

Collection of population-based cancer staging information in Western Australia – a feasibility study

Final Report

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Executive Summary

Project background

The aim of Western Australian Cancer Staging Project was to determine whether or not it is feasible to add cancer staging data to the routine data collections of the population-based Western Australian Cancer Registry (WACR).

In 2001, the West Australian Clinical Oncology Group held a symposium to discuss the WACR report, *Cancer survival in Western Australians, 1982-1997*. A concern voiced by many clinicians was the limited ability to interpret the survival analysis data because of the lack of adjustment for stage of cancer. While the WACR routinely collects data relating to tumour location, type, basis and date of diagnosis, and grade, together with demographic information, it does not currently collect information on cancer stage.

This study was funded by the Australian Government through the National Cancer Control Initiative (NCCI) and was a collaboration between the University of Western Australia School of Population Health, the Western Australian Cancer Registry (Department of Health) and the Western Australian Clinical Oncology Group (WACOG).

Aims

- To determine the data requirements for staging information, with reference to the Core Clinical Data Set currently being developed by NCCI.
- To determine the degree to which requirements for staging information can be met by pathology reports as currently supplied to the Western Australian Cancer Registry and Hospital based cancer registries.
- To determine the feasibility of data collection, prospectively for new cases, and retrospectively for older cases.
- To estimate the infrastructure requirements and costs of ongoing collection of cancer staging information.

Methods

A frequency-weighted caselist of 600 cancer cases comprising the 20 most frequent cancers in WA, excluding non-melanocytic skin cancers, was selected from WACR data. For each of the five most common cancer types (prostate, colorectal, melanoma, breast and lung cancers), 60 cases were selected for staging. For the remaining 15 cancer types, 20 cases were selected. Of the 600 cases, 450 were “retrospective” cases diagnosed in 1998 (300) or January – June 2002 (150); and 150 were prospective, diagnosed after June 2002.

There were four sources for collecting data for the staging: the WACR, the hospital based cancer registries (HBCRs), hospital medical records (HMR), and letters to treating doctors. The procedure used for the majority of cancer types was as follows: First the pathology reports and death notifications for each case at the WACR were reviewed and staging data extracted. If full staging data were not available, data were acquired from the HBCRs. Next case-notes at both private and public hospitals were reviewed. Finally, where necessary, letters were sent to clinicians requesting staging information.

Data collected included the actual stage information where available, as well as resource use in terms of time, transport, letters, set-up and administration costs, so as to support an accurate budget estimate.

For many of the cases in this study it was not possible to stage the cancer definitively, because of the lack of information on regional nodal status or the presence or absence of distant metastases. Clinically, many of these cases are likely to be early stage cancers. For those cases which were not stageable, two different assumptions were applied. The first assumption was applied to cases which had data for tumour (T) and regional lymph nodes (N), but which had no assessment of distant metastasis (MX). The assumption made was that MX was equivalent to M0 (no distant metastases). The second assumption was applied to cases with data for T and M, but with no assessment of regional nodal involvement (NX). The assumption made was that NX was equivalent to N0 (no regional nodal involvement). This is summarized as “NX=N0” in the tables.

As the appropriateness of such assumptions may differ with cancer type, they need to be applied very cautiously, and after further liaison with clinicians.

Results

The feasibility of staging the 20 cancer types is summarized as follows:

Cancer type	Staged from WACR data alone (%)	Staged from WACR and HBCRs, WARTN (%)	Staged after all completed steps (no assumptions) (%)	Staged after all steps with assumption/s (%)
Group A: Could be staged now				
Ovary	60 [^]	100	100	100
Cervix	16 [^]	95	100	100
Uterus	50 [^]	85	95	95
Group B: Could be staged now, making MX=M0 assumption				
Breast	0	12	65	95
Colorectal	12 [^]	53	80	92
Group C: Could be staged now, with NX=N0 and MX=M0 assumptions				
Melanoma	0	(0)	57	100
Prostate	2	5	34	97
Group D: Could be started now with MX=M0, but long term collection requires system changes				
Stomach**	25	25	70	95
Lung	18	38	76	86
Pancreas	45	45	70	80
Thyroid**	10	10	47	79
Testis**	10	10	75	75
Kidney**	15	20	65	70
Group E: Staging not feasible at present				
Oesophagus**	0	0	50	65
Bladder**	0	0	40	55
Lip	0	(0)	37	42
Lymphoma	44	(44)	44	44
Myeloma	0	(0)	0	0
Leukaemia	0	(0)	0	0
Brain	0	(0)	0	0

[^] These numbers could have been higher as the external databases were searched first, and WACR later searched only for incomplete cases.

** Only one HBCR currently collects data on these cancers except bladder, for which two HBCRs are collecting data.

() Numbers in parentheses indicate that the additional data source/s indicated by the column header, was/were not accessed as they were either not applicable to the cancer type, or research suggested the additional effort would be unrewarding. Percentages shown are cumulative, beginning from the left.

For cancers in Group A the use of the HBCR was clearly crucial, markedly increasing the stageable proportion of cases. Cancer types in Group B and Group C could be staged now, but only if the assumption $MX=M0$ or both assumptions ($NX=N0$ and $MX=M0$) were acceptable, respectively. Cancer types in Group D could be staged now, but additional clinical input – on pathology request forms, for example - would be required to achieve useable levels of completeness. For cancer types in Group E, either “staging” is widely regarded as not relevant, and no generally-accepted system exists, or an acceptable level of completeness is not achievable.

Estimated Costs

For each cancer type, the recorded times from the feasibility study were extrapolated to current annual based on a preliminary 2002 caselist. The estimated resources required ranged from less than 0.1 FTE for staging only cancers in Group A, to 1.5 FTE for adding cancers in Groups B-D. Although an estimate of Group D costs is included, clinical input would be necessary to make this option cost effective, and some cancers might be omitted as the percentage staged would still be too low to be of any clinical or statistical value. If the two main types of assumptions are not acceptable, then bringing completeness up to acceptable levels for some cancers might not be feasible without still further resources

Conclusions

1. Adding stage to the WA Cancer Registry routinely collected information is possible for many cancer types.
2. Good staging information can be obtained with relatively minimal effort, for the following cancers - if specialized gynaecological hospital-based cancer registries continue to operate: **Cervix, Ovary and Uterus.**
3. Making the assumption that $MX=M0$ for all cancers with $N0$; reasonable staging information (>75% complete) can be obtained for the following cancers: **Breast, Colorectal.**
4. Making the assumption that $MX=M0$ and $NX=N0$, reasonable staging information (>75% complete) can be obtained for the following cancers: **Prostate, Melanoma.** (However, for both these cancers, considerable improvement of the completeness and accuracy of the staging information would be possible if routine histopathology referral forms for melanoma and prostate cancer included information regarding presence or absence of clinically involved lymph nodes or metastases.)
5. Further work is needed to improve the staging data availability and systems for cancers of the lung, stomach, thyroid, testis, pancreas, and kidney. In particular, the acceptability of an $MX=M0$ assumption for lung cancer, needs to be debated with local clinicians.
6. Staging of brain cancer should not be considered further at the moment, as no accepted staging system exists.

7. At the moment it is not possible to stage oesophageal, bladder or lip cancers, lymphoma, myeloma or leukaemia with reasonable effort.
8. Data for “old” cases can be obtained, but costs will appear excessive if unrealistic emphasis is placed on staging historical data.
9. These findings should be generalizable to most cancer registries in Australia, if hospital-based cancer registries or other specialized databases are accessible.

Recommendations

1. Adding stage to the WA Cancer Registry routinely collected information should be started for the following cancers as soon as funding can be made available:
 - Cervix
 - Ovary
 - Uterus
 - Colorectal
 - Breast
 - Prostate
 - Melanoma
 2. Urgent further discussions with pathologists and relevant clinicians should be held to determine whether routine histopathology referral forms could include “tick boxes” for the clinician to indicate whether there were thought to be cancer-affected regional lymph nodes or distant metastases.
 3. Further work is needed in the near future to improve the staging data availability and systems for cancers of the lung, stomach, thyroid, testis, pancreas, and kidney.
 4. Staging of lip, oesophagus, bladder and brain cancers and lymphoma, myeloma and leukaemia are not possible at the moment, but this conclusion should be reviewed regularly to determine whether circumstances have changed so as to make staging of these cancers feasible.
 5. A special project should be funded to add staging to the data for cancers held by the WA Cancer Registry from 1998 onwards.
 6. The HBCRs should continue to be funded, on the condition that regular and timely data exchange with the WA Cancer Registry occurs, to facilitate the availability of population-based staging information. Extending coverage to private hospitals should also be considered.
 7. Any long term moves towards registration of “cancer treatment centres” should include a requirement that all cancers are staged and that such information is passed on to the WA Cancer Registry.
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Contents	Page
Executive summary	i
Contents	v
List of tables	viii
Abbreviations	ix
Acknowledgments	x
Foreword: Why is cancer staging such a challenge?	xi
1. Introduction and Overview	1
1.1 The WA Cancer Staging Project: Overview	1
1.2 Why collect staging data?	1
1.3 Cancer staging methods	2
1.4 Clinical and pathological staging	3
1.5 Cancer staging data collections overseas	3
1.5.1 Overview	3
1.5.2 Canada	3
1.5.3 United States of America	3
1.5.4 United Kingdom	4
1.5.5 New Zealand	4
1.5.6 Europe	4
1.6 Cancer Staging data collections in Australia	4
1.6.1 Overview	4
1.6.2 New South Wales	4
1.6.3 Northern Territory	5
1.6.4 Western Australia	5
1.6.4.1 Overview	5
1.6.4.2 Western Australian Cancer Registry (WACR)	5
1.6.4.3 Hospital Based Cancer Registries (HBCRs)	6
1.6.4.4 Western Australian Research Tissue Network	7
1.7 The WA Cancer Staging Project: origins, inception and aims.	7
1.7.1 Origins	7
1.7.2 Funding and project inception	7
1.7.3 Aims of the WA Cancer Staging Project	7
2. Methodology	9
2.1 Caselist	9
2.2 Ethics requirements	10
2.3 Database development	10
2.4 Data collection	11

2.4.1	Steps in obtaining staging information	11
2.4.2	Variations on the usual method of collecting staging information	13
2.4.3	Summary of staging schemes used for each cancer type	14
2.5	Data analysis	14
3.	Results	15
3.1	General findings	15
3.1.1	Assumptions	15
3.1.2	Description of table format	15
3.2	Lip - C00	17
3.3	Oesophagus - C15	18
3.4	Stomach - C16	19
3.5	Colorectal - C18	20
3.6	Pancreas - C25	21
3.7	Lung - C34	22
3.8	Melanoma - C44	23
3.9	Breast - C50	24
3.10	Cervix - C53	25
3.11	Uterus - C54	26
3.12	Ovary - C56	27
3.13	Prostate - C61	28
3.14	Testis - C62	29
3.15	Kidney - C63	30
3.16	Bladder - C67	31
3.17	Brain - C71	32
3.18	Thyroid - C73	33
3.19	Lymphohaematopoietic malignancies	34
3.19.1	Lymphoma	34
3.19.2	Myeloma	34
3.19.3	Leukaemia	34
3.19.4	Overview of lymphohaematopoietic malignancies	35
4.	Discussion	36
4.1	Results overview	36
4.2	Barriers to the collection of staging data	38
4.2.1	Current resources	38
4.2.2	Information not forwarded to WACR	39
4.2.3	Specimen unsuitable for staging	39
4.2.4	Applying assumptions	39
4.2.5	Confidentiality	40
4.2.6	Access to data	40
4.2.7	Specimens sent interstate	40
4.2.8	Who should be responsible for staging?	41

