APPENDICES
APPENDIX 1 GUIDELINE DEVELOPMENT PROCESS

After the Cancer Strategies Group ranked lymphoma as a major cancer in Australia, the Australian Cancer Network (ACN) was approached to develop clinical practice guidelines for the management of lymphoma. Originally, the guidelines were designated for non-Hodgkin lymphoma, but the underlying complexity of the disease spectrum led to the redirection of the guidelines to lymphoma in its broad aspects, with the exception of multiple myeloma and chronic lymphocytic leukaemia.

Working parties were established to address the diagnostic and clinical aspects of the disease complex, but after initial meetings of each group, it was decided that both sets of guidelines would be published in one volume and that the chair of each group would sit on both working parties. The chair of the clinical group assumed overall chairing responsibilities.

The guidelines have been developed by working parties of the ACN and as far as possible, follow the National Health and Medical Research Council (NHMRC) guide to the development, implementation, and evaluation of clinical practice guidelines.¹ The document being directed towards best practice.

The Working Parties (see Appendix 2), under the chair and guidance of Professor Richard Fox and Dr David Ellis, coordinated development of the guidelines.

Lymphoma represents a protean complex of disease presentations and so may present diagnosis and treatment challenges to a wide range of medical professionals. Diagnosis, management and cost of treatment were frequently seen as moving targets during the development of the guidelines. The Working Parties were developed on a representational and skills basis from royal colleges, specialty groups, and consumer advocates.

Purpose, scope and development of guidelines

Non-Hodgkin lymphoma is an increasingly diagnosed malignancy, with a rising death rate over the decade 1990–2000.² Its incidence places it as the sixth most common cancer in Australia. It represents 4.1% of all cancers and 4.5% of cancer deaths.

The Working Party aimed to review the available literature and provide a template for reducing variability in treatment where appropriate, and for management to include the latest products resulting from pharmacological and biotechnological activity. The document is being presented in a form that can be readily read and used by doctors and other health professionals.

The complexity and extent of the field determined that multiple myeloma and chronic lymphocytic leukaemia would not be addressed in these guidelines.

As the general practitioner is usually the first medical contact for patients with these diseases, a special document will be developed to assist general practitioners in determining the appropriate clinical steps and referral for patients with lymphoma.

A document to assist consumers in decision-making will also be developed when the guidelines are endorsed. The Lymphoma Guidelines Working Party has had excellent input from its consumer representative.

Special study

The development of the guidelines stemmed from a meeting of a small group of interested people at the office of Professor Robert Burton (then CEO, Anti-Cancer Council of Victoria) on 30 March 2001.
The meeting concluded the development of guidelines was desirable, given lymphoma is the sixth most common cancer, it consumes high levels of resources involving a range of treatments, and the strong interest of the National Health Priority Action Council (NHPAC) Cancer Strategies Group.

The inaugural meeting of the Clinical Management Group took place in Melbourne on 25 July 2001. The Chair of the Diagnostic Working Party was present.

The terms of reference were:

- To develop evidence-based guidelines that will assist in the clinical diagnosis and management of lymphoma.
- To provide a better level of understanding through education to all involved in the care of patients with lymphoma.
- To be helpful in promoting standardisation, completeness, clarity and openness of pathological reporting.
- To improve clinical care and subsequent outcomes.
- To promulgate clear and open reporting of diagnosis.
- To ensure that the resulting guidelines are portable — that is, pocket-sized, with clinical and diagnostic in one volume — and user friendly, with complexity reduced where possible.

The guidelines were developed on the basis that they would provide a framework within which the clinician would be able to apply clinical judgement and discuss individual patient needs. Guidelines should provide a sufficiently flexible atmosphere so that consumers can be informed of the risks and benefits that may accrue from recommended interventions. It was understood that some variations would result from reasonable differences that may result from different clinical presentations and patients’ perceptions, preferences and needs.

The guidelines are based on the principles that underpin the NHMRC’s recommendations for the guideline development:

- a focus on the improvement of patient outcomes
- a basis in the best available scientific evidence
- inclusion of statements concerning the strength of the recommendations
- the adoption of a multidisciplinary approach that involves all stakeholders, including consumers.

**Process employed**

The Working Party approached the development of guidelines by setting itself five essential tasks:

1. Identification of the known clinical problems and areas of uncertainty in each of the disciplines involved in lymphoma treatment.

2. Collection and review of scientific evidence, including meta-analyses, to identify the best and most appropriate practice for the various interventions in lymphoma treatment.

3. Collaboration of appropriate subgroups to review and present special issues for consideration by the full Working Group.

4. Development of a glossary of technical terms in relation to lymphoma, for incorporation in the practice guidelines.
A review and revision process following public consultation as required by NHMRC.

The Working Party received contributions from across Australia to help it in its task. It held regular face-to-face meetings, primarily to identify the scope of the guidelines and to review subgroup activity (see Table A1). The final editing of the document before it was submitted to NHMRC was undertaken by the Chairs of the Working Parties, with frequent electronic and telephone advice from the members.

