

Appendices

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Appendix 1:

Medico-legal considerations

A1.1 Australia

While clinical management of melanoma is a major component of clinical care (see Introduction page xiii), it is the source of few medico-legal matters. This reflects well on the general clinical management of melanoma.

Figures obtained from a major medical defence organisation reveal that over a fifteen-year period (1990–2005) there were 47 civil and unlitigated claims. The majority of claims arose from failure to diagnose melanoma, particularly in cases which were brought to the clinician's attention (see Table A1).

The guidelines have evaluated evidence in chapters that outline diagnosis, including appropriate investigations and biopsy. There are also chapters on the individual forms of cutaneous melanoma, psychosocial aspects of the disease, and palliative care.

Paying attention to the evidence in these chapters when making decisions about the appropriate care program to follow should ensure optimal care and outcome. This approach should assist in meeting the highest level of medico-legal requirements.

Should a question arise that may lead to a legal claim, it is well to remember that apart from consideration of guidelines, appropriate professionalism reassures patients and should ensure appropriate information for patients through observing the following:

- courtesy
- discussing the program of investigation

Table A1 Claims – National Medical Defence Organisation (1990–2005)*

Reason for claim	Surgeons (8) [†]	Dermatologists (2)	GPs (44)
Total number of claims	7	2	38 [‡]
Failure to diagnose patient observed melanoma (delayed or missed)	3	1	32
Incorrect pathology report	2	1	5
Problems in surgical technique and treatment	2		3
Failure to inform patient of diagnosis			2
Failure to obtain pathology report			1
Delay in referral for definitive specialist treatment			1

* 47 claims – 32 litigated civil claims, 15 unlitigated matters

[†] No claims 2000–2005

[‡] Six general practitioners involved in one claim

- discussing diagnosis and options of care
- clear communication
- compassion
- understanding
- skilful care.

Should there be any mishaps in care, the initial response by the clinician to a patient question should involve the process of open disclosure, which is clearly delineated in the National Open Disclosure Standard.¹

Reference

1. National Open Disclosure Standard. Office of the Safety and Quality Council, Canberra website: www.safetyandquality.org

A1.2 New Zealand*

New Zealand has a unique medico-legal system. Of particular note is that, as a general rule, patients in New Zealand cannot sue for treatment injuries (including delayed or missed diagnosis). Assistance is available from the New Zealand Accident Compensation Corporation for patients who are injured as a result of being treated by a registered health professional. Details of this assistance and the claim process are available at www.acc.co.nz

Accountability for negligence by medical professionals is achieved through the Health and Disability Commissioner process and through professional registration authorities under the Health Practitioners Competence Assurance Act 2003. The Health Practitioners Competence Assurance Act 2003 provides mechanisms for the registration, assessment and discipline of all registered health practitioners in New Zealand. All complaints about patient care are handled in the first instance by the Health and Disability Commissioner.

Clinicians' legal duties are set out in the Code of Health and Disability Services Consumers' Rights (available at www.hdc.org.nz). The duties of particular relevance in the context of melanoma treatment are that services must be provided with reasonable care and skill, and comply with legal, professional, ethical and other relevant standards. Patients must be given all information that a reasonable patient, in his or her circumstances, would expect to receive. Clinicians need to communicate effectively with patients, in a form, language and manner that enables the consumer to understand the information provided. The Code also requires that clinicians openly disclose any unintended harm that occurs during treatment.

* Prepared in consultation with the Office of the Health and Disability Commissioner, New Zealand.

Appendix 2:

Guideline development process

In 2005, the Australian Cancer Network (ACN) agreed to facilitate a revision of the 1999 *National Health and Medical Research Council (NHMRC) Clinical Practice Guidelines for the Management of Melanoma* based upon advice from melanoma experts across Australia.

A multidisciplinary group comprising clinical experts, a consumer representative and an epidemiologist was convened to develop the guidelines. This group became known as the Guidelines Working Party. Experts from within or outside the Working Party were nominated to become chapter leaders or members of a chapter group. Further experts were added to the Working Party to lead a chapter group when additional topics were proposed at subsequent meetings. Members of the New Zealand Melanoma Reference Group also joined the Working party in 2006 and New Zealand melanoma experts were added as members of chapter groups.

In early Working Party meetings, it became apparent that the guideline development processes required by the NHMRC for national guidelines had changed somewhat since the last set of guidelines were developed. The processes had become much more scientifically rigorous and involved substantially more documentation of the development processes. In addition, several new questions were posed by clinicians in the Working Party that had not been addressed in the 1999 guidelines. In response, the Working Party decided to develop a new set of melanoma clinical practice guidelines incorporating the newer more rigorous processes and including additional topics, rather than just updating the previous guidelines.

The Australian Cancer Network (ACN) received a grant from the Cancer Institute NSW to assist in the development of the guidelines. The grant made it possible for the ACN to contract a consultancy group, the Sydney Health Projects Group at the University of Sydney, to assist in the development of project methods and to complete the searches for each chapter of the guidelines. Further assistance in the development of the guidelines was provided by staff of the NSW Melanoma Network and the New Zealand Guidelines Group. The whole process was monitored and assisted by a representative of the NHMRC Guidelines Assessment Register (GAR).

A brief overview of the methods undertaken to complete the melanoma guidelines is outlined in the next few pages. Further details of guideline development methods including the specific questions posed, search strategies, inclusion and exclusion criteria and literature appraisal templates for individual chapters are available on request from the Australian Cancer Network or the New Zealand Guidelines Group (www.nzgg.org.nz).

A2.1 Development of methods handbook

A large number of publications have been produced by NHMRC on the development of guidelines.^{1–8} These can be accessed at www.nhmrc.gov.au/publications. The methods consultants recommended development of a summary handbook for the chapter leaders and their expert working groups to outline the major steps and expectations for the development process.⁹ The handbook provides the definitions and protocols for developing research questions and search strategies, conducting searches and critical appraisal, summarising and assessing the relevant literature, and finally formulating the recommendations. The series of checklists and templates within the handbook were created to satisfy NHMRC legislative requirements and designated standards of quality and process. Copies of the handbook are available on request from the Australian Cancer Network or the New Zealand Guidelines Group (www.nzgg.org.nz).