4.3	Opportunities	41
4.3.1	Hospital Based Cancer Registries	41
4.3.2	Synoptic reports	42
4.3.3	Current follow-up by WACR staff	42
4.3.4	Public support for cancer research	42
4.3.5	Less use of cross border health services, and net inward migration	42
4.3.6	Unique characteristics of WACR	43
4.3.7	Existence of WACOG	43
4.3.8	Uses of databases in the public and private sectors	43
4.3.9	Access to WA health services and data collections	43
4.4	Cost estimates for adding staging data to WACR	44
5.	Conclusions	45
6.	Recommendations	46
7.	References	47
Appendices		
A	Degree of spread of cancer (based on NSW definition)	A-1
B	Extent of disease code (New Zealand)	A-4
C	Data entry form	A-5
D	Cancer staging information request letter	A-6
E	Additional information from WACR and HBCR databases	A-8
F	Methods and details of costing estimates	A-11

List of tables	Page
1. Initial caselist for WA Cancer Staging Project	10
2. Most common/recommended staging scheme for each cancer type	14
3. Lip cancer staging results	17
4. Oesophageal cancer staging results	18
5. Stomach cancer staging results	19
6. Colorectal cancer staging results	20
7. Pancreatic cancer staging results	21
8. Lung cancer staging results	22
9. Melanoma staging results	23
10. Breast cancer staging results	24
11. Cervical cancer staging results	25
12. Uterine cancer staging results	26
13. Ovarian cancer staging results	27
14. Prostate cancer staging results	28
15. Testicular cancer staging results	29
16. Kidney cancer staging results	30
17. Bladder cancer staging results	31
18. Thyroid cancer staging results	33
19. Results for the lymphohaematopoietic malignancies	35
20. Percentage of cases staged by cancer type and process	38
21. Annual cost estimates for staging data collection	44
E1 Proportion of cases under-staged for lung cancer, if MX=M0	A-7
E2 Proportion of cases under-staged for breast cancer, if MX=M0	A-9
E3 Proportion of cases under-staged for colorectal cancer, if MX=M0	A-9
E4 Proportion of lung, breast and colorectal cancers, seen by 3 HBCRs	A-10
F1 Improvement in staging completeness, if reminder letters used	A-14
F2 Components of costing estimates, by cancer type and group	A-15

Abbreviations used in this report

The following abbreviations have been used at times in this report (although they may have other meanings in other contexts):

AACR	Australasian Association of Cancer Registries
AJCC	American Joint Committee on Cancer
CCHSA	Canadian Council for Health Services Accreditation
COC	Commission on Cancer
DHAC	Commonwealth Dept of Health and Age Care
FIGO	International Federation of Gynaecology and Obstetrics
FH	Fremantle Hospital
HBCR	Hospital Based Cancer Registries
HMR	Hospital Medical Records
KEMH	King Edward Memorial Hospital
M0	No distant metastasis
MX	Distant metastasis cannot be assessed
NCCI	National Cancer Control Initiative
NCIC	National Cancer Institute of Canada
NPCR	National Program of Cancer Registries
N0	No regional lymph node metastasis
NX	Regional lymph nodes cannot be assessed
NT	Northern Territory
RPH	Royal Perth Hospital
SCGH	Sir Charles Gairdner Hospital
SEER	Surveillance, Epidemiology and End Results
UICC	International Union Against Cancer
USA	United States of America
UWA	The University of Western Australia
WACOG	West Australian Clinical Oncology Group
WACR	Western Australian Cancer Registry

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While electronic data systems increasingly support the efforts of disease registers and health research, the involvement of interested individuals can make a fundamental difference in investigations such as those that have formed part of this project.

Foreword: Why is cancer staging such a challenge?

Mark Elwood, Director, National Cancer Control Initiative

As this Western Australian report indicates, plans for cancer staging systems go back over 100 years; the work leading to the TNM system started in occupied France during the 1940s.¹

Under the title of “How to achieve surgical results by really trying”, an American surgeon in 1963 showed how to maximise survival figures by such means as excluding sicker patients and early deaths, and adding lots of ‘grade ½’ lesions. He concluded, “With a little experience, one can become a superb paper-surgeon”.³ A more recent report notes that shifting patients between two stage categories can improve the apparent prognosis of both groups; what the Americans call the Will Rogers phenomenon, but my New Zealand colleagues might call the Rob Muldoon effect.²

Both examples show that cancer staging is not merely bookkeeping, but a complex process needing clinical knowledge. For the individual patient, valid staging of cancer is necessary for optimal clinical care: many treatment options depend on staging, and it is usually the most important predictor of prognosis. But why should we have cancer staging information available for populations? I see the main purposes as being to assess patient outcomes against accepted guidelines and international standards, and to monitor progress in achieving earlier diagnosis of cancer. We need consistent but practical systems, from both the individual and the population perspectives.

In discussions about this project, I have come across two contrasting assumptions. The first, from senior health managers, but also from some clinical oncologists, is that surely we already have cancer staging information? They assume that cancer registries must collect staging information and are surprised that information on survival by stage is not available routinely.

There is a related belief that collecting staging information is simple and routine, and that if it’s not available now, it should be, and from next month, please. Thus the Baume report on radiotherapy services⁴ recommends that “State and Territory cancer registries should, by 2003, collect information on diagnosed cancer stage and treatment regime for each patient suffering from cancer” with no discussion of the financial, logistic, or legal issues involved. Yet the viewpoint is quite logical. If the treating doctor has information on the stage of the cancer, that information should be in the patient’s record, and the only remaining issue is how to transfer it to a population-based registry, to maximise its value.

The contrasting viewpoint, often from those who have experience in cancer registries, is that collecting information on cancer stage, especially in TNM detail, may be a greater challenge than the human genome project.

The results of this Western Australia project illustrate that there is, as usual, a little truth in each of these extreme positions. The reality is that staging information at population level can be produced; but the process requires good system design, attention to confidentiality and ownership issues, and a modest sustained investment.

This Western Australia project is a thorough exploration of the issues involved in cancer staging in Australia. It is of great importance to cancer control development nationally, and the report will influence decisions on future developments. The research team is to be congratulated.

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1. INTRODUCTION AND OVERVIEW

1.1 The Western Australian Cancer Staging Project: Overview

The Western Australian Cancer Staging Project was a one-year project aimed at investigating the feasibility of adding cancer staging data to the routine collections of the population-based Western Australian Cancer Registry (WACR). The study was a collaboration between the University of Western Australia's School of Population Health, the Western Australian Cancer Registry (Department of Health) the Western Australian Clinical Oncology Group (WACOG), and the funders, the Australian Government through the National Cancer Control Initiative (NCCI).

The project consisted of an overview of current practice, the collection of staging data for a representative sample of Western Australian cancer cases, and an assessment of resources used. This report aims to present the findings in terms of an analysis of processes and resource requirements, rather than cancer-stage results themselves; and aims to make recommendations to support decisions, here and in other areas, about whether to collect staging information in cancer registries and to what extent this collection is possible.

1.2 Why collect staging data?

Cancer staging information is of fundamental importance at both population and individual levels. For the individual, it facilitates provision of appropriate patient care. It enables appropriate selection of treatment for individual cases, and it can also be used to explain variability in treatment outcomes. The staging of cancer allows an individual patient and their family to better understand the clinical condition and prognosis.

At the population level, staging data can guide the development of health promotion programs better tailored to suit particular target groups, and enable health promotion programs to be evaluated more accurately. For instance, the effectiveness of a cervical cancer awareness campaign aimed at increasing Pap smear compliance may be best evaluated by determining the proportion of cases presenting with early stage disease, as opposed to simply looking at overall incidence. Population data on cancer staging will facilitate more effective resource allocation as this can be affected by the relative proportions of “early” as opposed to “late” cases.

At a practical level, staging data at the population level can be used for stratifying outcome analyses, including those based on survival or relative survival. Such analyses are more meaningful and more comparable between different geographic areas, than all-cases analyses.

So as to be relevant to assessing prognosis, “staging information” has been used throughout this project, as elsewhere, to refer to the stage **at the time of diagnosis** of a cancer, and not at some later time when it may be altered because of treatment, or by progression of disease. In practice, data resulting from investigations performed within a short period of the original diagnosis (commonly 3 months) is treated as relating to the stage at diagnosis – as the information takes some time to be acquired as medical investigations proceed.

1.3 Cancer staging methods

Classification of the severity of cancer was attempted more than 90 years ago when Steintal initiated the development of an international language for staging cancers.¹ Heymann, Lacassagne and Voltz published work on cancer of the uterine cervix in 1928 and together with work done by Portmann in 1937 on breast cancer, this led to the publications on staging systems.² A project pioneered by Pierre Denoix and the International Union Against Cancer (UICC) resulted in the development of the Tumour Node Metastasis (TNM) classification system. This system is now recognised by many as the international standard for describing the anatomic extent of disease, and has been translated into many languages.

The TNM system describes different characteristics of the tumour. T describes the primary tumour size and/or extent, N describes the presence or absence of regional lymph node metastasis and M describes the presence or absence of distant metastasis. Each of these components is divided into numerical subsets (T0 - T4, N0 - N3, M0 - M1) which describe how advanced the malignancy is. The definitions of these subsets are specific for each tumour and are delineated in a TNM handbook, which undergoes regular revision and updates; the most recent version is the 6th Edition.³ There are general rules for assignment of these codes, as well as tumour-specific rules.

Depending on the specific combination of T, N and M, an individual cancer will be assigned to a “stage”. Different staging systems exist and they have different rules and guidelines. Commonly used staging systems include those of the American Joint Committee on Cancer (AJCC), UICC and International Federation of Gynaecology and Obstetrics (FIGO) which all use TNM as a basis. The Ann Arbor and Duke’s classifications also use similar definitions and principles.^{3,4}

The AJCC and UICC staging systems use the TNM system to summarise the anatomic extent of disease. In these systems, a cancer is assigned to a stage grouping 0 (in-situ disease) through to IV (very advanced disease), depending on the specific combination of T, N and M variables which may differ according to the cancer type.³

The staging system approved by the International Federation of Gynaecology and Obstetrics (FIGO) is used for staging cancers of the uterus, cervix and ovary. This system is identical to that of the UICC and AJCC for these cancers and therefore allows for universal interpretation of gynaecological cancer stage.⁴

For most cancers, the staging of the tumour depends only on TNM. However, some tumours also require additional information for staging (for example, serum tumour markers for testicular cancer).³ Additional prognostic factors may be increasingly included in the delineation of the TNM stage grouping. The TNM system is flexible and accepted worldwide for patient care, and has been validated as being relevant to the clinical practice of oncology.⁵

Alternatives to TNM-based staging are various “extent of disease” (EOD) classifications, which assign terms such as “localised”, “regional spread” and “distant metastasis”. While the determinations are made on the basis of similar information, these summarising categories have not had the same widespread acceptance as formal TNM-based staging systems, and hence may be less useful for comparisons between different tumour types or geographic areas.