Table A1 Schedule of Working Party meetings

<table>
<thead>
<tr>
<th>Date</th>
<th>Present</th>
<th>Location</th>
<th>Type of meeting</th>
</tr>
</thead>
<tbody>
<tr>
<td>30 March 2001</td>
<td>Prof S R Burton, R Fox, A Coates, T Reeve and Dr D Ellis, Apology: Dr Max Wolf</td>
<td>CEO’s office ACCV, Melbourne</td>
<td>Executive meeting</td>
</tr>
<tr>
<td>25 July 2001</td>
<td>Lymphoma Management Group</td>
<td>Ansett Golden Wing Conference Room, Melbourne Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>1 August 2001</td>
<td>Lymphoma Diagnosis Group</td>
<td>QANTAS Club Conference Rooms, Adelaide Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>13 March 2002</td>
<td>Lymphoma Management Group</td>
<td>QANTAS CLUB Conference Room, Melbourne Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>15 March 2002</td>
<td>Lymphoma Diagnosis Group</td>
<td>QANTAS Club Conference Rooms, Melbourne Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>8 July 2002</td>
<td>Lymphoma Management Group</td>
<td>QANTAS CLUB Conference Room, Melbourne Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>8 November 2002</td>
<td>Lymphoma Management Group</td>
<td>QANTAS CLUB Conference Room, Melbourne Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>13 March 2003</td>
<td>Lymphoma Management Group</td>
<td>QANTAS CLUB Conference Room, Melbourne Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>14 March 2003</td>
<td>Lymphoma Diagnosis Group</td>
<td>QANTAS Club Conference Rooms, Sydney Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>2 May 2003</td>
<td>Profs R Fox (Chairman), K Bradstock, T Reeve and Drs D Ellis and J Seymour</td>
<td>TCCA Conference Room, Sydney</td>
<td>Executive Group meeting</td>
</tr>
<tr>
<td>7 November 2003</td>
<td>Lymphoma Management Group</td>
<td>QANTAS CLUB Conference Room, Sydney Airport</td>
<td>Working Group meeting</td>
</tr>
<tr>
<td>15 March 2004</td>
<td>Lymphoma Management and Diagnosis Groups included in 200 delegates</td>
<td>Stamford Sydney Airport Hotel</td>
<td>Consensus meeting</td>
</tr>
</tbody>
</table>

Since the consensus meeting in March 2004, chapter authors have updated their manuscripts and each chapter has been reviewed and edited by the Chairs at a series of meetings.
**Task 1**

It was established that the guidelines should focus on recommendations that would improve the diagnosis and outcomes of patients with lymphoma, and that they would have a strong clinical emphasis.

The Working Party considered it was vital to distil the best elements of clinical management. To this end, it consulted widely with clinicians and involved consumers to ensure that the guidelines would gain broad acceptance. The complexity of the disease has led to a prolonged development process.

**Task 2**

Evidence was obtained through various avenues, including PubMed, Medline, CancerLit, Cochrane reviews and personal databases. Search questions identified evidence, which was evaluated by the Working Party before being included in the manuscript. The reviewed literature was analysed and the resulting information incorporated in the guidelines. The Working Party fully evaluated each of the papers offered by its members in support of arguments, and agreed as to whether the paper was to be either incorporated as a reference or rejected if it did not meet the criteria applied to the clinical area in question.

In many cases, decisions had to be made on the basis of low-level published evidence, and as a result, a number of recommendations are based on level IV evidence. For those recommendations for which level I–IV evidence was lacking, conclusions were drawn from the considered opinion of clinical experts. The processes used in developing these guidelines were designed to ensure that, as far as possible, the recommendations reflect the best evidence available to those involved in the treatment of lymphoma in Australia.

The Working Party decided that it was important to give a clear indication as to the strength of the evidence for guidelines and key statements, and to provide references where appropriate.

Relevant data that lacked sufficient strength to be designated as guidelines were listed as key points, or included in discussion in the text.

**Designation of levels of evidence**

I  Evidence obtained from a systematic review of all relevant randomised controlled trials.

II  Evidence obtained from at least one properly designed randomised controlled trial.

III-1 Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method).

III-2 Evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group.

III-3 Evidence obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group.

IV  Evidence obtained from case series, either post-test or pre-test and post-test. In effect we listed all level III as III, regardless of category.

These levels of evidence have been adapted from the United States Preventive Services Task Force guide to clinical preventive services and the NHMRC guide to the development, implementation, and evaluation of clinical practice guidelines.
Task 3

During the initial development of these guidelines, the Working Party established clinical assessment subgroups. The leaders of these subgroups were members of one of the primary Working Parties and identified diagnostic or clinical problems in their respective fields (see Appendix 2). They consulted more widely before submitting manuscripts to the appropriate Working Party for consideration. This process allowed the diagnostic or clinical subgroup’s contributions to be included in the relevant chapters in the guidelines.

Task 4

A glossary of terms used in the guideline document has been developed. It is expected that this will be expanded during public review.

Task 5

When the guidelines were in an advanced draft form, they were advertised as available for public comment. They were available on the ACN website and in hard copy from the ACN.

At a public meeting in Sydney on 15 March 2004, overseas and local speakers spoke about components of the guidelines.

The special matters raised at this meeting have led to further review of the guideline manuscript before its submission to public review and to a further planned review by a special overview committee.

When the process is complete, the guidelines will be submitted for evaluation to the Health Advisory Committee of NHMRC.

Target audience

The guidelines were developed to provide clinicians and treating doctors, nurses, allied health professionals and consumers with recommendations for the optimal care of people with lymphoma.

Costing issues

While the guidelines address costing matters, these are complex and the context is changing rapidly. Treatments are developing with the emergence of new knowledge, and costs of treatment are substantial. Laboratories are getting larger, and costs of diagnosis are increasing with the rapid expansion of biotechnology. It is suggested that this area be targeted for continuing research.

Implementation and dissemination

The ACN is responsible for disseminating, implementing, evaluating and updating the guidelines. The processes to evaluate and update them will be in accordance with NHMRC guidelines. The guidelines will also feature strongly in the accreditation and credentialing activity of the ACN.

On 15 March 2004, ACN and The Cancer Council Australia held a meeting in Sydney — “Improving the management of lymphoma”. The draft guidelines provided the foundation for discussion, and further amendments were made. The meeting provided a sound basis for a public review, dissemination and implementation. NHMRC endorsement of the guidelines will be sought.
The guidelines will have been promoted at a national seminar and a state seminar on lymphoma management, and subsequently through presentations at relevant professional meetings and conferences and submissions to professional journals.4

The initial print run of the guidelines will be offered to relevant professional groups. Copies will also be made available to allied health organisations, state and territory health authorities, professional colleges and associations, public policy makers, health economists and professional journals.

The draft guidelines have been available on the internet at the ACN website. It is anticipated that the approved guidelines will be available on NHMRC and ACN websites.