A2.2 Steps in the preparation of NHMRC clinical practice guidelines

All the chapter leaders and their expert working group went through the following steps to complete their recommendations. They received considerable assistance for the first four steps of this process from methods consultants, but the great majority of leaders completed their own critical appraisal and assessment of the body of evidence.

1. Structure the research question
2. Develop a search strategy
3. Search the literature
4. Select and sort the literature
5. Critically appraise and summarise each selected article
6. Assess the body of evidence and formulate recommendations

A2.2.1 Structure the research question

All chapter leaders and their expert working group were asked to contribute key questions to be researched for this set of guidelines. Over 230 questions were submitted to the Working Party for consideration. The Working Party prioritised the questions for systematic review and decided upon a final list of about 70 questions.

All chapter leaders were asked to specify the purpose, scope and target audience for their questions and structure their question according to the PICO (populations, interventions, comparisons, outcomes) formula. Typically, chapter leaders achieved this and specification of a search strategy (see A2.2.2 below) during a 30–60 minute meeting with a methods consultant.

A2.2.2 Develop a search strategy

A search strategy based on the PICO was developed for each research question. A generic search strategy for ‘melanoma’ was used by most chapter groups, and additional limits were imposed with regard to patients, interventions, comparisons, outcomes or other relevant aspects. Keywords were devised for each search following

discussion with the chapter leader(s) during the PICO process. Additional sources for keywords and MeSH or subject terms were determined by searching other relevant evidence-based clinical guidelines, systematic review articles, and literature pertaining to each question. These terms were then combined into a single systematic search strategy applied to all included electronic databases. For quality control, keywords, MeSH or subject terms, and searches were checked by other members in the chapter group, the University of Sydney's medical librarian, and an NHMRC representative.

A2.2.3 Search the literature

NHMRC specifies that clinical practice guidelines be based on systematic identification and synthesis of the best available scientific evidence.¹ Literature searching was conducted systematically using electronic databases concluding mid-2006 to early-2007, such as:

- **Medline:** bibliographic references and abstracts to articles in a range of languages on topics such as clinical medical information, biomedicine, including the allied health fields, biological and physical sciences¹⁰ <http://www.library.usyd.edu.au/databases/info/medline1.html>
- **EMBASE:** major pharmacological and biomedical database indexing drug information from 4550 journals published in 70 countries¹⁰
- **PubMed:** database of bibliographic information, drawn primarily from MEDLINE and PreMEDLINE. In addition, for participating journals indexed 'selectively' for MEDLINE, PubMed includes all articles from that journal, not just those included in Medline¹⁰
- **Cinahl:** bibliographic references and abstracts to journal articles, book chapters, pamphlets, audiovisual materials, software, dissertations, critical paths, and research instruments on topics including nursing and allied health, biomedicine, consumer health, health sciences librarianship, behavioural sciences, management, and education¹⁰
- **Cochrane Library:** regularly updated collection of evidence-based medicine databases, including The Cochrane Database of Systematic Reviews¹⁰
- **AUSThealth:** contains nine databases, including the Australasian Medical Index, Australia's leading medical information resources, and DRUG, produced by the Alcohol and other Drugs Council of Australia – Australia's leading organisation representing the interests of the alcohol and other drugs field¹¹
- **Clinical Evidence:** compendium of evidence on the effects of clinical interventions updated every six months published by the BMJ Publishing Group¹⁰
- **Psychinfo:** Bibliographic references and abstracts to journal articles, book chapters, dissertations and technical reports on psychology; social, clinical, cognitive and neuropsychology; psychiatry, sociology, anthropology and education.¹⁰ Source material comes from a wide range of languages.

Search histories were dated, documented and are available on request from the Australian Cancer Network or the New Zealand Guidelines Group (www.nzgg.org.nz). The chapter leaders and the methods consultants were asked to provide details on the following:

- electronic databases searched
- terms used to search the databases
- search inclusion/exclusion criteria

- dates the search included
- abbreviations
- methods used to assess the quality of the search
- language
- study type.

In addition, chapter leaders and their expert groups were asked to hand search the reference lists at the end of their relevant articles to identify additional articles not identified through searches of the electronic databases. Finally, bi-annual meetings of the guidelines Working Party provided a forum for discussion and sharing of overlapping evidence, and/or discovery of unpublished literature and information from other key organisations.

A2.2.4 Select and sort the literature

The literature generated by the electronic database searches was appraised for relevance to each question. The following steps were taken to select and sort the literature:

1. review titles from the search
2. review abstracts
3. where uncertain about relevance, download full text of article
4. identify articles answering the questions and those useful for background information
5. obtain articles from the Internet, library or interlibrary loans
6. sort studies by type (e.g. interventions, prognosis, diagnosis)
7. sort studies by design (e.g. systematic review, randomised controlled trial, cohort, case control, case series, descriptive)
8. determine whether systematic reviews account for all preceding literature
9. prepare folders to file searches, background papers and reviewed articles for each question addressed
10. enter selected articles for review into the guideline master list
11. assess the quality of the search and the appraisal.

All articles emerging from this process as potentially relevant to a guidelines question were forwarded to the chapter leader for his/her consideration and for critical appraisal.

A2.2.5 Critical appraisal and summary

Relevant articles selected from the search were reviewed and summarised by the chapter leader. Each article was summarised in a template with headings such as the type of study, level of evidence, number and characteristics of patients, type of analysis, outcome measure and results. Each article was then critically appraised with respect to level of evidence, quality of evidence, size of the effect and relevance of the study, and documented in another template.

Details on the templates, rating systems, and criteria for the critical appraisal process, are outlined in the methods handbook⁹ available on request from the Australian Cancer Network or the New Zealand Guidelines Group (www.nzgg.org.nz).