1.4 Clinical and pathological staging

There are two major types of staging: pathological and clinical, and these are obtained from different sources. Clinical staging is based on all data obtained prior to the first definitive treatment.³ It can include data obtained from physical examination, biopsy, surgical exploration, imaging and endoscopy for example. Pathological staging includes all information obtained prior to the first definitive treatment together with the information obtained from surgery, in particular information from pathology results. An overall, or “summary” stage, may be recorded, often as a “worst case” derived from the clinical and pathological staging codes.

1.5 Cancer staging data collections overseas

1.5.1 Overview

A survey of Cancer Registry reports and cancer-related Internet sites from Australia and other countries confirms that the collection of staging data is an issue of concern to clinicians and cancer registries at both the national and international level. Approaches to collecting such data vary, as do views on exactly what information should be collected. However, most appear to be based on the collection of TNM data.

1.5.2 Canada

Recently in Canada there have been concerted efforts being undertaken to have staging data collected at the population level. A series of workshops, opinion surveys and committee deliberations have helped to facilitate decisions on the best way to collect staging data and identify the barriers to this data collection. These consultations held in 1996 resulted in several draft recommendations as follows.⁵

- 1 “That the recording of TNM stage in medical records by the treating physician becomes a standard of care.”
- 2 “That consultation recommendations be submitted to the Association of Provincial Cancer Agencies and the Canadian Council for Health Services Accreditation (CCHSA)”
- 3 “That CCHSA be requested to include TNM in the records of every cancer patient as a requirement for accreditation of cancer centres.”
- 4 “That national agencies, especially the National Cancer Institute of Canada (NCIC), continue to play a lead role in processes involving education, training and facilitation of the National Cancer Staging Initiative.”
- 5 “That a quality assurance program be developed and coordinated to ensure quality and comparability of data gathered across jurisdictions.”

1.5.3 United States of America (USA)

There is no uniform, centrally controlled method of collecting staging data within the USA. Data from the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute covers about 14% - 26% of the population only. SEER began in 1973 and currently collects data from 11 population based cancer registries and three supplemental registries.⁶ They collect data including summary staging (which is also known as general staging, California staging and SEER staging).

The US Commission on Cancer (COC), SEER and the National Program of Cancer Registries (NPCR) have agreed that all cancer registrars will begin collecting staging information using

the coding rules developed by the Collaborative Task Force. The planned implementation date for this change is currently 2004. Registrars will now abstract and code the component elements at stage of diagnosis (similar to Extent of Disease coding) instead of the T, N and M stage group codes. The new system is called Collaborative Staging.⁷

1.5.4 United Kingdom

Several individual registries in the United Kingdom use various systems to collect various staging information. However, on a national level, collection of staging information is uncommon and incomplete. The NHS Action Programme For Cancer Registration acknowledges the need for staging data to support the introduction of clinical governance.⁸

1.5.5 New Zealand

New Zealand collects information on extent of disease, as defined in the New Zealand Cancer Registry Data Dictionary (Appendix B). This differs from the Australian National Health Data Dictionary definition in that there is an extra category for *in situ* tumours.

1.5.6 Europe

The European Network of Cancer Registries (ENCR) recommended that data on stage of cancer be collected according to a condensed TNM system for recording extent of disease.⁹ The extent of disease would be recorded according to the TNM system, but when this was not available the cancer registry should follow a “condensed TNM scheme”, where the tumour is classified as localised, advanced or “cannot be assessed”. The proposed scheme suggests the recording of a mixture of clinical and pathological information, when some but not all pathological staging data are available; it also specifies codes for use in recording the basis for the recorded stage information.

1.6 Cancer staging data collections in Australia

1.6.1 Overview

There is currently no on-going population-based collection of staging information in any Australian State or Territory, although hospital-based cancer registries have been collecting staging information in South Australia for many years, and in Western Australia since 1996.

1.6.2 New South Wales

The New South Wales (NSW) Central Cancer Registry currently collects data on degree of spread of cancer. The registry requests information on spread of cancer at diagnosis for all notifications. The definition used in this process has been submitted, with the agreement of all State and Territory Cancer Registries, for inclusion for in the national health data dictionary. The spread of cancer is classified as localised, regional, distant or unknown. The most recent draft definition is attached as Appendix A.

1.6.3 Northern Territory

A separate National Cancer Control Initiative (NCCI)-funded project is underway in the Northern Territory (NT) aimed at determining whether local indigenous people with cancer are diagnosed with more advanced disease than non-indigenous people, and whether the survival of indigenous people with cancer is lower before and after adjustment for stage of disease at diagnosis. This project has collected data on both summary staging and the T, N and M status of cancer cases. The NT project will be completed in early 2004.

1.6.4 Western Australia

1.6.4.1 Overview

As in every Australian State and Territory, Western Australia has a population-based cancer registry, which produces State-based incidence and mortality reports, and contributes to national reports via its relationship with the National Cancer Statistics Clearing House (NCSCCH) within the Australian Institute for Health and Welfare (AIHW), Canberra.

There are four major teaching hospitals in Perth: King Edward Memorial Hospital (KEMH); Royal Perth Hospital (RPH); Sir Charles Gairdner Hospital (SCGH) and Fremantle Hospital (FH). There are three major private hospitals: St John of God (SJOG), Hollywood Private Hospital (HPH) and Mount Hospital (MH). Each of the (public) teaching hospitals has a Hospital Based Cancer Registry (see section 1.6.4.3), which collects information on a designated list of cancer types, including information on staging.

1.6.4.2 Western Australian Cancer Registry (WACR)

The Western Australian Cancer Registry is a population-based cancer registry established in 1981, based on the mandatory reporting of cancers diagnosed by pathologists, haematologists and radiation oncologists as underpinned by the Health (Notification of Cancer) Regulations 1981 (WA Health Act, 1907). The Registry was established in recognition of the potential importance of reliable population-based cancer data in the planning of services and in the prevention and treatment of cancer.

The WACR cooperates with other State registries and the National Cancer Statistics Clearing House (NCSCCH) (a central cancer data collection for the whole of Australia based at the Australian Institute of Health and Welfare in Canberra). Data are also provided to the Australian Mesothelioma Register in Sydney, and the International Agency for Research on Cancer in Lyon, France, for inclusion in Australian statistics published nationally and worldwide.

The Registry is a member of the Australasian Association of Cancer Registries (AACR) which includes all Territory and State cancer registries, and the International Association of Cancer Registries. The Australasian Association meets annually to discuss matters such as common coding systems, comparability of data between areas in Australia and involvement in Australia-wide cancer research projects. Further details of the WACR's operations can be found in reports and other data referenced on the Registry's website, at www.health.wa.gov.au/wacr/.

The WACR routinely collects data relating to tumour location, type, basis and date of diagnosis, and grade, together with demographic information and administrative details including those required to identify a limited number of possible sources of further information. The WACR does not currently collect information on cancer stage, but is in a position to be

able to acquire and record such information, whether available from pathology reports supplied as per the Regulations, or other sources.

In particular, significant information in addition to pathology reports, is available as the result of a number of on-going activities. Registry staff write letters to nursing home administrators and clinicians, or visit hospital medical records departments, seeking confirmation of details for a variety of cancers, especially those where the primary site or cancer type, from the initial report, is unable to be determined. The Registry made 426 letter based enquiries regarding 360 people, and investigated 800 cases at hospitals, in the last completed year. The addition of cancer staging information to routine data requirements would add little to the workload or other resource requirements, for cases already being “researched” in this manner.

The WA Health Services Research Linked Database provides information to the Cancer Registry in two main areas: for existing cases, it may indicate hospitals and medical practitioners who may be useful sources of information, in addition to those already known from pathology reports. Hospital-based data extracts made available to the Registry also permit the creation of tumour records for persons not already known to the Registry. Such cases appear to be largely persons for whom no formal pathological diagnosis is available.

1.6.4.3 Hospital Based Cancer Registries (HBCRs)

The HBCRs currently collect information on cancer staging, together with data concerning treatment dates and types - albeit for a limited number of cancer types, and at a limited number of hospitals.

Health Department funding for HBCRs began in 1995, and there are currently four HBCRs in operation in WA at the four major teaching hospitals: King Edward Memorial Hospital (KEMH); Sir Charles Gairdner Hospital (SCGH); Royal Perth Hospital (RPH) and Fremantle Hospital (FH).

Initially, WACR supplied a database system for one hospital, while three others developed their own computer systems for data collection and storage. Since then, two have adopted a common system, and a third has appeared likely to do so in the near future.

The establishment of an HBCR subcommittee of the (then) State Cancer Services Planning Committee in 1997 assisted in improving collaboration and consistency between the HBCR and between the HBCR and the WACR. An HBCR Committee, now convened and supported by the WACR, currently serves similar aims. However, cancer types collected differ from one HBCR to another, reflecting the volumes of case types and the particular interests of clinicians at each site.

The use of HBCRs as a source of staging data has advantages in that there are people on-site within each registry to collect information and who are able to form a good rapport with the clinicians from whom they seek information. There should also exist a high degree of consistency of the staging data within each HBCR. A pathway thus exists for a flow of staging data from the HBCRs to the WACR, and successful operation of these registries may be crucial to the WACR’s ability to collect such data in a timely and economical fashion. There are also some limitations in that each HBCR has a limited coverage of the population and only covers select cancer types.

1.6.4.4 Western Australian Research Tissue Network (WARTN)

The WARTN is constituted as a Department of the Cancer Clinical Service Unit of the North Metropolitan Health Service at Sir Charles Gairdner Hospital. It functions as a state-wide tissue procurement service from a population of 2.4 million in Western Australia. This system is unique in Australia. WARTN's long term plans include expansion of tissue procurement activities to enable creation of population-based tissue collections linked to detailed clinical histories of patients, as well as continued co-operation with hospital based cancer registries. As the WARTN develops it may be of great importance to attempts to collect staging data.

1.7 The WA Cancer Staging Project: origins, inception and aims

1.7.1 Origins

A symposium organised by the WACOG was held in March 2001. The results and issues discussed in the WACR report, *Cancer survival in Western Australians, 1982-1997*¹⁰ were considered by over 90 participants. One of the main issues arising from this meeting was a common concern at the lack of staging data in the survival analyses presented. Presenters and other participants voiced a need to have staging data available for all cancers in order to better interpret the survival rates presented.

An action agreed at this meeting was that the WACR would discuss with each of the WACOG organ-specific advisory committees how staging could be added to the State Cancer Registry's database. One of the barriers highlighted was that of time and staffing. Currently, the Registry could only stage from pathology reports and the results of "routine" case follow-up, but many cancers required clinical input in order to be accurately staged. Other problems highlighted included the difficulty of data collection, privacy and access to the Registry by clinicians.

1.7.2 Funding and project inception

An application for funding for the WA Cancer Staging Project was initially developed by staff at the University of Western Australia's School of Population Health in 2001, supported and partnered by the Western Australian Cancer Registry in the Health Department of Western Australia. WACOG became involved as the proposed fund-holder and the employer of project-related staff. An offer of funds was made by the NCCI, terms were finalized in January 2002, and a project co-ordinator and project officer commenced work in June 2002.

The funding agreement between WACOG and the NCCI included the employment of a full-time project co-ordinator and half-time project officer. The agreement also included the setting up of a Steering Committee, with representatives of key organisations and individuals already involved in cancer control in Western Australia.

1.7.3 Aims of the Western Australian Cancer Staging Project

- To liaise with Western Australian special interest groups, namely WACOG subgroups and hospital-based cancer registries, and confirm and act upon pre-existing expressions of support for the need for the collection of staging information for cancers diagnosed in Western Australian residents.
- To determine, in liaison with Western Australian and other clinicians, the data requirements for staging information, with reference to the Core Clinical Data Set currently being developed by NCCI.