The guidelines will be advertised through the ACN quarterly newsletter, ‘Wongi Yabber’, which is distributed to professional colleges, ACN stakeholders and interest groups, including consumers, and also has a limited overseas circulation.

Consultation and feedback

As stakeholders’ acceptance of the guidelines is a critical first step towards their implementation, consultation is an essential part of the implementation process. ACN is developing an accreditation and credentialing program. Working Parties have been established to carry these processes and implementation activities forward.

Evaluation and updating

An essential part of the development and implementation of guidelines is to evaluate their effectiveness. An evaluation strategy will be drafted at the implementation stage and will include the collection of data to determine the impact of the guidelines on clinician behaviour and patient health outcomes.

The guidelines reflect the best available knowledge at the time of their publication. However, as new evidence emerges from systematic reviews, they will require regular revision in order to maintain validity. The ACN proposes to investigate the most cost-effective means of undertaking this.

References

1. National Health and Medical Research Council (NHMRC) guide to the development, implementation, and evaluation of clinical practice guidelines. AGPS Canberra 1998.
APPENDIX 2 MEMBERSHIP OF THE AUSTRALIAN CANCER NETWORK DIAGNOSIS AND MANAGEMENT OF LYMPHOMA GUIDELINE WORKING PARTY AND PUBLIC CONSULTATION SUBMISSIONS RECEIVED

Management Group

Dr Peter Bardy, Haematologist
A/ Professor Ken Bradstock, Haematologist
Mr Jeffrey Deslandes, Consumer
Dr David Ellis, Anatomical Pathologist
Professor Richard Fox (Chair), Medical Oncologist
Dr Andrew Grulich, Epidemiologist
Dr David Ma, Haematologist
Dr Michael MacManus, Radiotherapist
Dr Paula Marlton, Haematologist
Professor Robert Thomas, Surgical Oncologist
Dr John Seymour, Haematologist
Dr Max Wolf, Haematologist

Diagnostic Group

Dr Michael Eaton, Surgical Oncologist
Dr David Ellis (Chair), Anatomical Pathologist
Professor Richard Fox, Medical Oncologist
A/ Prof Surender Juneja, Haematologist
Prof Anthony SY Leong, Anatomical Pathologist
Dr John R Miliauskas, Anatomical Pathologist
Dr Debra Norris, Anatomical Pathologist
Professor Dominic Spagnolo, Anatomical Pathologist
Dr Jennifer Turner, Anatomical Pathologist
Emeritus Professor Tom Reeve, Convenor/ACN Senior Medical Advisor
Ms Christine Vuletich, Manuscript Coordinator/ACN Executive Assistant

The Australian Cancer Network would also like to gratefully acknowledge the assistance of the following:

Dr Steve Austin
A/Professor Michael Barton
Ms Janet Bell
Dr Debra Bresnan
A/Professor Lynda Campbell
Dr Paul Cannell
Dr Lawrence Cher
Dr Luciano Dalla Pozza
Professor Maurice Eisenbruch
Professor Wendy Erber
Ms Helen Francombe
Dr Devinder Gill
A/Professor Afaf Girgis
Dr David Goldstein
Dr Andrew Grigg
Dr Marion Haas
Dr Mark Hertzberg
Dr Rodney Hicks
Dr Philip James
Dr David Johnson
Dr Rajiv Khanna
Mr Bruce Mann
Dr Emma McMahon
Dr Joseph McKendrick
Dr Sam Milliken
Professor Denis Moss
Professor Peter O’Brien
Dr Alex Pitman
Dr Deborah Porter
Dr Gary Pratt
Professor Miles Prince
Dr Gail Ryan
Dr Kim Rooney
Professor Mark Rosenthal
Ms Emma Sayers
Dr Carole Smith
Ms Flora Tzelepis
Dr Claire Vajdic
Ms Rosalie Viney
Dr Andrew Wirth
A/Professor Graham Young
Ms Siggi Zapart

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

**Review Panel:**

Professor Robert Burton (Chair) Oncologist/Epidemiologist
Dr Peter Bardy Haematologist
Professor Bruce Barraclough Medical Director, ACN / Surgeon
Professor Michael Barton Radiation Oncologist
Mr Jeffrey Deslandes Consumer
Dr David Ellis Chair, Diagnosis Group Lymphoma Guidelines / Pathologist

Professor Richard Fox Chair, Management Lymphoma Guidelines Group / Medical Oncologist
Professor Michael Green Medical Oncologist
Emeritus Professor Tom Reeve Senior Medical Advisor, ACN / Surgeon
Ms Christine Vuletich Executive Assistant, ACN Secretariat
## 1. Consultation Submissions Received

<table>
<thead>
<tr>
<th>Submission No.</th>
<th>Sender/Organisation</th>
</tr>
</thead>
</table>
| 1              | Assoc. Professor David Johnson  
Director of Renal Medicine  
Princess Alexandra Hospital  
Woolloongabba QLD         |
| 2              | Dr Sam Milliken  
St Vincent’s Hospital  
SYDNEY                  |
| 3              | Dr Catherine Cole  
Paediatric and Adolescent Haematologist/Oncologist  
Princess Margaret Hospital for Children  
PERTH                    |
| 4              | Ms Donna Collett  
Business Unit Manager – Haematology / Oncology  
AMGEN Australia Pty Ltd  
North Ryde NSW           |
| 5              | Ms Karin Adams  
Medical Manager – Mab Thera  
Roche Products Pty Limited  
and  
Ms Jennifer Michael  
Mab Thera – Associate Product Manager  
Roche Products Pty Limited  
Dee Why NSW               |
| 6              | Dr Jeff Dunn  
Executive Director  
Queensland Cancer Fund  
Fortitude Valley QLD     |
| 7              | Ms Annette Kerr  
Pharmacoeconomics Manager  
Amgen Australia Pty Ltd  
North Ryde NSW            |
| 8              | Ms Jennifer Michael  
Mab Thera – Associate Product Manager  
Roche Products Pty Limited  
North Ryde NSW             |
## 2. Additional Comments

