

Informing Consent for the Publication of Case Material: Principles, Considerations and Recommendations

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Abstract

In this article, the authors examine the ethical issues involved in the use of case studies by health professionals when presenting research, specifically focusing on how informed consent is obtained from or, rather, negotiated with the client. It is argued that collecting personal information for the purposes of healing is not the same as collecting it for the purposes of research and, therefore, that informed and voluntary consent for this use is essential. The theoretical principles covering ethics in research are discussed in relation to the use of case studies in publications, based on international codes and declarations, on Te Tiriti o Waitangi, and framed in a relational paradigm. Practical considerations and recommendations for those writing for journals and, specifically, this journal, are presented and promoted.

Waitari

I tēnei tuhinga ka arotakehia e ngā kaituhi ngā take matatika o te whakamahi a ngā ngaio hauora i ngā tauria whaiaro i roto i ā rātou mahi rangahau. Ko te kii, he rerekā anō te kaupapa kōhi korero whaiaro hai whai oranga ki tērā o te kohikohi korero hai mahi rangahau. Nā tēnei, me mātua whakatau korero mātau, whai whakaetanga hoki ēnei momo mahi. Ka matapakihia nga mātāpono haukotī i te matatika rangahau ki te whakaurunga o ngā tauria whaiaro ki ngā tuhinga whakaputa, e ai ki ngā tohu me ngā whakahau o te ao me tā Te Tiriti o Waitangi: ka horaina, ka tautokohia ngā whakatauhanga whakaaro me ngā whakaritenga mā te hunga e tuhi ana mō ngā huataka, tohutika ki tēnei huataka.

Keywords: case material; case reports; case studies; informed consent; the Nuremburg Code; the *Universal Declaration of Human Rights*; the *Helsinki Declaration*; *Te Tiriti o Waitangi*

Tudor, K., & Grinter, C. (2014). Informing consent for the publication of case material: Principles, considerations and recommendations. *Ata: Journal of Psychotherapy Aotearoa New Zealand*, 18(1), 51-65. DOI: 10.9791/ajpanz.2014.05 © New Zealand Association of Psychotherapists Inc.

Editing a journal presents a number of challenges, not least in terms of developing processes and policies. One such challenge was stimulated by the submission of the first article since *Ata* was launched in 2012 that was based on a case study. As neither the journal (nor its predecessor *Forum*) nor the New Zealand Association of Psychotherapists (NZAP) had a policy or any procedures for determining the acceptability of a case study for publication with regard to ensuring the voluntary and informed consent of the client or patient who is the focus of the case study, the first author initiated some research and discussions which have led to the publication of this article.

Firstly, Keith consulted various sources (other journals, publishers, professional associations, and colleagues) and began to draft some guidelines for authors with regard to publishing case material. He then consulted Charles, the Kaitohutohu Matatika Rangahau | Research Ethics Advisor to the Auckland University of Technology Ethics Committee, and who contributed to widening the scope of the article, and hence our collaboration.

In writing this article and drafting the guidelines in it, we have sought to balance two interests, namely, and in order of priority:

- the well-being of the patient or client; and
- the benefit to the community of disseminating case material for the greater learning of practitioners.

Whilst the consideration and seeking of consent from a client raises a number of clinical, professional and ethical issues, these guidelines also involve research ethics and, therefore, we have also referred to and drawn on a number important documents, both within the New Zealand jurisdiction and at an international level. Although this article is written in the context of our experience as researchers in Aotearoa New Zealand, we think the principles we discuss and promote are able to inform practice in other countries and jurisdictions.

Case Reports, Codes and Declarations

Case studies or “case reports” from health or disability services are recognised by the Ministry of Health’s (MoH) National Ethics Advisory Committee (NEAC) as a type of observational research. NEAC’s Ethical Guidelines summarise the nature and purpose of such studies: “[they] give us vital evidence about our health and how best to protect and improve it. They do this by using personal information for public good” (p. iv).

As well as fulfilling their primary task of holding and discharging a duty of care to the patients or clients with whom they work, whether that is an individual, a couple, a family, whanau, a group and so on, health professionals working in the public sector (health care providers, registered health practitioners and others) work for the broader public good, and thus need to balance their specific task of care with consideration of the public good. We consider that all such health professionals hold — or should hold — this balance, though some private practitioners may focus more on their primary task i.e, their duty of care to the patient/client than to the broader or greater good.