- To determine and document the degree to which requirements for staging information can be met by pathology reports as currently supplied to the Western Australian Cancer Registry as required by the Health (Notification of Cancer) Regulations 1981 (last amended 1996).
- To determine and document the degree to which information legally available from HBCRs, hospital medical records and private practitioners can supplement that held by the WACR and meet requirements for staging information.
- To determine the optimal logistics for collection of both prospective and retrospective cancer staging information.
- To document the infrastructure requirements and costs of ongoing collection of cancer staging information.
- To report on progress and outcomes, and make recommendations for the extension of coverage of staging information to all Western Australia and all cancer types.
- To collect staging information retrospectively on 500 cancer cases notified to the WACR, and for 100 cases prospectively after project commencement, based on semi-random samples aimed at ensuring adequate representation of the most common cancer types diagnosed in Western Australia.

2. METHODOLOGY

2.1 Caselist

A key strategy of the project was the collection of staging data on a selection of cancer cases from among those notified to the WACR, including cases notified in the past (retrospective data collection) and in the present (prospective data collection). A mix of cases from different time periods was used to determine whether staging information was able to be collected more completely, or in a more cost-effective manner, for older or newer notifications. It was anticipated that while there was a risk that data might be “archived” or be otherwise difficult to obtain for older cases (particularly if the persons concerned were deceased), there might be an advantage in terms of a single most-complete repository of information. On the other hand, for more recent, still-evolving cases, more work might be required to trace information from a variety of current sources.

It was decided that an attempt to stage a total of 600 cases should be made. The “retrospective” cases were those diagnosed in 1998 (300) and in January – June 2002 (150); the “prospective” cases (150) being those diagnosed after June 2002. The number of cases to be investigated was set at 600 in order to allow enough cases to be studied to provide enough information on the ease with which staging data was available for the different cancer types. However, the number of cases did not need to be large enough to provide any statistically significant interpretation of the staging results. Time and budget restrictions also needed to be considered when finalising the number of cases.

Instead of focusing on the 5 most common cancer types it was decided that more information would be obtained from studying a caselist comprised of 20 different cancer types. These cancer types were selected on the basis of the most common incident cancers in 2000 apart from non-melanocytic skin cancers. For each of the five most common cancer types 60 cases were selected for staging (Table 1) and for the remaining 15 common cancer types, 20 cases were selected. Cases were randomly selected within the time period defined above, from WACR data files made available to the project staff.

Table 1: Initial Caselist for WA Cancer Staging Project

Type of Cancer	<u>Retrospective cases 1998</u> (Jan-Dec)	<u>Retrospective cases 2002</u> (Jan - June)	<u>Prospective cases 2002</u> (July -Dec)	Total
Prostate	30	15	15	60
Colorectal	30	15	15	60
Melanoma	30	15	15	60
Breast	30	15	15	60
Lung	30	15	15	60
Lymphoma	10	5	5	20
Kidney	10	5	5	20
Bladder	10	5	5	20
Stomach	10	5	5	20
Leukaemia	10	5	5	20
Pancreas	10	5	5	20
Lip	10	5	5	20
Brain	10	5	5	20
Myeloma	10	5	5	20
Thyroid	10	5	5	20
Oesophagus	10	5	5	20
Testis	10	5	5	20
Uterus	10	5	5	20
Ovary	10	5	5	20
Cervix	10	5	5	20
All cancers	300	150	150	600

2.2 Ethics requirements

The University of Western Australia’s Human Rights and Ethics Committee, and the Minister for Health’s Confidentiality of Health Information Committee were approached regarding this project. The project team’s view was that this study represented a study of process and methodology, and adequacy of existing information systems, rather than a study reporting on individual patient outcomes. Both of these bodies agreed with this assessment and advised that formal ethical approval was in their opinion, not required.

Approval for access to medical records was requested from each hospital in which selected cases had been treated. Where required, this request was forwarded on to the hospital Medical Advisory Committee to obtain their approval. All hospitals approached gave approval.

In parallel with these processes, the WACR commenced a process aimed at the addition of staging information to the schedule of data items listed under the Health (Notification of Cancer) Regulations 1981, as those which the Department of Health might legitimately require of doctors and hospital administrators. This was in order to indemnify those health care providers who provide such information on request.

2.3 Database development

An information database for this project was developed in conjunction with the WACR, using Microsoft® Access. The project caselist was imported into the Access database and new variables were added as required. These variables included data on staging information (TNM),

prognostic factors for individual cancer types and administrative items required to facilitate an assessment of the resources used in obtaining the staging information (Appendix C)

The caselist was then linked to data from the WACR and the Hospital Morbidity Data System (HMDS) as contained in the WACR's regular data extracts from this source. The WACR provided data on pathology and details of clinicians treating the patients. HMDS data provided information on which hospitals cases had attended. This information was used in the process of data collection, as hospital medical records are one possible source of staging information not routinely available to the WACR.

2.4 Data collection

There were 4 sources for collecting data for the staging: the WACR, the HBCRs, hospital medical records, and letters to treating doctors. The rationale behind the data collection was to use existing data sources as efficiently as possible. For most cancers, therefore, the order above was the order in which the sources were approached. For some cancers, the availability of specific data sources made other approaches more efficient and these are summarized in section 2.4.2. The process is summarized in the flowchart on the next page.

2.4.1 Steps in obtaining staging information.

Step 1: Source of information: WACR

The first step involved reviewing the pathology reports and death notifications for each case at the WACR and extracting available staging data. Cancer Registry cases who died prior to 1991 have had data stored on microfiche, however more recent cases have had paper records stored or (most recently) archived into electronically-accessible image files. For prospective cases, data could be accessed electronically but for the 1998 cases it was necessary to review hard copies of the pathology reports. Staging data were entered into the database previously described.

If the cancer could not be fully staged at this step, more information was sought for that case by proceeding to step 2.

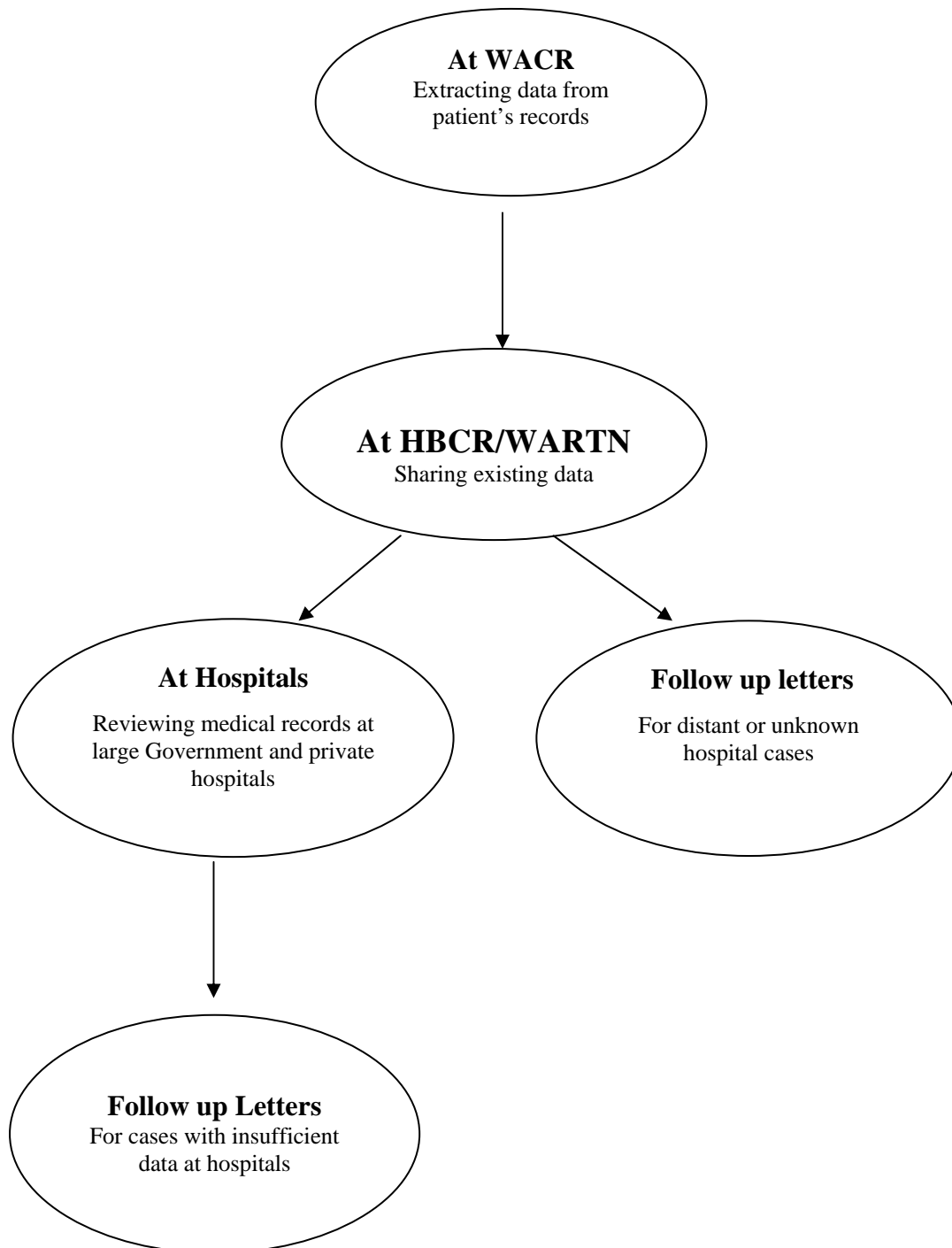
Step 2: Source of information: HBCRs (KEMH, SCGH, RPH and FH)

The second step involved acquiring data from the HBCRs. In the initial stages the project officer visited the HBCRs with a caselist and together with the HBCR staff, reviewed the records for staging data. As the project progressed and professional working relationships were established with the HBCRs, it was only necessary to electronically send a password-protected caselist to the HBCR, which would be returned with the available staging information. This substantially reduced the time required to complete this step.

At the time of writing this report, all HBCRs had agreed to incorporate staging information into their regular data extracts to the WACR and three of four had implemented this process. This is expected to further enhance the collection of statewide staging data from these sources.

If full staging information was not available from Step 2, it was necessary to proceed to Step 3.

Data Collection Summary



Step 3: Source of information: Hospital Medical Records

The third step involved reviewing casenotes at both private and public hospitals. These included three Metropolitan teaching hospitals (SCGH, RPH and FH) and the larger private hospitals (Mount Hospital, Hollywood Hospital, St John of God Hospital). As a hospital visit requires transport and extra time, only hospitals within the Perth metropolitan area were visited. The project officer supplied the Medical Records Department of the particular hospital with the caselists in advance, and casenotes were provided for the project officer to review.

For reasons related to costs, Step 3 was eliminated for cases from country hospitals and from small city hospitals as it was not considered cost-effective to follow these up in person.

If full staging information was not available from Step 3, or Step 3 was eliminated, it was necessary to proceed to Step 4.

Step 4: Source of information: Enquiry letters

In the fourth possible avenue for finding staging data, letters were sent to clinicians requesting staging information. Where possible the appropriate doctor was identified from pathology reports and a letter explaining the project together with a TNM table for the particular cancer type was included (Appendix D). Postal details of the doctor were obtained from the WACR database and project staff linked the cases with the WACR data to obtain these details.