<table>
<thead>
<tr>
<th>No.</th>
<th>Sender</th>
</tr>
</thead>
</table>
| 1   | Dr Marion Haas  
    Deputy Director  
    CHERE  
    Level 2, Building 5, Block D  
    1-59 Quay St  
    Haymarket NSW 2000  
    Email: marion.haas@chere.uts.edu.au |
| 2   | Dr Euan Walpole  
    Medical Oncology Department  
    Princess Alexandra Hospital  
    Ipswich Road  
    WOOLLOONGABBA QLD 4102  
    Email: Euan_Walpole@health.qld.gov.au |
# APPENDIX 3 ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC</td>
<td>activated B-cell-like</td>
</tr>
<tr>
<td>ABVD</td>
<td>doxorubicin, bleomycin, vinblastine and decarbazine</td>
</tr>
<tr>
<td>ACVBP</td>
<td>doxorubicin, cyclophosphamide, vindesine, bleomycin, prednisone (chemotherapy regimen)</td>
</tr>
<tr>
<td>AE</td>
<td>adverse events</td>
</tr>
<tr>
<td>AgR</td>
<td>antigen receptor</td>
</tr>
<tr>
<td>ALCL</td>
<td>anaplastic large-cell lymphoma</td>
</tr>
<tr>
<td>ALK</td>
<td>anaplastic lymphoma kinase</td>
</tr>
<tr>
<td>ALL</td>
<td>acute lymphoblastic lymphoma</td>
</tr>
<tr>
<td>ALLG</td>
<td>Australasian Leukaemia and Lymphoma Group</td>
</tr>
<tr>
<td>ANLL</td>
<td>acute non-lymphoblastic leukaemia</td>
</tr>
<tr>
<td>ASCO</td>
<td>Senior Adult Care Task Force of the National Comprehensive Cancer Network (NCCN)</td>
</tr>
<tr>
<td>ASCT</td>
<td>autologous stem cell transplantation</td>
</tr>
<tr>
<td>ATG</td>
<td>antithymocyte globulin</td>
</tr>
<tr>
<td>ATL</td>
<td>adult T-cell leukemia/lymphoma</td>
</tr>
<tr>
<td>auto-PBSCT</td>
<td>peripheral blood stem cell autologous transplant</td>
</tr>
<tr>
<td>B-ALL</td>
<td>precursor B acute lymphoblastic leukaemia</td>
</tr>
<tr>
<td>B-cell</td>
<td>Bursa-derived cell</td>
</tr>
<tr>
<td>BEACOPP</td>
<td>bleomycin, etoposide, doxorubicin, cyclophosphamide, vincristine, procarbazine, prednisone</td>
</tr>
<tr>
<td>BFM</td>
<td>Berlin-Frankfurt-Munster</td>
</tr>
<tr>
<td>BL</td>
<td>Burkitt lymphomas</td>
</tr>
<tr>
<td>B-LBL</td>
<td>B lymphoblastic lymphoma</td>
</tr>
<tr>
<td>BMT</td>
<td>bone marrow transplant</td>
</tr>
<tr>
<td>BNLI</td>
<td>British National Lymphoma Investigation</td>
</tr>
<tr>
<td>C-ALCL</td>
<td>cutaneous anaplastic large-cell lymphoma</td>
</tr>
<tr>
<td>CAM</td>
<td>complementary or alternative medicine</td>
</tr>
<tr>
<td>CD</td>
<td>cluster differentiation (prefix descriptor for antigen type — followed by number).</td>
</tr>
<tr>
<td>CDR3</td>
<td>complementarity determining region 3</td>
</tr>
<tr>
<td>CEA</td>
<td>cost-effectiveness evaluation</td>
</tr>
<tr>
<td>CEOP</td>
<td>cyclophosphamide plus etoposide</td>
</tr>
<tr>
<td>CER</td>
<td>cost-effectiveness ratio</td>
</tr>
<tr>
<td>CGH</td>
<td>comparative genomic hybridisation</td>
</tr>
<tr>
<td>Chl</td>
<td>chlorambucil</td>
</tr>
<tr>
<td>CHOEP</td>
<td>CHOP plus etoposide</td>
</tr>
<tr>
<td>CHOP</td>
<td>cyclophosphamide, doxorubicin, vincristine (oncovin) and prednisolone regimen</td>
</tr>
<tr>
<td>CHOP-R</td>
<td>cyclophosphamide, doxorubicin, vincristine (oncovin) and prednisolone (CHOP) regimen plus rituximab</td>
</tr>
<tr>
<td>CLL</td>
<td>chronic lymphocytic leukaemia</td>
</tr>
<tr>
<td>CMV</td>
<td>cytomegalovirus</td>
</tr>
<tr>
<td>CNS</td>
<td>central nervous system</td>
</tr>
<tr>
<td>COG</td>
<td>(United States) Children’s Oncology Group</td>
</tr>
<tr>
<td>CR</td>
<td>complete remission</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Definition</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>CR[u]</td>
<td>complete remission unconfirmed/</td>
</tr>
<tr>
<td>CSF</td>
<td>colony-stimulating factor</td>
</tr>
<tr>
<td>CSF</td>
<td>cerebrospinal fluid</td>
</tr>
<tr>
<td>CT</td>
<td>chemotherapy</td>
</tr>
<tr>
<td>CT</td>
<td>computed tomography</td>
</tr>
<tr>
<td>CTL</td>
<td>cytotoxic T cells</td>
</tr>
<tr>
<td>CVID</td>
<td>common variable immune deficiency</td>
</tr>
<tr>
<td>CVP</td>
<td>cyclophosphamide, vincristine and prednisolone</td>
</tr>
<tr>
<td>D+</td>
<td>seropositive donor</td>
</tr>
<tr>
<td>DALY</td>
<td>disability adjusted life years</td>
</tr>
<tr>
<td>DFS</td>
<td>disease-free survival</td>
</tr>
<tr>
<td>DHAP (or DHAC)</td>
<td>dexamethasone, high dose cytarabine and cisplatinum</td>
</tr>
<tr>
<td>DLBCL</td>
<td>diffuse large B-cell lymphoma</td>
</tr>
<tr>
<td>DSC</td>
<td>diffuse small cleaved cell</td>
</tr>
<tr>
<td>DSL</td>
<td>diffuse small lymphocytic</td>
</tr>
<tr>
<td>EBV</td>
<td>Epstein-Barr virus</td>
</tr>
<tr>
<td>ECOG</td>
<td>Eastern Cooperative Oncology Group</td>
</tr>
<tr>
<td>ECP</td>
<td>extracorporeal photopheresis</td>
</tr>
<tr>
<td>EFS</td>
<td>event-free survival</td>
</tr>
<tr>
<td>ENT</td>
<td>ear, nose and throat</td>
</tr>
<tr>
<td>EORTC</td>
<td>European Organisation for Research and Treatment of Cancer</td>
</tr>
<tr>
<td>EPOCH</td>