While there are many and diverse thoughts relating to the issue of publishing case material, we consider that the main concern of those involved in caring for, treating, operating on, curing, and/or healing people is the care and protection of the patient or client. As the NZAP's *Code of Ethics* (2008) has put it: "Protect client well-being. Psychotherapists shall have regard for the needs of clients who are unable to exercise self-determination or to ensure their own personal safety and act to protect the clients' best interests, rights and well-being" (Section 1.10). The same *Code* is also clear about psychotherapists' responsibility to self, colleagues and the profession: "2.12 Psychotherapists shall seek to maintain the anonymity of supervisees or trainees when clinical material is used in education, training, research or publications, unless prior informed consent has been obtained".

Codes of ethics are, of course, themselves informed by different ideas about ethics and, beyond, that, different traditions of and views about moral philosophy. These include instrumental ethics, which are those that are in principle logically deducible from fundamental ethical practices such as "Thou shalt not murder"; situational ethics, which take into account the particular context of an act when evaluating it ethically (see Fletcher, 1997) and relational ethics, which is a contemporary approach to ethics that views ethical action and decision-making in relationship (see Lee, 2004; Cornell et al., 2006). If ethics is concerned with how we should live, given that we are relational beings, then relational ethics is concerned with how we live together.

In the context of publishing case material, it is clear that in balancing the interests of both the client and the community, there are a number of considerations which need to be taken into account. Some of these considerations are derived from recognised international standards. In terms of the wider context of ethical concerns, there are three major, international codes or declarations that are relevant to our concerns. The first is the Nuremberg Code of 1947 which consolidated a submission from Dr Leo Alexander to the Council for War Crimes defining legitimate medical research, together with points that had arisen during the "Doctors' Trial" of Karl Brandt and 22 others who had been involved in human experiments in concentration camps (see Table 1). As we can see, the primary ethical value promoted in the provisions of this code is that of autonomy.

<i>TABLE 1. THE NUREMBERG CODE (1949)</i>	
1.	That the voluntary consent of the human subject is essential.
2.	That the experiment should yield fruitful results for the good of society.
3.	That the anticipated results will justify the experiment.
4.	That the experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
5.	That no experiment should be conducted where there is prior reason to believe that death or disabling injury will occur.

6.	That the degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7.	That proper preparation should be made and adequate facilities provided to protect the experimental subject against the possibilities of injury, disability, or death.
8.	That the experiment should be conducted only by scientifically qualified persons, and that the highest degree of skill and care should be required.
9.	That during the course of the experiment the human subject should be at liberty to bring the experiment to an end.
10.	That during the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage.

The next international document which is central to thinking about ethics in research is *The Universal Declaration of Human Rights* (United Nations, 1948). This consists of 30 articles, focused on the intrinsic freedom, equality, dignity, and rights of all human beings. This *Declaration* echoes Emmanuel Kant's famous categorical imperative which states that each human being is an end in themselves and may not be used as a means to someone else's ends (Kant, 1797/1993). From the perspective of a health professional who is undertaking research, one could express this idea succinctly: that patients or clients are to be treated always as people who have come to us for healing, not as information lodes to be mined for data. This is consistent with principles of humanistic research as outlined by the Task Force of the American Psychology Association's Division 32 (Humanistic Psychology) for the Development of Practice Recommendations for the Provision of Humanistic Psychosocial Services (Task Force, 2004), which argued, amongst other things, that "Research must be able to approach the person not just as a diagnostic category but as a whole" (p.34).

The ethos of the *Universal Declaration of Human Rights* focused on the rights and value of the individual, a point which has been incorporated into the law of a number of countries, and is, for example, echoed in New Zealand's 1994 *Privacy Act* which stipulates that identifiable information may only be used for the purpose for which it was collected, and that it is to be stored securely and kept confidential, and that once it has been used for the purpose for which it was collected, it is to be returned or destroyed (see Table 2, opposite).

