racial origin, political opinions, religious or philosophical beliefs, trade union membership or sexual activities?

Yes	☐	Go to question 9.
No	☐	Go to question 7.

7. Is the research activity directly related to the primary purpose for which the personal information was collected and would the person reasonably expect you to use or disclose their personal information for the activity?

Yes	☐	You can use or disclose personal information for research relying on the 'direct relation exemption' in s 17(b) or s 18(1)(a). You do not need to rely on the s 27B exemption and do not need to comply with the statutory guidelines on research.
No	☐	Go to question 8.

8. Is the use or disclosure of information for research necessary to prevent or lessen a serious and imminent threat to the life or health of the individual concerned or another person?

Yes	☐	You can use or disclose personal information relying on the exemption in s 17(c) and s 18(1)(c). You do not need to rely on the s 27B exemption and do not need to comply with the statutory guidelines on research.
No	☐	Go to question 9.

9. Can you rely on the s 27B exemption to collect, use or disclose personal information?

Yes	☐	Section 27B if you: • meet the five exemption criteria in Part 2 clause 1.2 of this publication; and • comply with the statutory guidelines on research in Part 1 of this publication.
No	☐	You cannot use or disclose personal information for research (unless you have identified another exemption in the PPIP Act that permits you to do so).

1.2 When can I rely on s 27B exemption and the statutory guidelines on research?

Under the s 27B exemption you can collect, use or disclose personal information, without the consent of the person, for the secondary purpose of research if all of the following five criteria are met.

Criterion 1

The collection, use or disclosure of the information is reasonably necessary for the purpose of research, or the compilation or analysis of statistics, in the public interest.

Criterion 2

In the case of collection of personal information, it is unreasonable or impracticable for the information to be collected directly from the individual to whom the information relates.

Criterion 3

In the case of the use or disclosure of the information, you have taken reasonable steps to de-identify the information, or, the purpose of the research cannot be served by using or disclosing de-identified information and it is impracticable to seek the consent of the person to the use or disclosure.

Criterion 4

If the information could reasonably be expected to identify individuals, the information is not published in a publicly available publication.

Criterion 5

The collection, use or disclosure of the information is in accordance with the statutory guidelines on research in Part 1 of this publication.

Please note that you must meet all five criteria to collect, use or disclose personal information relying on the s 27B exemption. The key terms in the criteria are explained below.

1.3 Key terms in s 27B explained

To help you decide whether you can rely on s 27B to collect, use or disclose information the key terms are explained below.

Is the use or disclosure ‘reasonably necessary’?

When deciding whether the collection, use or disclosure is ‘reasonably necessary’, consider to what degree personal information is needed for research. For example sometimes the research activity may be just as effectively carried out, without the need for the collection, use or disclosure of personal information.

What is meant by ‘research’?

There are many definitions of research. It can be a systematic investigation to establish facts, principles or knowledge or a study to obtain or confirm knowledge. A defining feature of research is the validity of its results. The knowledge that is generated by research is valid in the sense that what is discovered about the particular facts investigated can be justifiably claimed to be true for all like facts.

What is meant by ‘the compilation or analysis of statistics’?

The compilation or analysis of statistics is the act or process of collecting numerical data, or undertaking a detailed examination of the elements or structure of numerical data, especially in or about large quantities, and inferring conclusions for the whole from conclusions reached from the whole or a representative sample.

What does ‘in the public interest’ mean?

To be ‘in the public interest’ the outcome of a research should have a positive impact on, or be relevant to, the community or a segment of the community as distinct from being a matter of purely private or personal interest.

Could de-identified information be used?

If a research activity could be undertaken by using or disclosing de-identified information, then you should proceed this way. This may involve you converting ‘identifiable’ information (information that allows identification of a specific individual) into ‘de-identified’ information. De-identified information is information from which identifiers have been permanently removed, or where identifiers have never been included. De-identified information cannot be re-identified. However, sometimes de-identified information cannot achieve the purpose of the research. This could be, for example, where a project involves linking information about individuals from two or more sources and you need identified information to correctly link records from each data source.