Levels of evidence¹

Table A2		Designations of levels of evidence according to type of research question			
Level	Intervention	Diagnosis	Prognosis	Aetiology	Screening
I	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies
II	A randomised controlled trial	A study of test accuracy with: an independent, blinded comparison with a valid reference standard, among consecutive patients with a defined clinical presentation	A prospective cohort study	A prospective cohort study	A randomised controlled trial
III-1	A pseudo-randomised controlled trial (i.e. alternate allocation or some other method)	A study of test accuracy with: an independent, blinded comparison with a valid reference standard, among non-consecutive patients with a defined clinical presentation	All or none	All or none	A pseudo-randomised controlled trial (i.e. alternate allocation or some other method)
III-2	A comparative study with concurrent controls: <ul style="list-style-type: none"> • non-randomised, experimental trial • cohort study • case-control study • interrupted time series with a control group 	A comparison with reference standard that does not meet the criteria required for Level II and III-1 evidence	Analysis of prognostic factors amongst untreated control patients in a randomised controlled trial	A retrospective cohort study	A comparative study with concurrent controls: <ul style="list-style-type: none"> • non-randomised, experimental trial • cohort study • case-control study
III-3	A comparative study without concurrent controls: <ul style="list-style-type: none"> • historical control study • two or more single arm study • interrupted time series without a parallel control group 	Diagnostic case-control study	A retrospective cohort study	A case-control study	A comparative study without concurrent controls: <ul style="list-style-type: none"> • historical control study • two or more single arm study
IV	Case series with either post-test or pre-test/post-test outcomes	Study of diagnostic yield (no reference standard)	Case series, or cohort study of patients at different stages of disease	A cross-sectional study	Case series

Note: Explanatory notes for this table are outlined in the methods handbook⁹ available on request from the Australian Cancer Network or the New Zealand Guidelines Group.

A2.2.6 Assess the body of evidence and formulate recommendations

The body of literature was assessed by each chapter leader with respect to the volume of the evidence, its consistency, clinical impact, generalisability and applicability. These aspects were graded and documented in a template.

Following grading of the body of evidence, chapter leaders were asked to formulate a recommendation that related to the summarised body of evidence. This recommendation also had to be graded as follows:

Grading of recommendations	
Grade	Description
A	Body of evidence can be trusted to guide practice
B	Body of evidence can be trusted to guide practice in most situations
C	Body of evidence provides some support for recommendation(s) but care should be taken in its application ¹
D	Body of evidence is weak and recommendation must be applied with caution

A2.3 Writing the chapter

All the chapter leaders and their groups were asked to write their guidelines chapter using the following format:

- background
- review of the evidence
- evidence summary with levels of evidence and numbered references
- recommendation(s) and its grade
- references.

A2.4 Review of the chapters

The body of evidence and recommendations for each chapter were reviewed by the Working Party and final recommendations agreed by consensus.

A2.5 Public consultation

A complete draft of the guidelines was sent out for public consultation in Australia and New Zealand in October 2007. In Australia, the consultation process included soliciting public review of the document through advertisements in a range of newspapers. In New Zealand, the draft guideline was widely circulated to all individuals and organisations identified by the New Zealand Melanoma Reference Group as having a potential interest in the document. A large conference meeting was also organised for clinicians and other interested parties in February 2008 to outline the major recommendations in the guideline and to provide a forum for further discussion and debate.

All feedback received on the draft during the consultation period in Australia and New Zealand and from the conference meeting was reviewed by the Working Party and subsequent changes to the draft agreed by consensus.

A2.6 Dissemination and implementation

The Australian Cancer Network will lead in disseminating the guidelines in Australia and the New Zealand Guidelines Group will oversee the dissemination and implementation of the guidelines in New Zealand on behalf of the Ministry of Health. In both countries this will include a campaign to raise awareness of the new guidelines, with organised media coverage through multiple outlets and an official launch. Widespread dissemination will be achieved through distribution to relevant professional and other interested groups directly and through meetings, conferences, and other CME events. A significant effort will be undertaken to have the Guidelines be introduced to senior undergraduate medical students and to encourage the relevant learned Colleges, which are bi-national (surgeons, radiation oncologists and pathologists), to support the Guidelines and to foster integration of the Guidelines into hospital and community practice through resident and registrar educational activity.

The scope of implementation activities will depend on funding available. It is recognised that a planned approach is necessary to overcome specific barriers to implementation in particular settings and to identify appropriate incentives to encourage uptake of guideline recommendations. Implementation of the guideline will require a combination of effective strategies and may include further CME initiatives and interactive learning, the development and promotion of computer assisted decision aids and electronic decision support systems, and the creation of audit and other clinical tools.

References

1. National Health and Research Council. A guide to the development, evaluation and implementation of clinical practice guidelines. Commonwealth of Australia, 1999.
2. National Health and Research Council. How to review the evidence: Systematic identification and review of scientific literature. Commonwealth of Australia, 1999.
3. National Health and Research Council. How to present the evidence for consumers: Preparation of consumer publications. Commonwealth of Australia.
4. National Health and Research Council. How to prepare and present evidence-based information for consumers of health services: A literature review. Commonwealth of Australia, 1999.
5. National Health and Research Council. How to put evidence into practice: Implementation and dissemination strategies. Commonwealth of Australia, 2000.
6. National Health and Research Council. How to use the evidence: assessment and application of scientific evidence. Commonwealth of Australia, 2000.
7. National Health and Research Council. How to compare the costs and benefits: evaluation of the economic evidence. Commonwealth of Australia, 2001.
8. National Health and Research Council. Using socioeconomic evidence in clinical practice guidelines. Commonwealth of Australia, 2002.