In the letters sent, case details were included, with a table of stage-related data below, for the responding clinician to complete. The TNM tables in such letters were adapted from those in the AJCC Cancer Staging Manual 6th Ed. (2002).³ A reply paid envelope was supplied for returning this information, as is the usual WACR practice whenever seeking information from medical practitioners.

After step 4 was completed, there were still some cancers which could not be staged due to lack of response to a letter, inadequate information being received, or staging procedures having not been performed.

2.4.2 Variations on the usual method of collecting staging information

For some cancers, specific local circumstances meant it was more efficient to undertake the steps in a different order, or to omit some steps. The variations on the usual method of collecting staging information are outlined below.

Gynaecological cancers (cervix, uterus and ovary), are to a large extent treated in King Edward Memorial Hospital (KEMH). KEMH has an active HBCR which collects data on all public patients and most patients treated by private consultants. Staging data from the KEMH HBCR are routinely forwarded to the WACR and contained in a database accessible to WACR and Staging Project staff. The gynaecological cancers at KEMH HBCR are staged using the FIGO system and this FIGO “summary” stage grouping is sent to the WACR, without the individual TNM data. The process followed for these cancers was therefore to access the HBCR first (i.e. Step 2). For cases that could not be staged from the KEMH HBCR data, pathology reports at the WACR were reviewed (Step 1) and following this, if cancers could still not be staged, enquiry letters were sent out (Step 4).

For colorectal cancer, information was obtained initially from the HBCRs (Step 2) and also obtained from the WA Research Tissue Network (WARTN) (see section 1.6.4.4). Cases which could not be staged using these resources then proceeded to Steps 1, 3 and 4 as necessary.

For lymphohaematopoietic malignancies (leukaemia, lymphoma and myeloma) and brain cancers only pathology reports at the WACR were reviewed (Step 1 only).

For melanoma, reviewing casenotes at hospitals was not done, with the knowledge that these cases would normally not require hospital admission for an operation. HBCRS also do not collect melanoma data in WA. The process was therefore Step 1 followed by Step 4.

2.4.3 Summary of staging schemes used for each cancer type

In Table 2, the most promising staging systems for the tumour classes assessed are shown.

Table 2. Most common/recommended staging scheme for each cancer type

Cancer Type	Results on Page	TNM	FIGO	Other
Lip C00*	17	✓		
Oesophagus C15	18	✓		
Stomach C16	19	✓		
Colorectal C18	20	✓		
Pancreas C25	21	✓		
Lung C34	22	✓		
Melanoma C44	23	✓		
Breast C50	24	✓		
Cervix C53	25		✓	
Uterus C54	26		✓	
Ovary C56	27		✓	
Prostate C61	28	✓		
Testis C62	29	✓		
Kidney C64	30	✓		
Bladder C67	31	✓		
Brain C71	32			✓
Thyroid C73	33	✓		
Lymphoma	34			✓
Myeloma	34			✓
Leukaemia	34			✓

* The *Cmn* rubrics in the table are ICD-10 “diagnosis”-code-based labels referring to the “primary site” or “topography” of tumours. For tumours with morphology code \geq M9590, internationally-standardized tabulation routines are based on tumour morphology, rather than topography.

2.5 Data analysis

The main focus of this project was the process of collecting staging data, and not the outcomes. Using SPSS and Microsoft Access, the mean time taken to stage a case for the different cancer types was determined as well as the proportion of cases that could be staged after each step of the staging process. The percentage of cases that could be staged retrospectively and the percentage of cases that could be staged prospectively were also evaluated. From these results, it was intended that a budget for the ongoing collection of staging data at the population level, with various options, would be produced.

3. RESULTS

3.1 General findings

Results for each individual cancer type are presented in the following pages. A brief discussion of the staging and classification system is followed by a table illustrating the number of cases that could be fully staged from each step. All results should be interpreted with caution due to the relatively small numbers of cases included.

3.1.1 Assumptions

In order to definitively stage a cancer, a considerable amount of clinical investigation is required. For example, lymph nodes need to have been dissected or biopsied, or extensive searches for metastases need to have been undertaken. These further investigations have associated costs and risks and may not always be clinically warranted. For example, if a melanoma is found to be level 1, and there is no clinical evidence of spread, investigations such as chest X-rays and bone scans are unlikely to be performed. In addition, some cases do undergo further investigations but the results are held in private rooms, or medical records do not contain any negative information such as the absence of metastases. In addition, doctors may not have responded to our letters asking for information on stage (Step 4). For many of the cases in this study, therefore, it was not possible to stage the cancer definitively because of the lack of information on regional nodal status or the presence or absence of distant metastases. Clinically, many of these cases are most likely to be early stage cancers.

The data for those cases that were not stageable were further examined, and two different assumptions were applied. The first assumption was applied to cases which had data for T and N but which had no assessment of distant metastasis (MX). The assumption made was that MX was equivalent to M0 (no distant metastases). This is summarized as MX=M0 in the tables.

The second assumption was applied to cases with data for T and M, but with no assessment of regional nodal involvement (NX). The assumption made was that NX was equivalent to N0 (no regional nodal involvement). This is summarized as NX=N0 in the tables.

The number of cases that could be staged if both assumptions were made for the same case (ie NX=N0 and MX=M0) was also investigated.

In this study, data are presented with and without these assumptions made to all cases with inadequate data. In reality, these assumptions would need to be applied very cautiously and with considerable input from clinicians. For example, it may be very reasonable to assume that MX=M0 in early breast cancer with known negative nodes. However, it may be less reasonable to make this assumption for a larger breast cancer, with positive nodes.

3.1.2 Description of table format

The first line in each table describes the number and percent of cases able to be staged at each step of the collection process (Steps 1 through 4 as described in Sections 2.4.1 and 2.4.2). The number of cases in each cell represents the number of cases which could be staged at the relevant step (but which had been unable to be staged at any previous step). The total for the first line is the total number of cases able to be fully staged (ie the sum of the 4 cells).

The next rows in the column describe the results when the assumptions described above have been made. That is, for those cases still unstaged after all four steps, (1) how many additional cases could be staged, if the assumption $MX=M0$ was made; (2) how many further cases could be staged if the assumption $NX=N0$ was made; (3) how many additional cases could be staged if both assumptions were made; (4) the total number of cases staged including those fully staged with and without assumptions; and (5) the total number of cases not stageable, even after making the assumptions.

In addition, for four cancers (lung, breast, melanoma and prostate) we examined the effect of making the assumption $MX=M0$ after each step of data collection process (e.g. after examining only the pathology reports held at the WACR). For prostate and melanoma the number of cases that could be staged at each step if both assumptions were made for the same case (ie $NX=N0$ and $MX=M0$) is presented. These values are shown below the first line for these cancers.

The average amount of time per case taken to review the WACR data and hospital medical records is also displayed in the last rows of the table separately for the 1998 and 2002 cases.

A brief statement outlining the main barriers to acquiring staging data concludes each section.

3.2 Lip – C00

Staging and Classification System

Lip cancer is staged using the AJCC/TNM system. However, the AJCC also strongly recommend using the Karnofsky Performance Status (KPS) along with standard staging information. KPS provides information on the patient's functional status and the scale is in 10 point increments from 0 (dead) to 100 (normal). However the KPS is not explicitly used in staging of lip cancers and therefore not necessary to be collected at the population level for complete staging.

Results

Number of cases: 19 (9 from 1998; 10 from 2002). 1 case excluded as file missing.

Table 3: Lip cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	0 (0%)	n/a	1 (5%)	6 (32%)	7 (37%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					1 (5%)
Assume NX=N0.					0
Both assumptions					8 (42%)
No. (%) of cases staged including assumptions:					16 (84%)
No. (%) of cases not stageable					3 (16%)
Mean time (minutes) to stage 1998 cases.	5		3		
Mean time (minutes) to stage 2002 cases.	4		7		

Summary

Seven lip cancer cases could be staged and this number increased to eight with the assumption that MX=M0. It was not possible to stage any cases from pathology reports at the WACR. Three cases had no information on TNM and 16 cases had data on T only.

Barriers

Obtaining staging information on lip cancer was limited by the specimen type collected. Biopsies were able to provide T status, but do not describe N or M. Lip cancer staging data was not collected by any of the HBCRs.

3.3 Oesophagus - C15

Staging and Classification System

Oesophageal cancer is staged using the AJCC/TNM staging scheme. Endoscopic ultrasound (EUS) is performed on many patients and can assist in providing information on the T and N status of patients with oesophageal cancer.

Results

Number of cases: 20 (10 from 1998; 10 from 2002)

Table 4: Oesophageal cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	0 (0%)	0 (0%)	5 (25%)	5 (25%)	10 (50%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					3 (15%)
Assume NX=N0.					0
Both assumptions					1 (5%)
No. (%) of cases staged including assumptions:					14 (70%)
No. (%) of cases not stageable					6 (30%)
Mean time (minutes) to stage 1998 cases.	6.5		10		
Mean time (minutes) to stage 2002 cases.	7.5		8		

Summary

Ten oesophageal cancer cases could be staged but this increased to 13 if MX cases were assumed to be M0. Six cases had no data on T, N or M and one case had information on T only.

Barriers

Consultation with local clinicians indicated that some patients are treated for their cancer with radiotherapy and/or chemotherapy prior to surgery, which will mean that TNM recorded at the time of surgery does not accurately reflect stage at diagnosis.

Furthermore, oesophageal cancer reports were often based on biopsies and as such yielded no information on N and M status.

Only one HBCR (RPH) has been collecting information on oesophageal cancer.

3.4 Stomach - C16

Staging and Classification System

Stomach cancer is staged using the AJCC/TNM staging system. Another classification system (Borrman's classification) is used but requires very explicit pathology reports. The Borrman system has 5 categories: type I tumours are polypoid or fungating; type II have ulceration surrounded by elevated borders; type III have ulceration with invasion of the gastric wall; type IV are diffusely infiltrating and type V cannot be classified.¹¹ The wording in pathology reports is usually insufficient to allow use of this system and this project followed the TNM staging system.

Results

Number of cases: 20 (10 from 1998; 10 from 2002)

Table 5: Stomach cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	5 (25%)	0 (0%)	5 (25%)	4 (20%)	14 (70%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					5 (25%)
Assume NX=N0.					0
Both assumptions					1 (5%)
No. (%) of cases staged including assumptions:					20 (100%)
No. (%) of cases not stageable					0
Mean time (minutes) to stage 1998 cases.	8		8		
Mean time (minutes) to stage 2002 cases.	9		7		

Summary

Fourteen cases of stomach cancer were able to be staged, but this increased to nineteen if five MX cases were assumed to be M0. Amongst these five cases was one with more advanced disease, T4N1, raising the issue that some cases may need to be excluded if this assumption is to be followed.

Barriers

The main barrier to staging stomach cancer lies in obtaining information on M status.

Only one HBCR (RPH) collected information on stomach cancer.

3.5 Colorectal – C18

Staging and Classification System

Several different classification systems exist for colorectal cancer. The most widely used are the TNM system and the Duke's classification system. The Duke's classification system separates colorectal cancers into four groups, Stage A to D.¹² Stage A tumours are confined to the bowel wall. Stage B tumours involve or penetrate through the serosa. Stage C tumours have involvement of lymph nodes and Stage D tumours have metastasized. The TNM system is compatible with the Duke's classification (Stage A in Duke's classification is equivalent to Stage I in the TNM system), however the TNM system identifies subgroups within each stage, increasing prognostic utility.