<td>etoposide, prednisolone, vincristine, cyclophosphamide and doxorubicin</td>
</tr>
<tr>
<td>ESHAP</td>
<td>etoposide, cisplatinum, high dose cytarabine and methylprednisolone</td>
</tr>
<tr>
<td>ESR</td>
<td>erythrocyte sedimentation rate</td>
</tr>
<tr>
<td>EUS</td>
<td>endoscopic ultrasound</td>
</tr>
<tr>
<td>FBC</td>
<td>full blood count</td>
</tr>
<tr>
<td>FC</td>
<td>follicle center (lymphoma)</td>
</tr>
<tr>
<td>FCC</td>
<td>follicle center cell (lymphoma)</td>
</tr>
<tr>
<td>FCM</td>
<td>flow cytometry</td>
</tr>
<tr>
<td>FCM</td>
<td>fludarabine, cyclophosphamide and mitoxantrone</td>
</tr>
<tr>
<td>FDC</td>
<td>follicular dendritic cell</td>
</tr>
<tr>
<td>FDG</td>
<td>fluorodeoxyglucose</td>
</tr>
<tr>
<td>FFP</td>
<td>freedom-from-progression</td>
</tr>
<tr>
<td>FFR</td>
<td>freedom from relapse</td>
</tr>
<tr>
<td>FISH</td>
<td>fluorescence in situ hybridisation</td>
</tr>
<tr>
<td>FL</td>
<td>follicular lymphoma</td>
</tr>
<tr>
<td>FLC</td>
<td>follicular large cell</td>
</tr>
<tr>
<td>FLIPI</td>
<td>follicular lymphoma international prognostic index</td>
</tr>
<tr>
<td>FM</td>
<td>follicular mixed</td>
</tr>
<tr>
<td>FNA</td>
<td>fine needle aspiration</td>
</tr>
<tr>
<td>FR3</td>
<td>framework region</td>
</tr>
<tr>
<td>FSC</td>
<td>follicular small cleaved cell</td>
</tr>
<tr>
<td>GC</td>
<td>germinal centre</td>
</tr>
<tr>
<td>GCB</td>
<td>germinal center B-cell-like</td>
</tr>
<tr>
<td>G-CSF</td>
<td>granulocyte colony stimulating factor</td>
</tr>
<tr>
<td>GELA</td>
<td>Groupe d’Etudes des Lymphomes des l’Adultes</td>
</tr>
</tbody>
</table>
GIT  gastro intestinal tract
GLSG  German Low Grade Lymphoma Study Group
GM-CSF  granulocyte macrophage colony stimulating factor
GnRH  gonadotrophin releasing hormone
GVHD  graft versus host disease
H pylori  Helicobacter pylori
H&E  haematoxylin and eosin
HAART  highly active anti-retroviral therapy
HD  Hodgkin’s disease
HDC  high-dose chemotherapy
HDCT  high-dose chemotherapy
HDSG  Hodgkin Disease Study Group
HGL  high-grade lymphoma
HGNHL  high-grade NHL
HHV8  human herpesvirus-8
HIV  human immunodeficiency virus
HL  Hodgkin lymphoma
HOVON  Stichting Haemato-Oncologie voor Volwassenen Nederland (Dutch haemato-oncology association)
HRT  hormone replacement therapy
HSCT  hematopoietic stem cell transplant
HTLV  human T-lymphotropic virus
ICE  ifosfamide, carboplatin and etoposide
ICER  incremental cost-effectiveness ratio
IELSG  International Extranodal Lymphoma Study Group
IFN  interferon
IgH  immunoglobulin heavy
IgL  immunoglobulin light (chain)
IgV(H)  Variable region of the immunoglobulin heavy chain gene
IPI  International Prognostic Index
IV  intravenous
J  joining
LDHL  lymphocyte depletion Hodgkin lymphoma
LL  lymphoblastic lymphoma
LOS  length of stay
LPD  lymphoproliferative disorder
LPD  Lymphoproliferative disease
LPHL  lymphocyte predominance Hodgkin lymphoma
LRCHL  lymphocyte-rich classical Hodgkin lymphoma
LyP  lymphomatoid papulosis
LYS  life years saved
MACOP-B  methotrexate, doxorubicin, cyclophosphamide, vincristine, prednisone and bleomycin
MALT  mucosa-associated lymphoid tissue
m-BACOD  (chemotherapy regimen of) methotrexate, bleomycin, doxorubicin, cyclophosphamide, vincristine, dexamethasone
MCHL  mixed cellularity Hodgkin lymphoma
MCL  mantle cell lymphoma
PTLD  post-transplant lymphoproliferative disorder
PUVA  ultraviolet-A radiation
QALM  quality-adjusted life-months
QALY  quality of life on utility
R-    EBV seronegative recipient
R+    EBV-seropositive recipients
RAR   retinoic acid receptor
RDI   relative dose intensity
REAL  Revised European-American Lymphoma
RFS   relapse-free survival
RQ-PCR real-time quantitative Polymerase chain reaction
RR    relative risk
RT    radiation therapy
RXR   retinoid X receptor
SB    Southern blot
SC    Sézary cells
S-CHOP standard CHOP
SCT   stem cell transplantation
SEER  Surveillance Epidemiology and End Results
SFOP  French Society of Pediatric Oncology
SKY   spectral karyotyping
SLL   small lymphocytic lymphoma
SLP   standard local practice
SS    Sézary syndrome
STNI  subtotal nodal irradiation
SV40  Simian virus 40
SWOG  Southwest Oncology Group
T-ALL  T-cell variant of acute lymphoblastic leukaemia
TBI   total body irradiation
T-cell thymus-derived cell (not really an abbreviation now)
TCR   T-cell receptor
TCRB  T cell receptor beta
T-LL   T-cell lymphoblastic lymphoma
T-NHL  non-Hodgkin lymphoma of T-cell type
TNI   total nodal irradiation
TPN   total parenteral nutrition
TSEB  total skin electron beam
UKCCSG United Kingdom Children’s Cancer Study Group
UVB   ultraviolet-B
UVR   ultraviolet radiation
V     variable
WAS  Wiskott-Aldrich syndrome
WHO  World Health Organization
XLP   x-linked lymphoproliferative disorder (Duncan syndrome)
YLD   years lost due to disability
YLL   years of life lost
ZAP-70 zeta-associated protein 70
## APPENDIX 4GLOSSARY