A third relevant document is the World Medical Association's (WMA) *Declaration of Helsinki* (WMA, 1964/2008) which emphasises that the benefits of any research must outweigh any risks or harms to the patients and that medical personnel are always to act in the best interests of their patients, a declaration that is the basis for the commonly used health-related research ethical principles of beneficence and non-maleficence. There is a common belief that non-maleficence is prior to beneficence and a common misconception that "First do no harm" forms part of the Hippocratic Oath (Table 3), which it does not. This misconception is believed to have originated with the 19th century British surgeon, Thomas Inman who coined the phrase "Primum non nocere" (Smith, 2005).

<i>TABLE 2. PRINCIPLES OF THE PRIVACY ACT 1974 WITH REGARD TO PERSONAL INFORMATION</i>	
Principle 1	Purpose for collection of personal information.
Principle 2	Source of personal information, i.e., direct collection (unless the information is publicly available).
Principle 3	Collection of information, i.e., that the client is aware of the collection, its purpose, the recipients, the consequences, and their rights of access and of correction.
Principle 4	Manner of collection of personal information, i.e., that it is not unfair, unlawful, or unreasonably intrusive.
Principle 5	Storage and security of personal information, i.e., that it is protected against loss, access and disclosure.
Principle 6	Access to personal information.
Principle 7	Correction of personal information.
Principle 8	Accuracy of personal information, i.e., that is checked before use.
Principle 9	Retention of personal information, i.e., that an agency shall not keep personal information for longer than necessary.
Principle 10	Limits on use of personal information.
Principle 11	Limits on disclosure of personal information.
Principle 12	Unique identifiers, i.e., that an agency shall not assign a unique identifier to an individual.

We think that recognising the priority of beneficence is a significant, useful and positive way to think about research ethics.

TABLE 3. THE HIPPOCRATIC OATH (5TH CENTURY BEFORE COMMON ERA)

I swear by Apollo the physician, and Aesculapius the surgeon, likewise Hygeia and Panacea, and call all the Gods and Goddesses to witness, that I will observe and keep this underwritten oath, to the utmost of my power and judgement.

I will reverence my master [sic] who taught me the art. Equally with my parents, will I allow him [sic] things necessary for his support, and will consider his sons as brothers. I will teach them my art without reward or agreement; and I will impart all my acquirements, instructions, and whatever I know, to my master's children,

as to my own; and likewise to all my pupils, who shall bind and tie themselves by a professional oath, but to none else.

With regard to healing the sick, I will devise and order for them the best diet, according to my judgement and means; and I will take care that they suffer no hurt or damage.

Nor shall any man's entreaty prevail upon me to administer poison to anyone; neither will I counsel any man to do so. Moreover, I will get no sort of medicine to any pregnant woman, with a view to destroy the child.

Further, I will comport myself and use my knowledge in a godly manner.

I will not cut for the stone, but will commit that affair entirely to the surgeons.

Whatsoever house I may enter, my visit shall be for the convenience and advantage of the patient; and I will willingly refrain from doing any injury or wrong from falsehood, and (in an especial manner) from acts of an amorous nature, whatever may be the rank of those who it may be my duty to cure, whether mistress or servant, bond or free.

Whatever, in the course of my practice, I may see or hear (even when not invited), whatever I may happen to obtain knowledge of, if it be not proper to repeat it, I will keep sacred and secret within my own breast.

If I faithfully observe this oath, may I thrive and prosper in my fortune and profession, and live in the estimation of posterity; or on breach thereof, may the reverse be my fate!

These three documents and the Oath are useful in providing the background to and the framework of current ethical concerns and codes. The values which each emphasise — of autonomy, dignity and beneficence as well as non-maleficence — however, are not always in harmony. Indeed, a number of codes of ethics acknowledge that the practitioner may need to weigh up competing ethical considerations, not least as many practitioners may subscribe and be subject to two or more codes of ethics. As the British Association for Counselling and Psychotherapy (BACP) (2013) has acknowledged:

Ethical decisions that are strongly supported by one or more of these principles without any contradiction from others may be regarded as reasonably well founded. However, practitioners will encounter circumstances in which it is impossible to reconcile all the applicable principles and choosing between principles may be required. (p. 2)

More broadly, the NZAP has asserted that: "The challenge of working ethically means that psychotherapists will inevitably encounter situations where there are competing obligations." In this sense, we perhaps need to think less in terms of codes, clauses and rules, and more in terms of principles and guidelines on which we can draw in order to

balance and manage often competing concerns, complexities, and dilemmas. Some years ago, the BACP changed the title of its “code” of ethics (BACP, 2000) to that of an Ethical “Framework” (BACP, 2002), precisely to acknowledge this point.