9. Holt P, Frommer M. Development of Clinical Practice Guidelines for the management of Cutaneous Melanoma and Melanoma in special sites: Handbook for chapter leaders and expert working groups. Sydney Health Projects Group, University of Sydney, 2006.
10. University of Sydney Library, 2007 (Electronic Access Librarian: Lorraine Falconer).
11. Austhealth 2007. <http://www.informit.com.au/products_details_indexesComp.asp?CompilationID=AUSTHEALTH_OL&type=OL&ContainerID=indexproducts>

Appendix 3:

Working party membership and contributors to guidelines and public consultation submissions received

Management of Melanoma Guidelines Working Party

Professor John Thompson (Chair)
Surgical Oncologist – Sydney

Professor Bruce Armstrong
Epidemiologist – Sydney

Dr Andrew Barbour
Surgeon – Brisbane

Professor Ross Barnetson
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Ms Heather Beanland
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Dr Trevor Beer
Histopathologist – Perth

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A/Professor Bryan Burmeister
Radiation Oncologist – Brisbane

A/Professor Phyllis Butow
Psychologist – Sydney

Dr Katherine Clark
Palliative care specialist – Sydney

Dr Max Conway
Ophthalmologist – Sydney

A/Professor Brendon Coventry
Surgeon – Adelaide

A/Professor Diona Damian
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Ms Marianne Griffin
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Histopathologist – Perth

A/Professor Michael Henderson
Surgical Oncologist – Melbourne

Professor Richard Kefford
Medical Oncologist – Sydney

A/Professor John Kelly
Dermatologist – Melbourne

Clinical A/Professor Stephen Lee
Dermatologist – Sydney

Dr Graham Mann
Senior Medical Researcher – Sydney

Professor Rebecca Mason
Physiologist – Sydney

A/Professor Grant McArthur
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Dr Joseph Ohana
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Professor Ian Olver
Medical Oncologist – Sydney

Mr Michael Quinn
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Dr Maureen Rogers
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Medical Advisor, ACN/Convenor,
Working Party – Sydney

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Mrs Kerry Hocquard

Consumer perspective –
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Maori perspective, General Practitioner
– Auckland, New Zealand

Dr Ate Moala

Pacific perspective, General Practitioner
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General Practitioner – Auckland,
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**Chapter leaders and
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Introduction

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Prevention

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**Identification and management
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Classification of melanoma

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Lentigo maligna

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Treatment of primary melanoma

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Management of regional lymph nodes

Professor John Thompson*
Professor Bruce Barraclough AO
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Dr Marc Moncrieff
Dr Michael Sladden
Dr Mark Smithers

Management of locoregionally recurrent melanoma

A/Professor Graham Stevens*
Dr Shas Casala
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Adjuvant systemic therapy

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Psychosocial issues

A/Professor Phyllis Butow*

Palliative Care

Dr Mary Brooksbank*
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Dr Anne McLennan (NZ)

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Ocular melanoma

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Dr Trevor Beer*
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Emeritus Professor Tom Reeve AC CBE
Ms Lauren Haydu

Complementary and alternative medicine

Emeritus Professor Tom Reeve AC CBE*

Melanoma in specific populations in Australia

Clinical A/Professor Stephen Lee*
Dr Brian Wallace

Melanoma in Māori and melanoma in Pacific peoples in New Zealand

New Zealand Melanoma Reference Group

Appendix 1 – Medico-legal considerations: New Zealand

Ms Nicola Sladden, Chief Legal Advisor, HDC

Appendix 2 – Guidelines development process

Ms Shelly Acland-Goben
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** The Australian Cancer Network would also like to acknowledge Dr Mary Brooksbank and Dr Alison Evans for their input in the Multidisciplinary Care chapter.

Thank you to Ms Hester Gascoigne of Hester Gascoigne & Associates, Canberra for editing the draft document for public consultation.

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Draft ACN Clinical Practice Guidelines for the Management of Melanoma

Public consultation October 2007

Consultation submissions received

No.	Sender/Organisation	No.	Sender/Organisation
1	Ann Robertson Manager, Women's Health Services Royal Australian and New Zealand College of Obstetricians and Gynaecologists	9	Professor Bruce Armstrong AM Director of Research, Sydney Cancer Centre & Professor of Public Health and Medical Foundation Fellow The University of Sydney Level 6 Gloucester House Royal Prince Alfred Hospital Missenden Rd Camperdown NSW 2050
2	Associate Professor Bryan Burmeister Division of Cancer Services Princess Alexandra Hospital Ipswich Road Woolloongabba QLD 4102	10	Dr Michael Sladden Dermatology Dermatologist, Launceston Tasmania Hon Senior Lecturer Department of Medicine University of Tasmania
3	A/Professor Scott Menzies Melanoma Unit Royal Prince Alfred Hospital Missenden Road Camperdown NSW 2050	11	Adrian Knowles Cancer Society Auckland Division New Zealand
4	Professor John Kelly 746 Malvern Road Armadale VIC 3143	12	Amanda Oakley Waikato District Health Board New Zealand
5	Professor John Kelly 746 Malvern Road Armadale VIC 3143	13	Betsy Marshall Policy Advisor, Cancer Society of New Zealand New Zealand
6	Anne Buckley Medical Writer, New Zealand Guidelines Group PO Box 10 665, The Terrace, Wellington New Zealand	14	Chris Adams Hutt Valley District Health Board New Zealand
7	A/Professor Scott Menzies Melanoma Unit Royal Prince Alfred Hospital Missenden Road Camperdown NSW 2050	15	Christine Martin Northern DHB Support Agency Auckland District Health Board (ADHB), Waitemata DHB (WDHB) and Counties Manukau DHB (CMDHB) New Zealand
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17	Dr Fergus Oliver Dermatologist, Dermatopathologist New Zealand	29	Carla Saunders Medical and Scientific Unit The Cancer Council NSW 153 Dowling Street Woolloomooloo NSW 2011
18	Judith Galtry Cancer Society of New Zealand New Zealand	30	Dr Stephen Shumack Honorary Secretary The Australasian College of Dermatologists Suite 2A, Level 2, 9 Blaxland Road Rhodes NSW 2138
19	Steven Williams Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) New Zealand	31	Dr Peter Heenan Histopathologist Cutaneous Pathology 26 Leura Street Nedlands WA 6009
20	Dr Steven Lamb New Zealand Dermatological Society Incorporated New Zealand	32	Professor William H McCarthy AM Surgeon 1 Avon Street Glebe NSW 2037
21	Jo Anson Central Cancer Network New Zealand	33	A/Professor John Kelly Head, Victorian Melanoma Service The Alfred St Kilda Road Melbourne VIC 3004
22	Kara Hudson National Screening Advisory Committee New Zealand	34	A/Professor Scott Menzies Melanoma Unit Royal Prince Alfred Hospital Missenden Road Camperdown NSW 2050
23	KP Wong Middlemore Hospital New Zealand	35	Jennifer Beaulac Population Health Directorate Ministry of Health New Zealand
24	Marius Rademaker Dermatologist New Zealand	36	Dr Chris Boberg General Practitioner New Zealand
25	Mary Schumacher Hospice New Zealand New Zealand		
26	Nicola Sladden Chief Legal Advisor Health and Disability Commissioner's office (HDC) New Zealand		
27	Peter Hadden Ophthalmologist ADHB and Eye Institute		

Appendix 4:

Dermoscopy versus naked eye examination for the diagnosis of melanoma

A systematic review of statistical methods and results

See Chapter 5 *Clinical diagnosis* for the evidence developed in the chapter.