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdomen</td>
<td>The part of the body between the chest and hips, which contains the stomach, liver, intestines, bladder and kidneys.</td>
</tr>
<tr>
<td>Adjuvant chemotherapy</td>
<td>Chemotherapy that is used in a supplementary but not dominant therapy.</td>
</tr>
<tr>
<td>Advanced cancer</td>
<td>Cancer that has metastasised and/or is unlikely to be cured</td>
</tr>
<tr>
<td>Adriamycin</td>
<td>A cytotoxic agent or drug used during chemotherapy to kill cancer or lymphoma cells.</td>
</tr>
<tr>
<td>Aetiology</td>
<td>Cause or causality</td>
</tr>
<tr>
<td>Age-standardised rate</td>
<td>A procedure for adjusting rates eg death rates, designed to minimise the effects of differences in age composition when comparing rates for different populations.</td>
</tr>
<tr>
<td>Aggressive</td>
<td>A word for a fast-growing cancer.</td>
</tr>
<tr>
<td>Allogeneic</td>
<td>Tissue from a donor.</td>
</tr>
<tr>
<td>Alpha interferon</td>
<td>A glycoprotein used in the treatment of cancer. One of its effects is to inhibit cell growth.</td>
</tr>
<tr>
<td>Alternative therapies</td>
<td>A term used to loosely describe any type of therapy outside the orthodox circle of surgery, radiation or chemotherapy. Alternative therapies include things such as diet therapy, vitamins and herbs. (See also Complementary therapies)</td>
</tr>
<tr>
<td>Antibody</td>
<td>A protein that is made in lymph tissue to destroy infections and other potentially harmful ‘invaders’ in the body.</td>
</tr>
<tr>
<td>Anticoagulant</td>
<td>A substance that prevents blood clotting.</td>
</tr>
<tr>
<td>Anxiety</td>
<td>A diffuse highly unpleasant, often vague feeling of apprehension, accompanied by bodily sensations such as pounding heart or sweating. There is an associated anticipation of future misfortune or danger, external or internal.</td>
</tr>
<tr>
<td>Apheresis</td>
<td>The process in which blood is temporarily taken from the body, one or more parts of it removed, and the blood returned to the body.</td>
</tr>
<tr>
<td>Apoptosis</td>
<td>Process of cell death.</td>
</tr>
<tr>
<td>Autologous</td>
<td>Tissue graft, blood transfusion etc arising from the recipient.</td>
</tr>
<tr>
<td>Benign</td>
<td>Not cancerous. Benign cells are not able to spread like cancer cells.</td>
</tr>
<tr>
<td>Biopsy</td>
<td>The removal of a small sample of tissue from the body, for examination under a microscope, to help diagnose a disease</td>
</tr>
<tr>
<td>Bleomycin</td>
<td>A cytotoxic agent or drug used during chemotherapy to kill cancer or lymphoma cells.</td>
</tr>
<tr>
<td>Bone Marrow</td>
<td>The soft, spongy tissue in the centre of large bones that produces white blood cells, red blood cells and platelets.</td>
</tr>
<tr>
<td>Cancer registry</td>
<td>A centre in each state and territory where details of cancers are collected to monitor trends.</td>
</tr>
<tr>
<td>Case control study</td>
<td>A study that starts with the identification of people with the</td>
</tr>
</tbody>
</table>
disease of interest and uses a suitable group without the disease for comparison to assess possible factors involved in the development of the disease. Such studies are often called retrospective as they look back from the outcome to its causes.