Results

Number of cases: 60 (30 from 1998; 30 from 2002)

Table 6: Colorectal cancer staging results

	Step 1 HBCR/ WARTN	Step 2 WACR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	25 (41%)	7 (12%)	7 (12%)	9 (15%)	48 (80%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					7 (12%)
Assume NX=N0.					0
Both assumptions					4 (7%)
No. (%) of cases staged including assumptions:					59 (99%)
No. (%) of cases not stageable					1 (1%)
Mean time (minutes) to stage 1998 cases.		6	5		
Mean time (minutes) to stage 2002 cases.		8	7		

Summary

Forty-eight (80%) of colorectal cancers could be staged and this increased to 55 (92%) with the assumption of MX=M0. Three cases included in this assumption were more advanced, T3N1, and it may not be appropriate to apply the assumption to these cases. Very few pathology reports at WACR contained any information on M status. Some of these reports contained histological results from liver biopsies.

Barriers

The main barrier to staging colorectal cancer was obtaining information on M status.

3.6 Pancreas - C25

Staging and Classification Systems

Pancreatic cancer can be staged using either the AJCC/TNM staging system or the Japanese staging system. In 1980 the Japanese Pancreas Society (JPS) published a guideline for staging pancreatic cancer that contained factors in addition to those used in the TNM classification.¹³ For example in the JPS system, the T category is categorised in regard to six factors concerning degree of invasion: anterior pancreatic capsule, retroperitoneal tissue, portal venous system, arterial system, distal bile duct and duodenal wall.

However, the AJCC/TNM system is more widely used in WA. Locally, standard pathology reports appear unlikely to support the additional detail required by the Japanese staging system.

Results

Number of cases: 20 (10 from 1998; 10 from 2002)

Table 7: Pancreatic cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	9 (45%)	0 (0%)	4 (20%)	1 (5%)	14 (70%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					2 (10%)
Assume NX=N0.					0
Both assumptions					1 (5%)
No. (%) of cases staged including assumptions:					17 (85%)
No. (%) of cases not stageable					3 (15%)
Mean time (minutes) to stage 1998 cases.	9		7		
Mean time (minutes) to stage 2002 cases.	7		6		

Summary

Fourteen cases of pancreatic cancer could be staged but this increased to sixteen if MX cases were assumed to be M0. All of the nine cases that could be staged at WACR were stage IV. There were two cases for which no information was available on T, N or M and one case had information on N and M, but no data on T to distinguish between stage II and stage III.

Barriers

One difficulty in staging pancreatic cancer occurred when the specimen was only a biopsy or FNA. Although the biopsy may prove the case is malignant it provides no information on T, N or M status. An exception to this was when the biopsy or FNA was sampled from a site of distant metastasis and the case is therefore a Stage IV.

3.7 Lung – C34

Staging and Classification Systems

Lung cancer is staged using the AJCC/TNM classification system. The recent purchase of a PET scanner in November 2002 will be an important contributor to lung cancer staging in WA. The inclusion of PET results in clinical staging will cause a stage migration, as PET scans are more sensitive and specific than CT scan for detecting mediastinal lymph nodes.

Results

Number of cases: 60 (30 from 1998; 30 from 2002)

Table 8: Lung cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No.(%) of cases fully staged from each step	11 (18%)	12 (20%)	18 (30%)	5 (8%)	46 (76%)
No.(%) of cases staged assuming MX=M0	26 (43%)	8 (13%)	14 (23%)	4 (7%)	52 (86%)
Not stageable					8 (14%)
Mean time (minutes) to stage 1998 cases.	8		4		
Mean time (minutes) to stage 2002 cases.	7		5		

Summary

Forty-six (76%) cases of lung cancer could be staged and this number increased to 52 (86%) when assuming that MX=M0. Six cases reviewed had no information available on T, N or M status, two cases had information only on T but not N and M.

If we assumed MX=M0 at each step we were able to stage 43% of cases at step 1.

Barriers

A difficulty concerning the staging of lung cancers was that many pathological specimens were simply fine needle aspirations (FNAs) and biopsies, and therefore could not be fully staged. Lung cancer staging accordingly will be based on information from the surgeons and referring physicians, and pathology reports alone cannot be expected to provide significant staging information.

3.8 Melanoma – C44

Staging and Classification System

The AJCC/TNM staging system for melanoma is widely used and accepted. It appears that the most important prognostic factor for melanoma is tumour thickness (Breslow), although depth of invasion (Clark) is also used to distinguish between T1a and T1b tumours.^{14,15} Together with collecting data on T, N and M status the full staging of melanoma also requires information on ulceration, site of distant metastasis and lactate dehydrogenase (LDH) level. The presence or absence of ulceration determines the T categories. The LDH level and the site of distant metastasis divide the M category in three subcategories (M1a, M1b and M1c).

Results

Number of cases: 60 (30 from 1998; 30 from 2002)

Table 9: Melanoma staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No.(%) of cases fully staged from each step	0 (0%)	0 (0%)	-	34 (57%)	34 (57%)
No.(%) of cases staged assuming MX=M0	0 (0%)	0 (0%)	-	35 (59%)	35 (59%)
No.(%) of cases staged assuming Nx=N0 and MX=M0	60 (100%)	-	-	-	60 (100%)
Not stageable					0 (0%)
Mean time (minutes) to stage 1998 cases.	7.5	n/a	n/a		
Mean time (minutes) to stage 2002 cases.	7				

Thirty-four (57%) melanoma cases could be staged and this increased to 35 (59%) when assuming that MX=M0. If we assumed NX=N0 we were able to stage a further three cases. It was not possible to stage any cases from reports at the WACR alone, as no reports held any information on N or M status. If the assumption NX=N0 and MX=M0 was applied at Step 1, 100% of cases could be staged after only reviewing reports at WACR. Out of 34 cases which were fully staged, 33 (97%) cases were classified as N0 and M0.

The stage results from enquiry letters include an additional 7 results from 24 reminder letters which were sent when there had been no reply after 11 weeks to the initial enquiry letter.

Barriers

The collection of information concerning LDH level and presence or absence of ulceration is an anticipated difficulty for the staging of melanoma. However, information on the LDH level does not differentiate a tumour into different stages, but rather subcategories of stage IV disease.

The main limitation to staging melanoma was the lack of information available on N and M status.

3.9 Breast – C50

Staging and Classification System

The TNM system for staging breast cancer is widely accepted and used. Through meetings with local clinicians it has become apparent that oestrogen and progesterone receptor status is also regarded as very important, though not required for staging.

In WA, both BreastScreen and the WACR currently collect information on tumour size and lymph node status. BreastScreen collect information (including staging data) on approximately 30 – 40% of all breast cancers, and as their information comes from screen-detected tumours they tend to be at an earlier stage.

Results

Number of cases: 60 (30 from 1998; 30 from 2002)

Table 10: Breast cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	0 (0%)	7 (12%)	11 (18%)	21 (35%)	39 (65%)
No.(%) of cases staged assuming MX=M0	52 (86%)	1 (2%)	1 (2%)	3 (5%)	57 (95%)
Not stageable					3 (5%)
Mean time (minutes) to stage 1998 cases.	8		4		
Mean time (minutes) to stage 2002 cases.	7		5		

Summary

Thirty-nine (65%) cases of breast cancer were able to be staged, and this number increased to 57 (95%) when cases with MX were assumed to be M0. Of these 18 cases, two (T4N1, T1bN1) were possibly a later stage disease and the assumption of MX=M0 may not be appropriate for such cases.

If the MX=M0 assumption was applied at step 1 over 80% of breast cancers could be staged at WACR. Less than 10% of cases could be staged from working through 3 more steps (HBCRs, hospital medical records and enquiry letters). The numbers that could be staged at HBCRs may appear low, but would be considerably higher in the long term (see Section 4.3.1).

Barriers

At the time of this report, node-negative biopsies were not, strictly-speaking, legally-notifiable, and a revision of the Health (Notification of Cancer) Regulations 1981 has been sought, to incorporate provision of “related reports” as a legal requirement.

As can be seen by the increase to 95% of cases staged when applying the MX=M0 assumption, the main barrier to staging breast cancer was in acquiring the information on M status.

3.10 Cervix – C53

Staging and Classification System

Cervical cancer is commonly staged using either the FIGO staging system or the TNM/AJCC staging system. These two staging systems are identical and completely interchangeable. The KEMH HBCR is using the FIGO staging system. This is also the case for uterine and ovarian cancer.

Results

Number of cases: 19 (10 from 1998; 9 from 2002) 1 case excluded as it was an in-situ case.

Table 11: Cervical cancer staging results

	Step 1 KEMH HBCR	Step 2 WACR	Step 3 Letters	Total
No. (%) of cases fully staged from each step	15 (79%)	3 (16%)	1 (5%)	19 (100%)
Cases requiring assumptions for staging:				
Assume MX=M0.				0
Assume NX=N0.				0
Both assumptions				0
No. of cases staged including assumptions:				19 (100%)
Not stageable				0
Mean time (minutes) to stage 1998 cases.		5		
Mean time (minutes) to stage 2002 cases.		6		

Summary

Nineteen (100%) cases of cervical cancer could be staged. Fifteen of these cases were staged from the KEMH HBCR.

3.11 Uterus – C54

Staging and Classification System

As for cervix..

Results

Number of cases: 20 (10 from 1998; 10 from 2002)

Table 12: Uterine cancer staging results

	Step 1 KEMH HBCR	Step 2 WACR	Step 3 Letters	Total
No. (%) of cases fully staged from each step	7 (35%)	10 (50%)	2 (10%)	19 (95%)
No. (%) cases requiring assumptions for staging:				
Assume MX=M0.				0
Assume NX=N0.				0
Both assumptions				0
No. of cases staged including assumptions:				19 (95%)
No. (%) cases not stageable				1 (5%)
Mean time (minutes) to stage 1998 cases.	2	6		
Mean time (minutes) to stage 2002 cases.	2	6.5		

Summary

Nineteen cases (95%) of uterine cancer cases could be staged.

3.12 Ovary – C56

Staging and Classification System

As for cervix.

Results

Number of cases: 20 (10 from 1998; 10 from 2002)

Table 13: Ovarian cancer staging results

	Step 1 KEMH HBCR	Step 2 WACR	Step 3 Letters	Total
No. (%) of cases fully staged from each step	8 (40%)	12 (60%)	n/a	20 (100%)
No. (%) cases requiring assumptions for staging:				
Assume MX=M0.				0
Assume NX=N0.				0
Both assumptions				0
No. (%) of cases staged including assumptions:				20 (100%)
No. (%) of cases not stageable				
Mean time (minutes) to stage 1998 cases.	2	6		
Mean time (minutes) to stage 2002 cases.	2	7		

Summary

Twenty cases (100%) of ovarian cancer could be staged.

3.13 Prostate – C61

Staging and Classification System

Prostate cancer is staged using the AJCC/TNM staging system. This staging scheme also requires data on the histopathological grade of the tumour.

The Gleason system for prostate cancer has 5 grades, designated 1 through 5, with 1 being well differentiated and 5 being poorly differentiated. Some, but not all, pathologists report this variable. It has been suggested that the “%4/5” or the proportion of Gleason grades 4 or 5 in the tumour is another potential staging variable.