Considering these three documents and the Hippocratic Oath is useful as they offer an historical context to ethics concerns and practice. The problem with using them to inform a specific ethical stance is that they conflict with each other, as we have discussed. The *Nuremberg Code* is very focused on individual autonomy, while the WMA’s *Declaration of Helsinki* embodies a more social focus on the good and benefit for others. Moreover, whilst there is an argument that the *Universal Declaration of Human Rights* is universal, it, too, is grounded in a specific, Western, liberal, philosophical tradition. Given the potential for conflict, we favour an agreed — and local — starting point. As Connell (2008) put it in her work on *Southern Theory*: “Since the ground is different, the form of theorising is often different too” (p. xii). Thus, we consider that principles and practice that flow from the Articles of Te Tiriti o Waitangi are more grounded and relevant, especially in the context of health and social research conducted and reported in Aotearoa New Zealand.

In the following discussion we refer to “the Treaty” as the partially signed English language version, whence certain principles derive, and to “te Tiriti” as the version that was written in te reo Māori and the one that was signed by all the Māori rangatira (chiefs) and William Hobson, the representative of the British Crown.

The Treaty of Waitangi

In this country, many practitioners, and especially those working in the public sector, turn to the Treaty of Waitangi as a starting point for agreed values and the principle therein, i.e., those of partnership, participation and protection, as identified by the *Education Act 1981* and the Royal Commission on Social Policy (1988) following judgements in the courts and findings and recommendations of the Waitangi Tribunal. These principles also form the basis for *Te Ara Tika: Guidelines for Māori Research Ethics* (The Pūtaiora Writing Group, n.d.). Relating these principles to the use of case studies in publications, we would suggest the following:

In terms of partnership — determining whether, how and where to use case material is something that should be negotiated in partnership with the client.

In terms of participation — any use of case studies must be with the consent of the patient or clients concerned. It is important to realise that they are primarily seeking healing — of themselves — and so it cannot be assumed that they also seek the healing of others through the use of their own case data, however admirable we might think that would be.

In terms of protection — this requires that patients are protected by having their information published in such a manner that their identity is protected and that only information pertinent to the issue under discussion is used.

We are of the view that partnership, participation and protection are useful principles

drawn from the Treaty of Waitangi and that they provide a good starting point for researchers a) because they did arise from consultation between Crown agencies and Māori, and b) because they are widely accepted and implemented.

As with anything ethical, however, they are not without problems, as they and indeed a number of other principles associated with the Treaty over the years have been the result of court, Waitangi Tribunal, government, or state sector decisions. With the exception of the Waitangi Tribunal, these have largely been non-Māori in origin and also give priority to the largely unsigned English version of the Treaty.

Te Tiriti o Waitangi

Accordingly, we also suggest drawing on the fully signed te reo version, Te Tiriti o Waitangi, and using the four articles which acknowledge *kāwanatanga* (governorship), *tino rangatiratanga* (sovereignty), *ōritetanga* (equitable outcomes), and, acknowledging the orally accepted fourth clause, *wairuatanga* (spiritual freedom) as alternative “principles” that could guide the use of case studies in publications. This approach reflects and is strengthened by the United Nations’ (2007) Declaration on the Rights of Indigenous Peoples and the principle of *contra proferentem* whereby the indigenous language version of a treaty takes preference over that written in the language(s) of the colonisers.

Kāwanatanga (governorship) — If we view *kāwanatanga* in this context as a form of stewardship, then we can consider that the patient or client has given *kāwanatanga* in relation to their information to the health professional for the purposes of healing and thus an extension of this *kāwanatanga* is required for the information to be used for research. We think that the concept of stewardship with regard to client material is a significant and useful one in promoting firstly, the explicit obligation for the respectful and sustainable collection and use of such material; and, secondly, the particular framing of the therapist-client relationship as one of steward/host-guest (see Orange, 2012; and Table 2). It also clarifies that information collected should ultimately be returned to the one who has *tino rangatiratanga* in this matter (see next point).