**Cells**

The ‘building blocks’ of the body. A human is made of millions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

**Chemotherapy**

The use of drugs (which are cytotoxic) or a combination of drugs to kill cancer cells or prevent or slow their growth.

**Chest cavity**

The area enclosed by the ribs, above the diaphragm.

**Chemo-responsiveness**

The measure of how a tumour reacts when an anti-tumour drug is administered.

**Chlorambucil**

A cytotoxic agent or drug used during chemotherapy to kill cancer or lymphoma cells.

**Cladribine**

A cytotoxic agent or drug used during chemotherapy to kill cancer or lymphoma cells.

**Clinical practice guidelines**

The bringing together by a central authority of the best available evidence to support recommendations for the prevention, diagnosis and treatment of cancer.

**Complementary therapies**

A term used to refer to therapies, such as meditation and relaxation therapy, that can work alongside conventional therapy.

**Counselling**

Refers generically to a form of supportive care delivered by all health professionals. There are differing levels of sophistication depending on the training and experiences of the practitioner involved.

**CT scanning**

Computerised tomography is a technique for constructing pictures from cross sections of the body, by x-raying from many different angles the part of the body to be examined.

**Cyclophosphamide**

A cytotoxic agent used during chemotherapy to kill cancer or lymphoma cells.

**Cytology**

The study of the origin, structure, function and pathology of cells.

**Dacarbazine**

A cytotoxic agent or drug used during chemotherapy to kill cancer or lymphoma cells.

**Depression**

A pervasive or sustained lowering of mood or the loss of interest in nearly all activities. When used clinically, it is a cluster of symptoms or a syndrome, whose other features may include: changes in appetite or weight, sleep or psychomotor activity; decreased energy; feelings of worthlessness or guilt; difficulty thinking, concentrating or making decisions; or recurrent thoughts of death or suicide ideation, plans or attempts.

**Diagnosis**

The process of identifying a person’s illness.

**Diaphragm**

A thin muscle below the lungs and heart. It separates the chest cavity from the abdominal cavity.

**Doxorubicin/liposomal doxorubicin**

Agent used in chemotherapy.
Efficacy  The ability of a drug or intervention to produce the desired beneficial effect under ideal conditions.

Epidemiology  The study of the distribution and determinants of health-related states or events in specified populations and the application of this study to the control of health problems.

FDG  Fluoro-deoxy glucose (see PET scanning)

First line therapy  The first administration of therapy such as chemotherapy following surgical removal of the tumour.

Fludarabine  A cytotoxic agent or drug used during chemotherapy to kill cancer or lymphoma cells.

FNA  Fine needle aspiration is a procedure in which a fine needle is used to suck up a few cells from a tumour, for biopsy

Frozen section  A specimen of tissue that has been quick frozen, cut and stained immediately for rapid diagnosis of malignant tissue

Gene  One of the biologic units of heredity which are situated in specific locations on particular chromosomes in the body. Genes make up the DNA molecules that control cell reproduction and function.

Genome  A complete set of hereditary factors in the chromosomes

Growth factor  A substance that stimulates cells to reproduce and rapidly multiply.

H&E sections  Use of a stain -Hematoxylin-eosin - for routine examination of tissue under a microscope. Cell nuclei are stained deep blue and the surrounds (cytoplasm) pink.

Histology  The study of the minute structure, composition and function of tissues.

Immune system  The body’s natural defence system. It protects against anything it recognises as an “invader”, for example, bacteria, viruses, transplanted organs and tissues, tumour cells and parasites.

Immunotherapy  Treatment with immunopotentials and immunosuppressnats.

Incidence  The number of new cases of illness or disease during a given period in a specified population.

Indolent  A word for a slow-growing cancer.

Interferon  A substance made by the body in response to viral infection. It inhibits virus multiplication and has shown some activity against a few uncommon cancers.

Infusion  Introduction of a fluid as a saline solution into the blood by gravity flow.

Intravenous chemotherapy  Administration of a chemotherapy using the veins

Laparoscopy  Examination by means of a laparoscope.

Laparotomy  Surgery where an incision is made through the abdominal wall to expose abdominal contents.

Lymph nodes  Also called lymph glands. Small, bean-shaped structures which form part of the lymphatic system. Lymph is the fluid that flows through this system and carries cells that help to fight disease and
infection. The lymph nodes filter the lymph to remove bacteria and other harmful agents, such as cancer cells.

**Lymphatic system**

The lymphatic system is part of the immune system, which protects the body against ‘invaders’, like bacteria and parasites. The lymphatic system is a network of small lymph nodes connected by very thin lymph vessels, which branch into every part of the body.

**Lymphocyte**

A type of white blood cell formed in lymph nodes. It is part of the body’s immune system which helps to fight infection.

**Lymphoma**

A general term for any cancer that starts in the lymph tissue.

**MabThera (Rituximab)**

An antibody made by genetic engineering technology that is toxic to lymphoma cells.

**Malignant Cancerous**

Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.

**Mediastinum**

The area in the chest cavity between the lungs. It contains the heart and large blood vessels, the oesophagus, the trachea and many lymph nodes.

**Meta-analysis**

A statistical method used to combine the results of different studies on the same topic. Used to pool results from a number of small randomised controlled trials to provide an aggregate that will allow for demonstration of statistically significant results.

**Metastasis**

Also known as a secondary tumour. A tumour that develops when cancer cells break away from the original (or primary) tumour and are carried by the lymph and blood systems to other parts of the body.

**Mitosis**

The process of cell division where new cells are formed. Used by the body to replace dead cells.

**Morbidity**

Term used to report on illness. Can also be used to show persons who were ill, the period of illness and the duration of the illness.

**Mortality**

Death rate due to a particular cause or disease.

**MRI**

A special imaging technique used to image internal structures of the body. It uses the influence of a large magnet to polarize hydrogen atoms in the tissues and then monitors the summation of the spinning energies within living cells. Images are very clear and are particularly good for soft tissue, brain and spinal cord, joints and abdomen. These scans may be used for detecting some cancers or for following their progress.

**Multidisciplinary care**

Multidisciplinary care is the co-ordinated approach using a collaborative group of health professionals and a range of treatment modalities. The team as a whole is responsible for the diagnosis, continuing management and palliative care of the woman with ovarian cancer.

**Multidisciplinary team**

A group of clinicians and health professionals, from a number of disciplines, working together to manage the care of a patient. The members of the team may include: a gynaecological oncologist, gynaecological pathologist, medical oncologist with special experience in ovarian cancer, radiation oncologist with special experience in ovarian cancer, radiologist with a special interest,
general practitioners, specialist nurses, physiotherapists, pharmacists, psychologists, social workers, genetic counsellors, geneticists, and palliative care specialists.