Results

Number of cases: 60 (30 from 1998; 30 from 2002)

Table 14: Prostate cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. of cases fully staged from each step	1 (2%)	2 (3%)	4 (7%)	13 (22%)	20 (34%)
No.(%) of cases staged assuming MX=M0	8 (13%)	2 (3%)	6 (10%)	7 (12%)	23 (38%)
No.(%) of cases staged assuming NX=N0 and MX=M0	54 (90%)	1 (2%)	1 (2%)	2 (3%)	58 (97%)
Not stageable					2 (3%)
Mean time (minutes) to stage 1998 cases.	5		6		
Mean time (minutes) to stage 2002 cases.	4		5		

Summary

Twenty cases (34%) of prostate cancer could be staged with the number increasing to 23 (38%) with the MX=M0 assumption. For 27 cases there was only data on T status. Eight cases had information available on both T and M, but no data on N status. Most data were achieved at Step 4, the most labour intensive step. If both assumption of NX=N0 and MX=M0 were applied at step 1, 90% of cases could be staged from reports at the WACR.

Barriers

The main barrier to staging prostate cancer was the lack of information available on N status, with 37 cases out of 60 having no such data available.

3.14 Testis – C62

Staging and Classification System

Testicular cancer is staged using the AJCC/TNM staging system. In addition to T, N and M status this scheme also requires information on the serum tumour markers, collected pre-operatively. These tumour markers are beta-HCG and alpha-feto-protein.

Results

Number of cases: 20 (10 from 1998; 10 from 2002)

Table 15: Testicular cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	2 (10%)	0 (0%)	4 (20%)	9 (45%)	15 (75%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					0
Assume NX=N0.					0
Both assumptions					3 (15%)
No. (%) of cases staged including assumptions:					18 (90%)
No. (%) of cases not stageable					2 (10%)
Mean time (minutes) to stage 1998 cases.	5		8		
Mean time (minutes) to stage 2002 cases.	6		7		

Summary

Fifteen cases of testicular cancer were able to be staged. Two cases had no information available on T, N or M status and three cases had data on T, but nothing on N or M. However the MX=M0 assumption could not be applied as the cases with MX also had data missing on serum tumour markers.

Barriers

The main barriers to staging testicular cancer was in obtaining information on N, M and serum tumour marker status. Collection of the serum tumour markers would require significant additional resources at a cancer registry level, where results of such tests are not routinely received. Only one HBCR (RPH) collects information on testicular cancer.

3.15 Kidney – C64

Staging and Classification System

Kidney cancer is staged using the AJCC/TNM staging system. The TNM staging system for kidney cancer applies only to renal cell carcinoma, and does not include transitional cell carcinomas.

Results

Number of cases: 20 (10 from 1998; 10 from 2002)

Table 16: Kidney cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	3 (15%)	1 (5%)	3 (15%)	6 (30%)	13 (65%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					1 (5%)
Assume NX=N0.					3 (15%)
Both assumptions					2 (10%)
No. (%) of cases staged including assumptions:					19 (95%)
No. (%) of cases not stageable					1 (5%)
Mean time (minutes) to stage 1998 cases.	6		7		
Mean time (minutes) to stage 2002 cases.	4		7		

Summary

Thirteen cases of kidney cancers could be staged with this number increasing to 14 when assuming that MX=M0. One case had no data available on either T, N or M.

Barriers

Obtaining data on N and M status was the main barrier to effectively staging kidney cancer. Only one HBCR collected information on kidney cancer.

3.16 Bladder – C67

Staging and Classification System

The staging system for bladder cancer is based on the TNM system. Bladder cancers can also be classified as superficial or invasive. About 80% of superficial bladder cancers remain in the mucosa and submucosa. However, most invasive bladder cancers have penetrated through the muscle layers and are associated with a poor prognosis.

Results

Number of cases: 20 (10 from 1998; 10 from 2002)

Table 17: Bladder cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	0 (0%)	0 (0%)	6 (30%)	2 (10%)	8 (40%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					3 (15%)
Assume NX=N0.					1 (5%)
Both assumptions					7 (35%)
No. (%) of cases staged including assumptions:					19 (95%)
No. (%) of cases not stageable					1(5%)
Mean time (minutes) to stage 1998 cases.	10		6		
Mean time (minutes) to stage 2002 cases.	9		7		

Summary

Eight cases of bladder cancers were able to be fully staged, but this increased to 11 cases with the assumption of MX=M0. If both assumptions were applied 19 cases could be staged.

Barriers

The main barrier to staging these cancers was obtaining information on N and M. Two HBCRs collected information on bladder cancer, however, none of the cases being studied had been recorded at the HBCRs.

3.17 Brain – C71

There is no internationally accepted scheme for the staging of brain cancer. Tumour size has a much lesser importance than the histology and location of the tumour. As there is no lymphatic system within the brain the “N” classification is irrelevant. “M” classification is commonly thought to be also relatively unimportant, as many patients with brain tumours do not live long enough to develop metastatic disease.

However, consultation with local clinicians suggested that additional data that would be worth collecting at the population level include site of the tumour (already collected by WACR) and whether the tumour is unilateral or bilateral (may require further data in some cases).

Results

The pathology reports at the WACR were reviewed and there was no extra available information available.

Barriers

The main barrier to staging brain cancer was the lack of an internationally recognised staging scheme.

3.18 Thyroid – C73

Staging and Classification System

Thyroid cancer is staged using the AJCC/TNM staging system. The staging of thyroid cancer also takes into account the age of the patient and the histopathological type of cancer. The four major histopathological types are papillary carcinoma, follicular carcinoma, medullary carcinoma and anaplastic/undifferentiated carcinoma.³ For the purposes of staging however, follicular and papillary carcinoma are categorised together. WACR system already records morphologic type of tumour and age at diagnosis.

Results

Number of cases: 19 (10 from 1998; 9 from 2002)

Table 18: Thyroid cancer staging results

	Step 1 WACR	Step 2 HBCR	Step 3 HMR	Step 4 Letters	Total
No. (%) of cases fully staged from each step	2 (10%)	0 (0%)	3 (16%)	4 (21%)	9 (47%)
No. (%) of cases requiring assumptions for staging:					
Assume MX=M0.					6 (32%)
Assume NX=N0.					1 (5%)
Both assumptions					2 (11%)
No. (%) of cases staged including assumptions:					18 (95%)
No. (%) of cases not stageable					1 (5%)
Mean time (minutes) to stage 1998 cases.	8		5		
Mean time (minutes) to stage 2002 cases.	8		5		

Summary

Nine cases (47%) of thyroid cancer could be staged and the number increased to 15 (79%) if we assumed MX=M0. Of these six cases, three had positive lymph nodes and one case was T4aN1MX. However, for the grouping of thyroid cancer into stages, M0 or M1 only distinguishes between stage IVA or IVC, so the issue of the T and N status being more advanced is not the concern it is for some other cancers. This would imply that the assumption MX=M0 is appropriate for thyroid cancer and likely to be correct in the majority of cases.

Barriers

The main barrier to staging thyroid cancer was acquiring information on M status. Only one HBCR collected information on thyroid cancer, but none of those on the caselist were available at this HBCR.

3.19 Lymphohaematopoietic malignancies

The issues pertaining to the staging of the three main types of lymphohaematopoietic malignancies were very similar. The staging and classification systems will first be discussed for each of these followed by a combined results table and discussion of the common barriers to staging these cancers.

3.19.1 Lymphoma

Classification

There are two major groups of lymphomas - Hodgkin lymphoma and non-Hodgkin Lymphoma (NHL). In this project it was decided to collect staging data only for the NHL cases, as Hodgkin lymphoma is much less common.

Over the years there have been several different histological classification systems for NHL. The Rappaport classification of NHL was introduced in 1956 and became very popular with clinicians and was very widely used.¹⁶ By the late 1970s there were several other classification systems in use throughout the world. In an attempt to develop one universal system, the Working Formulation, based only on histologic information, was developed and published in 1982. Following this, the Revised European American Lymphoma (REAL) classification from the International Lymphoma Study Group was published in 1994. The REAL classification has gained acceptance as the new standard lymphoma classification.

Staging

The Ann Arbor staging classification was first developed for Hodgkin lymphoma but is also accepted as useful for staging NHL, and is included in the AJCC manual. However, other factors are also very important in determining prognosis for patients with lymphoma. This has led to the development of the International Prognostic Index, which identifies 5 significant risk factors, which are thought to determine overall survival probability.² These factors include age, serum lactate dehydrogenase level (LDH), performance status, stage and extranodal site involvement.

3.19.2 Myeloma

Staging

The staging of myeloma is determined using the Durie-Salmon staging system. In this staging scheme, stage is determined by the level of M protein (including Immunoglobulin G (IgG), Immunoglobulin A (IgA), and Bence Jones protein level), the number of lytic bone lesions, haemoglobin concentration and serum calcium. There are three stages (I, II and III) in the Durie-Salmon staging system.¹⁷

3.19.3 Leukaemia

Classification

Leukaemias were originally classified as either acute or chronic, depending on life expectancy but are now classified according to cellular maturity. The acute leukaemias are comprised of mostly immature cells and the chronic leukaemias consist of leukaemias with more mature cells. The acute leukaemias are further subdivided into lymphoblastic (ALL) and myelogenous (AML). These can be further subdivided into categories according to the French-American-British (FAB) classification system based on their morphologic and cytochemical appearance. The chronic leukaemias are divided into lymphocytic (CLL) or myelocytic (CML).¹⁸

Staging

The Rai and Binet systems can be used for staging CLL and this system divides the leukaemia into 3 different stages, I through III. CML can be divided into three stages: chronic or stable, accelerated and acute or blast crisis.

3.19.4 Overview of lymphohaematopoietic malignancies

Table 19: Results for the lymphohaematopoietic malignancies

	Lymphoma	Myeloma	Leukaemia
No. of cases	18*	20	20
No. (%) of cases staged from WACR	8 (44%)	0 (0%)	0 (0%)
Mean time (mins) to stage 1998 cases	5	6	4
Mean time (mins) to stage 2002 cases	6	4	6

*Two cases were excluded from the lymphoma caselist. One case was actually from 1996 and not 1998, and a second case was actually Hodgkin's lymphoma, and not NHL.

Summary

Eight (44%) lymphoma cases could be staged from reports at the WACR using the Ann Arbor system. All of these cases were positive bone marrow biopsies, indicative of Stage IV disease. It was not possible to stage any of the myeloma or leukaemia cases from reports at the WACR. There was no staging or classification information available in the pathology reports at the WACR.

Barriers

The problem with the need for collection of clinical data was an area of difficulty for the staging of all the lymphohaematopoietic malignancies. Accurate staging requires information that is not routinely available to the WACR. For CLL, for example, staging includes data on lymphocytosis, haemoglobin levels, platelet count, presence or absence of splenomegaly and hepatomegaly, and number of node-bearing areas. This level of clinical information required made it difficult to accurately stage these cancers. The need for clinical information for the staging of the haematological neoplasms made the staging of these cancers difficult.

4. DISCUSSION

4.1 Results Overview

The main conclusion from this feasibility study is that staging completeness is very dependent on cancer site. Each site has its own issues and complications. However, in order to summarize the results we have grouped some sites together as follows:

- Group A: cancers for which virtually complete staging data could be obtained relatively easily. Staging could be started now.
- Group B: cancers for which relatively high proportions of cancers could be fully staged, and for which the assumption $MX=M0$ allows almost complete staging. Staging could be started now, if it was considered reasonable to apply this assumption.
- Group C; cancers which can almost all be staged making the assumptions $NX=N0$ and $MX=M0$. Staging could be started now, if it was considered reasonable to apply this assumption.
- Group D; cancers for which staging could be started now, but for which it is more risky to apply the assumptions. Staging could be started now, but long term collection requires system changes in order to obtain better information.
- Group E; cancers for which staging is not feasible at present.