This extract is from a systematic review undertaken on dermoscopy compared with naked eye examination for melanoma diagnosis. The systematic review has subsequently been published: Vestergaard ME, Macaskill P, Holt PE, Menzies SW. Dermoscopy compared with naked eye examination for the diagnosis of primary melanoma: a meta-analysis of studies performed in a clinical setting. *Br J Dermatol*. 2008 Sep;159(3):669-76.

Inclusion criteria

The included level 2 diagnostic studies were those comparing diagnostic accuracy (sensitivity and specificity) of clinical examination with and without dermoscopy compared independent to a valid reference test (histopathologically diagnosis or diagnosis made by an expert in the field) on consecutive patients with a defined clinical presentation. All studies examined sensitivity and specificity for the diagnosis of melanoma except the randomised trial by Argenziano et al. which used as its end point all suspicious lesions identified by an expert. For this reason the meta-analysis was performed with and without this study (see below).

Statistical methods

Since a comparison of the diagnostic performance of two tests (eye only versus dermoscopy examination) was the major focus of the analysis, attention was restricted to 'paired' studies that directly compared the two tests using either a truly paired or randomised study design. Even though heterogeneity between studies is expected in underlying test performance because of differences in patient and/or design characteristics across studies, the test comparison should not be confounded by these factors because each study acts as its own control. Hence, the primary aim of the analysis was to assess the relative performance of the tests, rather than the diagnostic performance of each test separately.

Study specific estimates of sensitivity and specificity for the two tests were displayed in forest plots. The study specific estimates of sensitivity and specificity for each test were also represented in ROC space, with the two resulting points for each study joined by a line to highlight the pair of estimates for each study. The Hierarchical Summary

ROC (HSROC) method^{1,2} was used to estimate a summary ROC (SROC) curve for each test, and the relative accuracy of the two tests. The HSROC method provides a statistically rigorous approach because it takes appropriate account of both the within and between study variability in the estimates of sensitivity and specificity through the inclusion of random study effects that allow for heterogeneity in underlying test accuracy and test positivity rate (a proxy for test threshold) between studies. The 'pairing' of results for sensitivity (and also specificity) for the two tests within each study was also taken into account in the analysis. A more detailed technical description of the HSROC model is provided in the appendix.

Because the primary purpose of the analysis was to compare test performance, a covariate for test type (eye examination versus dermoscopy) was included in the HSROC model to test for differences in the shape of the SROC, accuracy and positivity rates of the two tests. The diagnostic odds ratio (DOR), which takes account of both sensitivity and specificity and the trade-off between them, is used as the measure of test accuracy in the model. As the DOR increases, the ability of the test to discriminate between 'diseased' and 'non-diseased' improves. Since the modelling is performed in terms of the log DOR, the comparison of the accuracy of the two tests is expressed as the relative DOR (RDOR) which is multiplicative.

The model parameters for the HSROC model were used to obtain an expected operating point (average sensitivity and specificity) for each test. The summary estimates of the DOR, sensitivity and specificity for each test will be affected by patient and study design factors of the included studies. Nevertheless, the comparison between the DOR's (i.e. the RDOR) for the two tests, and the comparison of the expected operating points of the two tests does provide a basis for assessing whether there is evidence of a difference in diagnostic performance between the tests because the analysis is restricted to 'paired' studies only.

Results

The forest plots shown in Figure 1 provide an overview of the study specific data and estimates of sensitivity and specificity for each of the nine studies included in the analysis. As can be seen from these plots, the study size varied markedly. For eye examination, sensitivity ranged from 0.43 to 1.0 compared with 0.79 to 1.0 for dermoscopy. Two studies (Carli⁴ and Carli⁶) had a sensitivity of 1.0 for both tests, however the denominators were extremely small. For the remaining seven studies, the observed sensitivity was higher for dermoscopy than for eye examination alone. Specificity ranged between 0 (Carli⁶) and 0.99 for eye examination, and between 0.69 and 0.99 for dermoscopy. For seven of the studies, the observed specificity for dermoscopy was higher than or equal to specificity for eye examination.

Figure 2 provides a plot of sensitivity against 1-specificity for each test and study. The paired points for each study serve to illustrate the within study differences in sensitivity and specificity for the two tests. HSROC analysis showed no evidence that the underlying shape of the SROC curve differed between the two tests, indicating

that the RDOR does not depend on threshold. The overall RDOR was statistically significant, indicating higher accuracy for dermoscopy compared with eye examination alone. The diagnostic odds ratio was estimated to be 15.6 times higher for dermoscopy than for eye examination (95% CI 2.9 to 83.7; $P=0.016$). This difference in accuracy of the tests is reflected in the separation between the estimated SROC curves shown in Figure 2. Summary estimates for both sensitivity and specificity were higher for dermoscopy than for eye examination, but the difference in specificity was not statistically significant (Table 1).

Removal from the analysis of two studies which had extreme values of sensitivity based on very small numbers of cases of disease (Carli⁴ and Carli⁶) and also a large difference in specificity favouring dermoscopy (Carli⁶), resulted in a relative diagnostic odds ratio of 9.0 (95% CI 1.5 to 54.6; $P=0.03$). The summary estimates for sensitivity were 0.69 and 0.87 for eye examination and dermoscopy respectively; and the corresponding estimates for specificity were 0.88 and 0.91. Removal of these two studies reduced the difference in expected specificity between the tests but had little effect on the expected sensitivities.