**Mutation**
A permanent and transmissible change in genetic material.

**Myelosuppression**
Suppression of bone marrow activity resulting in a decrease in the number of platelets, red cells and white cells.

**Neo-adjuvant**
Chemotherapy that is administered before the dominant therapy, for example, radiotherapy/surgery.

**Oral alkylating agent therapy**
An anti-cancer or cytotoxic agent eg a platinum compound. An alkylating agent is one which substitutes an alkyl group for an active hydrogen in an organic compound.

**Palliative care**
The active total care of patients whose disease is not responsive to curative treatment. It encompasses the provision of co-ordinated medical, nursing and allied services to help relieve physical symptoms and to provide psychological, emotional and spiritual support.

**Pathology**
The study of diseases, especially their causes and nature.

**Pathogenesis**
The development of a disease, specifically the cellular events, reactions and other pathologic mechanisms that occur.

**Peritoneum**
The lining of the abdomen.

**PET scan**
Positron emission tomography. A technique that is used to build up clear and detailed cross-section pictures of the body. The person is injected with a glucose solution containing a small amount of radioactive material. The PET scanner can ‘see’ the radioactive substance. Damaged or cancerous cells show up as areas where the glucose solution is being used.

**Phase I, II, III trial**
The different stages of a clinical trial. Phase I is designed to evaluate the relationship between dose and toxicity. In Phase II new treatments are screened for their anti-tumour effect, to see which are worthy of further evaluation and in Phase III patients are randomly allocated to receive the new treatment or the best available standard treatment.

**Platelets**
Part of the blood. Platelets are important for blood clotting.

**Ploidy studies**
Identification of the number of genomes (complete set of chromosomes) it contains.

**Pooled data**
Data from a number of studies combined for analysis to look for an effect/result.

**Prednisolone**
A corticosteroid drug that is toxic to lymphocytes and lymphoma cells.

**Prognosis**
A forecast as to the probable outcome of a disease and the prospect of recovery based on the nature of the case.

**Proliferating**
Growth by reproduction of similar cells.

**Quality of life**
A person’s view of their situation and well-being. It encompasses symptoms of disease, side effects of treatment, relationships, occupational and social functioning and a subjective evaluation of adjustment to daily life.
Radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Radiotherapy treatment can also harm normal cells, but they are able to repair themselves.

Randomised controlled trial (RCT)

A study or experiment where subjects are allocated at random to receive or not receive the treatment, procedure or intervention. The results for each group are compared. Generally held to be the most scientifically rigorous method of testing an hypothesis.

Red blood cells

Blood cells that contain haemoglobin, which carries oxygen to the blood.

Reed-Sternberg cell

A malignant cell found in Hodgkin lymphoma (also known as Hodgkin’s disease).

Relapse

The return of a disease after a period of improvement or remission.

Relative risk

The risk (of a disease or death) among those exposed to the risk compared to those who are not exposed to the risk.

Relative survival

Relative survival analysis aims to quantify how long someone with a specific disease might survive when compared to the “general population”. The general population are matched to the “disease” cases by age, sex and year of diagnosis. Relative survival is thus the ratio of the proportion of survivors in the disease group to the proportion of survivors in a similar group of people without the disease. A relative survival of 100% would indicate that persons with disease do not die any more rapidly as they age than people without the disease whereas a result of less than 100% indicates that the disease is resulting in premature death, even when other causes of death have been accounted for.

Remission

The decrease or disappearance of the symptoms of a disease. A person is said to be in complete remission when there is no evidence of active disease.

Resection

Surgical removal of part of all of an organ or tissue.

Retroperitoneal lymph nodes

Lymph nodes situated external or posterior to the peritoneum.

Risk factor

Things that cause people to have a greater chance of developing an illness. Risk factors for cancer include exposure to harmful substances (such as asbestos, some viruses and cigarette smoke) and inheriting a predisposition to a cancer.

Spleen

An organ in the upper part of the abdomen on the left side, below and behind the stomach. The spleen produces lymphocytes, filters blood, stores blood and destroys cells that are ageing. It can mount an immune response to infections in the blood system.

Staging

Investigations to find out how far a cancer has progressed. This is important in planning the best treatment.

Stage/staging/stage distribution

The classification of a tumour according to its extent.

Stem cell

Any precursor cell; a blood cell progenitor or ‘mother’ cell, having the capacity for both replication and differentiation.

Thymus

An organ in the chest in front of the heart where lymphocytes
mature and multiply.

**Tissue**

A collection of cells

**Tissue biopsy**

Examination of tissue, which has been removed from the body, under a microscope so that any abnormalities in the cells can be seen.

**Toxicity**

The quality of being poisonous,

**Transformation**

Change from benign or resting to dividing or malignant cell.

**Transformed disease**

Change from low grade or benign disease to a more malignant type.

**Trephine**

Core biopsy of bone marrow.

**Tumour**

Also called neoplasm. A new growth of tissue in which cell multiplication is uncontrolled and progressive. Tumours are classified in a number of ways the simplest being their origin and whether they are malignant or benign.

**Tumour/tumourgenesis**

The production of tumours.

**Tumour marker**

A substance found in the body that suggests the presence of a tumour.

**Ultrasound**

‘Ultrasound’ is sound waves of a very high frequency (higher than the human ear can hear). If ultrasound is directed at the body, it is reflected back differently by different types of tissue. In an ultrasound scan, these differences are measured and used to build up pictures of structures in the body. Ultrasound pictures are usually taken by an ultrasound technician, who guides the scanning by watching the images on a screen like a television.

**Vinblastine**

A cytotoxic agent or drug used during chemotherapy to kill cancer or lymphoma cells.

**Vincristine**

A cytotoxic agent or drug used during chemotherapy to kill cancer or lymphoma cells.

**White blood cells**

Also known as leucocytes. One of the two main types of cells present in blood. They play a major role in fighting infection.

*Partly adopted from The Cancer Council Victoria handbook titled: ‘Lymphoma, a guide for people with cancer, their families and friends’.*