What are ‘reasonable steps to de-identify’?

When de-identifying information, you should consider the capacity of the person or agency receiving the information to re-identify it or re-link it to identifiable information. Removing the name and address may not always be enough, particularly if there are unusual features in the case or a small population. Reasonable steps to de-identify might also include removing other features, such as date of birth or ethnic background that could otherwise allow an individual to be identified in certain circumstances.

When is it ‘impracticable to seek consent’?

The fact that seeking consent is inconvenient or would involve some effort or expense is not of itself sufficient to warrant it ‘impracticable’. Some examples of where it might be impracticable to seek consent include if:

- the age and / or volume of the information is such that it would be very difficult or even impossible to track down all the individuals involved;
- there are no current contact details for the individuals in question and there is insufficient information to get up-to-date contact details; and
- a complete sample is essential to the integrity and success of the research project and the research would not be possible if any of the subjects refused to allow their information to be used.

What does ‘in accordance with the statutory guidelines on research’ mean?

The statutory guidelines on research are legally binding. You must comply with them to lawfully collect, use or disclose personal information relying on the ‘research exemption’. They are contained in Part 1 of this publication.

Appendix A

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    Q1[1. Is the research a lawful purpose that is directly related to the agency's function and the collection of information is reasonably necessary for that purpose? (IPP 1)] -- Yes --> Q2[2. Is the information collected by lawful means? (IPP 1)]
    Q1 -- No --> Q9[9. Can you rely on the s 27B exemption to collect, use or disclose personal information?]
    Q2 -- Yes --> Q3[3. Is it possible to collect the information directly from the individual or an authorised representative? (IPP 2)]
    Q2 -- No --> Q9
    Q3 -- Yes --> C1[You can collect personal information for research, provided you fulfil the requirements of IPPs 1-4. You do not need to rely on the s 27B exemption and comply with the statutory guidelines on research.]
    Q3 -- No --> Q4[4. Could the purpose of the research be served by using or disclosing de-identified information?]
    Q4 -- Yes --> C2[You should use or disclose de-identified information only. If you de-identify the information then you do not need to read any further, and you do not need to rely on the s 27B exemption and comply with the statutory guidelines on research.]
    Q4 -- No --> Q5[5. Are you proposing to use or disclose personal information with the consent of the individual(s) concerned? (IPPs 10-12)]
    Q5 -- Yes --> C3[You can use or disclose personal information relying on s 17(a) or the exemption in s 26(2) if the consent is express. You do not need to rely on the s 27B exemption and do not need to comply with the statutory guidelines on research.]
    Q5 -- No --> Q6[6. Is the information related to an individual's ethnic or racial origin, political opinions, religious or philosophical beliefs, trade union membership or sexual activities? (IPP 12)]
    Q6 -- Yes --> Q7[7. Is the research activity directly related to the primary purpose for which personal information was collected and would the person reasonably expect you to use or disclose their personal information for the activity? (IPPs 10, 11)]
    Q6 -- No --> Q9
    Q7 -- Yes --> C4[You can use or disclose personal information for research relying on the 'direct relation exemption' in s 17(b) or s 18(1)(a). You do not need to rely on the s 27B exemption and do not need to comply with the statutory guidelines on research.]
    Q7 -- No --> Q8[8. Is the use or disclosure for research necessary to prevent or lessen a serious and imminent threat to the life or health of the individual concerned or another person? (IPPs 10-12)]
    Q8 -- Yes --> C5[You can use or disclose personal information relying on the exemption in s 17(c) and s 18(1)(c). You do not need to rely on the s 27B exemption and do not need to comply with the statutory guidelines on research.]
    Q8 -- No --> C6[You cannot collect, use or disclose personal information for research (unless you have identified another exemption in the PPIP Act that permits you to do so).]
    Q9 -- Yes --> C7[Section 27B if you:  
• meet the five exemption criteria in Part 2 clause 1.2 of this publication; and  
• comply with the statutory guidelines on research in Part 1 of this publication.]
    Q9 -- No --> C6
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Collection

Use and Disclosure

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