Since the randomised trial of Argenziano et al. in primary care had suspicious lesions requiring excision following expert evaluation as the endpoint, the overall HSROC analysis was repeated without this study. The omission of this study had a negligible effect on the overall model estimates.

Because estimates of sensitivity and specificity for some studies may be subject to verification bias, the positive predictive value (PPV) was also computed for each test within each study. This measure is less likely to be affected by verification bias as it computes the proportion of positive test results that are true positives. The PPV for eye examination ranged from 0.06 to 0.53 with a median of 0.36. The PPV for dermoscopy examination ranged from 0.07 to 0.81 with a median of 0.43. For seven of the nine studies, the PPV for dermoscopy was higher than the PPV for eye examination.

Tables and figures

Test	Sensitivity (95% CI)	Specificity (95% CI)
Eye examination	0.71 (0.59, 0.82)	0.81 (0.48, 0.95)
Dermoscopy examination	0.90 (0.80, 0.95) $P=0.002$	0.90 (0.57, 0.98) $P=0.18$

Table 1: Summary estimates of sensitivity and specificity based on HSROC model

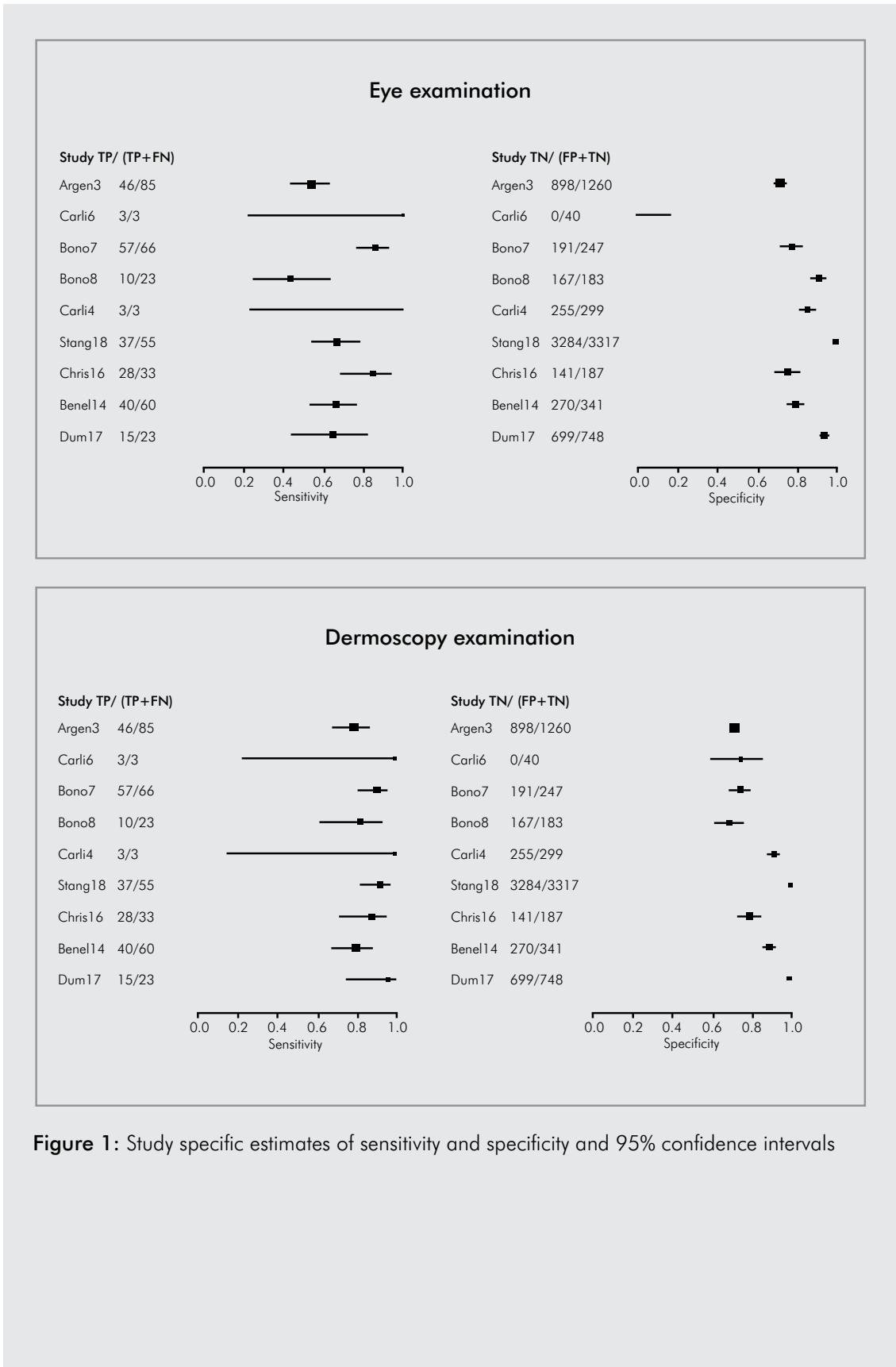


Figure 1: Study specific estimates of sensitivity and specificity and 95% confidence intervals