Tino rangatiratanga (sovereignty) — Applying this to case study information, *tino rangatiratanga* is vested in the patient or client of whom it is the focus, and this is the person who must have and retain the final say on how that information is to be used. This is echoed in another statement in the APA Task Force’s (2004) recommended principles and practices: that “Research must be able to consider the participating individual as an agent and interpreter of the therapeutic situation” (p. 34). This alternative “principle” recognises that people in therapeutic relationships have different roles and, therefore, different duties of care and responsibility, and, whilst these may be mutual, they are asymmetrical (see Aron, 1996).

Ōritetanga (equitable outcomes) — The achievement of *ōritetanga* in relation to case studies involves two uses of equity: one is the promotion of a mutuality within the relationship, and the other is the encouragement of an equality of interest within the

relationship — and, of course, this is more complex in an asymmetrical relationship such as that between client and therapist. In sharing the personal information of a patient or client as part of a case study, we consider that some form of mutual benefit should be sought and made explicit. In the application of contract law to therapy, this is represented by the criterion of valid consideration (Steiner & Cassidy, 1969), (the others being mutual consent, competency and lawful object). For instance, in Hawthorne's (2014) article, (which stimulated this article and is published elsewhere in this issue), it is clear that "Maria" wanted the article published in order to help others and, therefore, to contribute to the public good.

Wairuatanga (spiritual freedom) — Implementing wairuatanga when using case studies involves a respect for the patient or client as a fellow human being, and the presentation of the case study material in a manner that demonstrates this. In the words of the APA Task Force (2004), it is important that such research "must be able to capture the nonquantifiable and the meaningful" (p. 34). We think that the therapist always needs to recognise and hold that a "case study" — or, perhaps, better, a study of the person — is a precious record of and perspective on the patient's or client's life or, at least, an aspect of it.

Considerations and Recommendation for Best Practice in the use of Case Studies

Taking all of the above into account, we recommend that before therapists seek consent (or assent) for the use of case study material, they consider the following points:

1. Thought needs to be given to the issue of publishing case material about a specific patient or client in terms of the impact on her/him/them, including possible future consequences.
2. If the patient or client is still in therapy this is especially complicated as some would argue that it is impossible for the therapist to obtain voluntary consent due to the power imbalance in the therapeutic relationship. We are not suggesting that this is impossible but that it is important to consider this seriously and to address the power imbalances, possibly by means of engaging an independent third party to manage the consent/assent process.
3. In any case, we recommend therapists who are considering publishing case material to discuss this initially with their supervisor(s).
4. If the proposed publication is a full or even part of a case study, then the patient or client needs to give written consent for it to be written and published.
5. Thought should be given as to the whether it would be appropriate for the patient or client to see the final draft for their comments.
6. In any case, and even though the NZAP's *Code of Ethics* 2.12 allows for the possibility that patients or clients could waive their right to anonymity, we strongly recommend that the patient's or client's identity needs to be protected by the use of a pseudonym, and the removal or disguising of other identifying aspects.
7. If the patient or client is a psychotherapist, a psychotherapy student, or in any other

way related to the psychotherapy/counselling/psychology/psychiatry community, then serious thought needs to be given as to whether publication should go ahead, even taking into consideration matters of consent, anonymity, etc. Such consideration would also apply to any member(s) of relatively small professional communities.

8. It is recognised that the capacity of some patients or clients to give informed consent is impaired or legally deemed absent, for example, some people with learning disabilities, brain injury, or a dementia. In some ways, it would be easier to exclude case reports of such patient or clients, however, a blanket ban on publication in and of these circumstances denies the voice of those patients or clients. In these circumstances, it would be good practice to involve the person or persons who have an enduring power of attorney for the patient or client, or their parent or legal guardian.
9. Although children acquire rights to give consent for themselves as they grow older, and are deemed to be competent from the age of 16, parents retain the right to give consent on the child's behalf until they are 20. Thus, up to the age of 16 the parent has to give consent and, wherever possible the child should give assent; from 16 to 20, the child or, rather, young person has to give consent, and the parent may also give consent. The decision to involve the parent depends on whether the young person is deemed competent to consent in terms of their understanding and experience. It would normally be considered good practice to seek assent or consent from the child and consent from the parent or legal guardian to publish the material, although the view of the child/young person is always paramount.