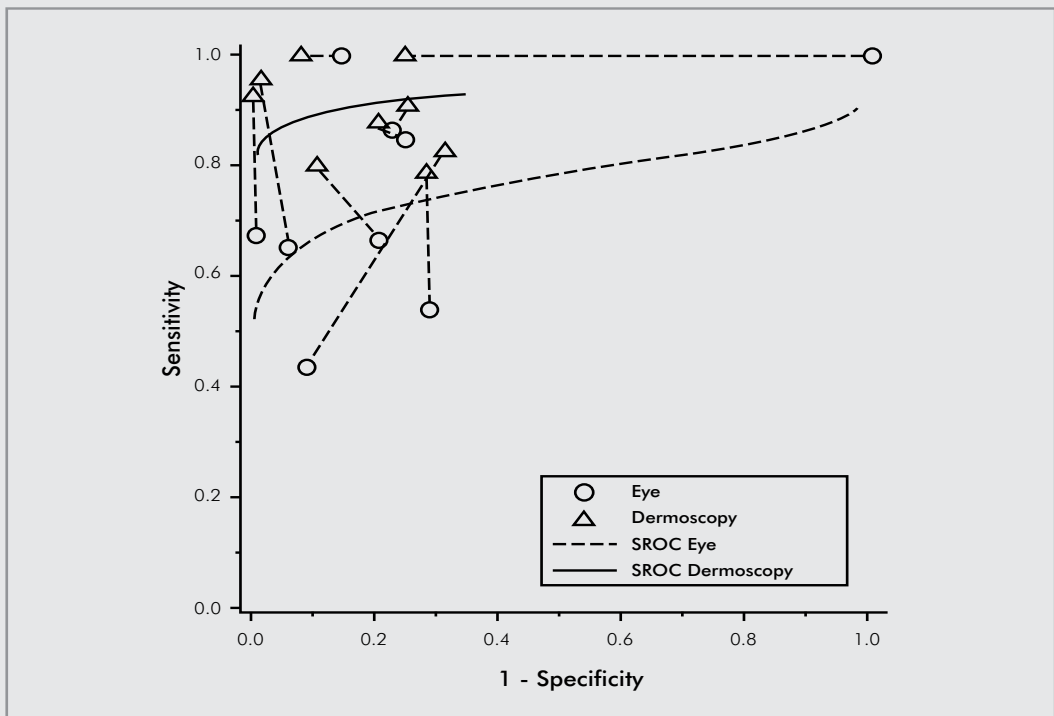


Figure 2: Plot of sensitivity against 1-specificity for each study and each test with the SROC for each test superimposed. (Note: The two estimates for each study are joined by a line.)

Appendix

Heterogeneity in sensitivity and specificity across studies is common, and hence summary ROC analysis is the appropriate method of analysis for the meta-analysis of diagnostic accuracy studies. The expected trade-off between sensitivity and specificity within studies also means that separate pooling of sensitivity is not recommended. For these reasons, summary ROC analysis is the recommended method of analysis in the Cochrane draft handbook for diagnostic reviews.

The HSROC model used in this analysis takes account of the ‘coupling’ of sensitivity and specificity within studies as well as the within and between study variability in these measures of test accuracy. It is a more up-to-date and statistically more rigorous approach than the commonly used method of Moses et al.³

HSROC model

The HSROC model is a two-level (multi-level) model that focuses on the estimation of a summary ROC curve. At the first level, the within study sampling error is taken into account by assuming a binomial error distribution for the sensitivity and 1-specificity for each study. Each study provides an estimate of test accuracy (log diagnostic odds ratio) and a proxy for threshold which are both taken to be random effects that follow a normal distribution at level two.

Level 1

For each study ($i, i = 1, \dots, k$) the number testing positive (y_{ij}) for both the diseased ($j=1$) and non-diseased ($j=2$) groups is assumed to follow a binomial distribution $B(\pi_{ij}, n_{ij})$, where π_{ij} represents the probability of a positive test result in group j , and n_{ij} represents the number of subjects in group j). The model takes the form $\text{logit}(\pi_{ij}) = (0_i + \alpha_i \text{dis}_{ij}) \exp(-\beta \text{dis}_{ij})$ where dis_{ij} is coded as -0.5 for the non-diseased and 0.5 for the diseased; θ_i are random effects for test threshold; α_i are random effects for accuracy for each study; and β is a fixed effect for dependence between accuracy and threshold.

Level 2

The θ_i and α_i are assumed to be normally distributed random effects, and the two distributions of random effects are assumed to be uncorrelated.

Test accuracy, threshold and the dependence between them (shape of the SROC) can be modeled as a function of study level covariates (e.g. test type) to assess whether test performance is associated with the covariate(s). The SAS procedure PROC NLMIXED can be used to identify the model that provides the best fit.² The parameter estimates of the final model are used to derive the SROC curve(s), expected operating point(s) and corresponding 95% confidence intervals.² In this analysis, the final model also included random study effects for the relative accuracy of the tests.

It is important to note that the HSROC model does not take into account the relative 'cost' of a false positive or a false negative. The purpose here is to assess the relative accuracy of the tests in terms of their ability to discriminate between 'diseased' and 'non-diseased' individuals. The results of the HSROC analysis can be used in conjunction with estimates of prevalence, costs etc to address such issues. However, this is beyond the scope of the analysis presented here.

Statistical References

1. Rutter C. and Gatsonis C. A hierarchical regression approach to meta-analysis of diagnostic test accuracy evaluations. *Statistics in Medicine*, 2001; 20: 2865-2884.
2. Macaskill P. Empirical Bayes estimates generated in a hierarchical summary ROC analysis agreed closely with those of a full Bayesian analysis. *J Clin Epidemiol.* 2004 Sep;57(9):925-32.
3. Moses LE, Shapiro D, Littenberg B. Combining independent studies of a diagnostic test into a summary ROC curve: data-analytic approaches and some additional considerations. *Stat Med* 1993;12:1293–316.

Dermoscopy Study References

- Argenziano, G. et al (2006). Dermoscopy improves the accuracy of primary care physicians to triage lesions suggestive of skin cancer. *J Clin Oncol* 24(12):1877–82.
- Carli, P. et al (2004) denoted as Carli4. Addition of dermoscopy to conventional naked-eye examination in melanoma detection: a randomized study. *Journal of the American Academy of Dermatology* 50(5): 683–689.

Carli, P. et al (2003) denoted as Carli6. The problem of false-positive diagnosis in the melanoma screening: the impact of dermoscopy. *Melanoma Res* 13(2): 179–82.

Bono, A. et al (2002) denoted as Bono7. Melanoma detection. A prospective study comparing diagnosis with the naked eye, dermoscopy and telespectrophotometry. *Dermatology* 205(4): 362–366.

Bono, A. et al (2006) denoted as Bono8. Micro-melanoma detection: a clinical study on 206 consecutive cases of pigmented skin lesions with a diameter ≤ 3 mm. *Br J Dermatol* Sep;155(3):570–3.

Benelli, C. et al (1999). The dermoscopic versus the clinical diagnosis of melanoma. *Eur J Dermatol*. 1999 Sep;9(6):470–6.

Christofolini, M. et al (1994). Dermoscopy: usefulness in the differential diagnosis of cutaneous pigmented lesions. *Melanoma Res*. 1994 Dec;4(6):391–4.

Dummer, W. et al (1993). Videomicroscopy in differential diagnosis of skin tumors and secondary prevention of malignant melanoma. *Hautarzt*. 1993 Dec;44(12):772–6. German.

Stanganelli, I. et al (2000). A cancer-registry-assisted evaluation of the accuracy of digital epiluminescence microscopy associated with clinical examination of the pigmented skin lesions. *Dermatology* 200:11–16.

Appendix 5: Recommended terminology and synonyms for cutaneous melanoma

Recommended terminology	Synonyms
Melanoma of common type	
Melanoma, <i>in situ</i>	Lentigo maligna (Hutchinson's melanocytic freckle) Superficial spreading melanoma <i>in situ</i> Acral lentiginous melanoma <i>in situ</i>
Melanoma, invasive	Lentigo maligna melanoma Superficial spreading melanoma Acral lentiginous melanoma Nodular melanoma Unclassified melanoma
Uncommon Variants	
Desmoplastic melanoma	
Others (controversial and provisional)	
Malignant blue naevus (melanoma resembling or arising in a blue naevus)	
Melanoma in congenital naevus	
Minimal deviation (naevoid) melanoma	
Animal type melanoma (pigmented epithelioid melanocytoma)	
Primary dermal melanoma	

Appendix 6:

New Zealand palliative care definition

The following is reproduced from: Subcommittee, NZ Cancer Treatment Working Party. 26 February 2007.

New Zealand Palliative Care: A Working Definition

1. Preamble

The NZ Palliative Care Strategy (2001) aims to set in place a systematic and informed approach to the provision and funding of palliative care services. Furthermore, any approach must address inequalities in palliative care. Current inequalities include access for Māori, Pacific peoples, isolated communities, children, the very old, those with non malignant disease, as well as those with special needs: asylum seekers/refugees, people in prison, and those with mental illness.

Fundamental to the strategy's success will be clarity around palliative care definitions. Definitions form the basis upon which a comprehensive, cohesive and effective palliative care service can be built and sustained. They help clarify core service components, elucidate structure, and promote understanding. They are also key components for national palliative care service specifications.

As a starting point for defining palliative care in a NZ context we have used the 2002 WHO palliative care definitions:

Palliative care: World Health Organization Definition, 2002

For Adults:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patients' care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated

- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

For Children:

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows (the principles also apply to other paediatric chronic disorders):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- Health providers must evaluate and alleviate a child's physical, psychological and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- It can be provided in tertiary care facilities, in community health centres and even in children's homes

In applying the WHO definitions, New Zealand also needs to take into account the following:

1. The fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection. In addition, we must acknowledge and include He Korowai Oranga (the Māori Health Strategy (2002)). Furthermore, acknowledgement of a holistic Māori philosophy/model, such as Te Whare Tapa Whā (four sided house) towards health/wellbeing is appropriate when applied to palliative care: Te Taha Tinana (physical health), Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health) and Te Taha Whānau (family health).
2. Palliative care continues to evolve. Thus definitions need to be flexible enough to adapt to changes in society, disease and illness, and individual and society's expectations. Palliative care recognises and respects the rights of patients as detailed in the Code of Health and Disability Services Consumers' Rights.
3. Generalist Palliative Care will be available throughout the course of a life-limiting illness, with specialist palliative care provided on the basis of assessed need, rather than simply diagnosis or prognosis. Palliative care will also be available wherever the patient is – be that home, hospital, residential care, or hospice. Palliative care is centred on the patient and family / whānau. The level of palliative care support required for any individual, family or whānau is dynamic and varies during the course of illness (and into bereavement).

4. Palliative care services will acknowledge the diverse cultural beliefs, values and practices of patients and their families or whānau in contemporary New Zealand society.
5. Palliative care is best delivered through an integrated approach to care that recognises the roles and responsibilities of both palliative care generalists and specialists, in meeting palliative care need. This integrated model or framework of care delivery is essential for effective palliative care provision.
6. The patient's primary care team will continue to provide continuity of care through illness. Depending on need, the involvement of specialist palliative care may be episodic or continuous.
7. In the case of children and young people, palliative care will also be available on the basis of assessed need. Specialist palliative care will be provided in collaboration with formally trained or experienced paediatric healthcare professionals either community (eg GP, district nurse) or hospital based. In New Zealand, home is the preferred and usual location for palliative care for children and young people. It is recognised, however, that some children and young people spend long periods of time in tertiary hospitals far from the primary care team.

2. In detail

Generalist palliative care is palliative care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. It is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Some of the generalist providers, e.g. general practice teams, will have ongoing contact with a family throughout and following illness. Others, such as district nurses or ward nurses will have episodic contact, depending on the needs of the patient and family.

Providers of generalist palliative care will have defined links with (a) specialist palliative care team(s) for the purposes of support and advice or in order to refer patients with complex needs. They will also have access to palliative care education to support their practice.

Specialist palliative care is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.

Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care will be provided through accredited services (or organisations) that work exclusively in palliative care and meet specific palliative care standards as they are developed nationally. Specialist palliative care practice builds on the palliative

care provided by generalist providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement. Specialist palliative care provision works in two ways:

1. Directly – to provide direct management and support of patients and families/whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need.

Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.

2. Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the generalist provision of palliative care provision.

Generalist/Specialist Integration

Generalist and specialist services need to be part of an integrated framework of care provision which may be facilitated through local and regional networks, with defined formal linkages to key services including community primary care, local acute hospitals, regional cancer centres, and other regional palliative providers.

- Depending on the complexity of palliative care need, smaller specialist palliative care services will at times require input from a more comprehensive service with greater specialist resources which may be geographically distant. This must be readily available through defined linkages and processes.

Therefore, the New Zealand definition of Palliative Care is:

Care for people of all ages with a life-limiting illness which aims to:

1. **optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.**
2. **support the individual's family, whānau, and other caregivers where needed, through the illness and after death.**

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be.

It should be provided by all health care professionals, supported where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.