The Process of Consent

Once the therapist has decided to ask the patient or client for permission to use case material based on their work together, or a patient or client has offered this and the therapist has taken the above into consideration, the process should be as follows:

1. To seek to obtain consent from the patient or client (see formats below). At this stage, the patient or client should be given the fullest details of the study and its purpose so as to be able to make an informed decision. The patient or client should be given two copies to sign; one should be retained by them and the other by the practitioner.
2. Where obtaining consent is not possible, to identify if there is another case study that would be fit for purpose and for which consent would be able to be obtained.
3. When consent is not possible and the information is identifiable, to seek appropriate ethics approval (Health Research Council of New Zealand, 2014). In our view, in such circumstances the preferred option is not to publish, however, we note that current Aotearoa New Zealand legislation on privacy does allow for this. Therapists who are employed by an institution with their own ethics committee should apply there first, others need to apply to a Health and Disability Ethics Committee (see <http://ethics.health.govt.nz/>).
4. When consent is not possible, and the information is not identifiable in any way, then our preference is that the use of the personal information in a case study should be avoided unless compelling evidence favours its publication for the public good.

5. In all cases, the article should contain a brief statement of what has been done to obtain approval and consent to use the case study material and how it has been implemented.

Conclusion

In conclusion, we would like to recommend that NZAP members who are seeking to publish using case studies based upon their patient or client notes use the consent process outlined above. We have also included consent and assent formats (below) for consideration and use. When considering any ethical issues around the use of case studies, we have argued that the best starting place for those living, working researching and/or publishing in Aotearoa New Zealand is the Articles of Te Tiriti o Waitangi. Furthermore, as the Articles of te Tiriti describe a relational ethics, we think that these “principles” could inform ethical, relational practice in other jurisdictions.

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Consent to publication of material about the client/
patient in *Ata: Journal of Psychotherapy Aotearoa New
Zealand*

SUBJECT OF ARTICLE:

I have seen this material and I hereby give my consent for it to appear in educational publications, journals and textbooks. In addition, I give permission for this same material to be used in any other form or medium, including all forms of electronic publication or distribution anywhere in the world. As a result, I understand that the general public may see the material.

I understand that the material will be published without my name attached, and that every attempt will be made to ensure my confidentiality. I accept, however, that given the nature of the information, complete confidentiality cannot be absolutely guaranteed.

I understand that my name will only be known to the editor(s) of the journal and then only in the event that the editor(s) wishes(wish) to verify my consent.

I understand that I will have an opportunity to review the case data relating to me prior to publishing.

I understand that the material will not be used for advertising or packaging; neither will it be taken out of context.

SIGNED:

DATE:

Assent to publication of material about the client/
patient in *Ata: Journal of Psychotherapy Aotearoa New
Zealand*

SUBJECT OF ARTICLE:

I have seen this material and I hereby give my consent for it to appear in educational publications, journals and textbooks. In addition, I give permission for this same material to be used in any other form or medium, including all forms of electronic publication or distribution anywhere in the world. As a result, I understand that the general public may see the material.

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I understand that my name will only be known to the editor(s) of the journal and then only in the event that the editor(s) wishes(wish) to verify my consent.

I understand that I will have an opportunity to review the case data relating to me prior to publishing.

I understand that the material will not be used for advertising or packaging; neither will it be taken out of context.

SIGNED:

DATE:

Please note that there are more user-friendly formats that may be used for seeking the assent of children (see, for instance, the *Information sheet exemplar for use with child participants* produced by Auckland University of Technology's Ethics Committee, available from www.aut.ac.nz/researchethics/forms).

ACKNOWLEDGEMENTS

We are grateful to Susan Hawthorne for her original article which stimulated our thinking and led to this article; to the anonymous peer reviewers for their helpful comments; and to Dr Jonathan Fay and Stephanie Forde for their comments and support.



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