Group A cancers (Table 20) consisted of the gynaecological cancers: ovary, cervix and uterus. For cancers in Group A the use of the KEMH HBCR was clearly crucial, increasing the stageable proportion of cases from 60% to 100% for ovarian cancer and from 16% to 95% for cervical cancer. For these cancers there was no need to apply any assumptions. These cancers could be staged now.

Group B cancers consisted of breast and colorectal cancer. For these two cancers, a reasonable number of cases could be staged fully using the standard 4 steps. For colorectal cancer, 80% of cases could be staged after all four steps were completed, with this increasing to 92% if the assumption $MX=M0$ was applied. For breast cancer 65% of the cases could be staged after all four steps were completed, increasing to 95% when applying the assumption $MX=M0$. However, if this assumption was applied at Step 1 (refer Table 10), 86% of cases could be staged through reviewing reports at the WACR. The completion of the next three steps only yielded a 9% increase in the percentage of cases staged.

If it is not thought appropriate to apply the $MX=M0$ assumption to all unstaged breast and colorectal cancer cases, an alternative strategy would be to work with clinicians in order to develop rules about for which cases it would be appropriate to apply this assumption. A separate study (summarized in Appendix E) suggests that it is safe to make the $MX=M0$ assumption in 90% of breast cancer cases with T1,T2 or T3 and either N0 or N1 and about 85% of similar colorectal cancer cases.

Group C cancers included melanoma and prostate cancer. Cancer types in Group C could be staged now, but only if both assumptions of $NX=N0$ and $MX=M0$ were applied. For prostate cancer, only 34% of cases could be staged after completing all four steps. However, if both these assumptions were applied at step 1 (Table 14), 90% of cases could be staged. Similarly, for melanoma, 100% of cases could be staged at step 1 (Table 9) after including both assumptions. Again, the acceptability of these assumptions does need to be ascertained. For example, for melanomas below Clark level 1, it may be quite reasonable to assume that $NX=N0$

and MX=M0. This may not be an acceptable assumption for thicker melanomas, or for prostate cancer.

Group D cancers include cancers of the stomach, lung, pancreas, thyroid, testis and kidney. Cancer types in Group D could be staged now, but there would be a requirement for additional clinical input to achieve this.

Making the assumption of MX=M0, a relatively high proportion of cases may be able to be staged. However, the acceptability of the assumptions differs among cancers. For example, for thyroid cancer, the presence of distant metastases is only relevant in classifying a cancer into stage IVA or IVB. For this cancer, it may be quite reasonable to make the MX=M0 assumption. For lung cancer, 76% of cases could be staged after all four steps, without applying assumptions. Although preliminary results of further investigation suggest that the MX=M0 assumption may be valid for many lung cancer cases (Appendix E), any decision to use it routinely should be deferred pending further discussion with clinicians. For stomach and pancreatic cancer, the viability of the MX=M0 assumption is questionable as these cancers are often at a late stage when diagnosed. For kidney cancer, even with the MX=M0 assumption, a relatively low proportion of cancers could be staged. Staging of testis cancer requires detailed clinical information on serum markers which is almost always carried out by the treating clinician but is difficult for cancer registries to obtain routinely.

To obtain a near-completeness of staging for these cancer types, funding and resources would be required to enable all four steps to be completed. In addition, increasing the proportion of cancers stageable would require a greater level of input from clinicians than currently exists. For instance, the use of synoptic pathology reports would assist the staging of these cancers, by providing a consistent approach to staging, as well as an easy format for the clinicians to provide this information to the WACR. Expansion of the HBCRs to cover some or all of these cancers would also increase the proportion of cases which can be staged, and the efficiency of staging.

A further issue that must be considered is whether staging in a Cancer Registry setting is worthwhile if reasonable levels of completeness cannot be achieved. For example, it may be hard to justify collection of data for kidney, testis, thyroid or pancreatic cancer as 20% - 30% of cases in a statistical analysis would be “missing values” and likely to render the results questionable. The routine use of reminder letters can improve staging completeness and bring results for thyroid cancer up to a more reasonable 84%, but completeness for kidney cancers would remain low at 78% (Appendix F).

Cancer types in Group E are not able to be staged at present. After all four steps were completed, only 50%, 40% and 37% of cases could be staged, for oesophagus bladder and lip, respectively, and these low levels of staging cannot support reasonable statistical analysis (Table 20). These levels of completeness are still inadequate even after applying the assumption MX=M0. No myeloma or leukaemia cases could be staged at only step 1, and the only lymphoma cases that could be staged were Stage 4. The amount of clinical information required for these cancers goes far beyond the pathological details available. There is no accepted staging system for brain cancer.

Table 20. Percentage of cases staged, by cancer type and process used

Cancer type	Staged from WACR data alone (%)	Staged from WACR and HBCRs, WARTN (%)	Staged after all completed steps (no assumptions) (%)	Staged after all steps with assumption/s (%)
Group A: Could be staged now				
Ovary	60^	100	100	100
Cervix	16^	95	100	100
Uterus	50^	85	95	95
Group B: Could be staged now, making MX=M0 assumption				
Breast	0	12	65	95
Colorectal	12^	53	80	92
Group C: Could be staged now, with NX=N0 and MX=M0 assumptions				
Melanoma	0	(0)	57	100
Prostate	2	5	34	97
Group D: Could be started now with MX=M0, but long term collection requires system changes				
Stomach**	25	25	70	95
Lung	18	38	76	86
Pancreas	45	45	70	80
Thyroid**	10	10	47	79
Testis**	10	10	75	75
Kidney**	15	20	65	70
Group E: Staging not feasible at present				
Oesophagus**	0	0	50	65
Bladder**	0	0	40	55
Lip	0	(0)	37	42
Lymphoma	44	(44)	44	44
Myeloma	0	(0)	0	0
Leukaemia	0	(0)	0	0
Brain	0	(0)	0	0

^ These numbers could have been higher as the external databases were searched first, and WACR later searched only for incomplete cases.

** Only one HBCR currently collects data on these cancers except bladder, for which two HBCRs are collecting data.

() Numbers in parentheses indicate that the additional data source/s indicated by the column header, was/were not accessed as they were either not applicable to the cancer type, or research suggested the additional effort would be unrewarding. Percentages shown are cumulative, beginning from the left.

4.2 Barriers to the collection of staging data

The process of attempting to collect staging data for a variety of different cancer types facilitated the identification of several barriers to collecting staging data that were common to many of the cancer types.

4.2.1 Current resources

Currently there is no system in place for the ongoing collection of staging data at a population level. This currently presents as a barrier, as funding will be required to enable the employment of staff and provision of resources for this collection. Current WACR resources are fully utilised in maintaining the basic data collections as well as certain specific additional items such as breast cancer size and nodal status, at a time when population growth and increased public demand for medical services inexorably increases the amount of data handled. Computer-related processes have already been improved to more efficiently handle such data. However

there is no substitute for the human intervention required to accurately assess and summarize the data derived from disparate sources. The Registry is required to meet certain expectations regarding completeness, quality and maximum use of data-linkage opportunities in all data collections. Any expansion of the range of data items routinely collected would require appropriate additional resources. As can be seen in section 4.4 those resources depend on the choice of cancer types for which to collect staging data.

4.2.2 Information not forwarded to WACR

The WACR routinely receive reports from pathologists and radiation oncologists. However, information on both N and M status can be obtained from reports on CT scans, X-rays and PET scans that are not routinely forwarded to the WACR. This information is also not always easily accessed through hospital medical records, making it more difficult to fully stage cases. This highlights the importance of, and need for, greater clinical input to provide information on the staging of cancer cases. Some information not routinely supplied may be crucial to staging, such as hormonal assays for testicular cancer, negative lymph node biopsies for breast cancer, and haemoglobin level and cell counts in leukaemia; access to such information might be improved by use of “tick boxes” or other reminder formats on pathology request forms.

4.2.3 Specimen unsuitable for staging

Pathology reports provided the majority of the information on staging. The amount of available information on T, N and M depended on the type of specimen submitted for histological examination. For example, some lung cancers were clinically decided to be inoperable and it was not possible to obtain full information on T, N and M when the specimen was simply a FNA or a biopsy, and no further medical investigation was planned. This will be a potential barrier for the ongoing collection of staging data as it simply will not be possible to fully stage all cases, due to restrictions of specimen type. This again highlights that without significant clinical input, staging of many cancer cases will not be possible. An important exception to this is when a specimen is collected from a site of distant metastasis, and the tumour can thus be assigned to Stage IV without further information.

4.2.4 Applying assumptions

It was possible to stage more cases for several cancer types when the assumption $MX=M0$ was applied. However, there is an associated risk, in that some cases will have the assumption applied when there is distant metastasis present, resulting in an under-staging. This risk would seem to be greater for cases who present with a later stage for T and N, but have no data on M available. The risk may also vary between cancers, the assumption being more suitable for some cancer types than for others. Decisions regarding the acceptability of this assumption need to be clarified by specialist clinicians working with particular cancer types.

For the purpose of this pilot study to illustrate the risk of making assumption for different type of cancers and a case with a later stage for T and N status, a preliminary sub-analysis funded by WACOG using existing data available at 3 HBCRs was conducted. All cases with full details on pathological TNM for lung, breast and colorectal were selected as a study sample. There were 686 lung cancers, 3196 breast cancers and 1580 colorectal cancers with complete data on pathological TNM from 1996 onward. From these preliminary results it appeared that in almost 90% of cases, it was safe to apply the assumption $MX=M0$ for cases that presented with early T and N status. For example more than 90% of breast cancer cases with T1, T2 or T3 and with either N0 or N1 were M0. The majority of cases (>60%) were early stage, particularly for breast cancer (See Appendix E for more details). Further investigations of these assumptions are required in order for them to be validated.

4.2.5 Confidentiality

Consultation with clinicians highlighted their concerns regarding the confidentiality of the information which we were seeking. To obtain information from hospitals the appropriate bodies were approached, such as the Medical Advisory Committees, to discuss the project and the type of information being sought. However, the project sought additional information concerning individuals already known to the WACR. The project was described to both the University of Western Australia's Human Rights and Ethics Committee, and the Minister for Health's Confidentiality of Health Information (CHIC) Committee, neither of which felt that formal ethical approval was required as the study (being process-related, rather than outcome-related), falls within the area of "audit". A major barrier to collecting staging data from clinicians lies in their perception of the data being collected as confidential and information that should not be released to the cancer registry. This issue would need to be clarified for medical personnel, to facilitate the forwarding of this information to the cancer registry. Plans to include cancer staging information in the Schedule of data items required under the Health (Notification of Cancer) Regulations (1981) are progressing. This would extend legal protection to those who supply such information.

4.2.6 Access to data

Ownership of the data being sought is a concern to some. Some data potentially available from HBCRs falls within this area of concern. The HBCRS have their own source of funding and are separate entities from the WACR and as such, ownership of the data lies with them. Private clinicians may also have their own privately-funded databases which contain information on staging. Any co-operation between WACR and these other possible sources of data needs to clearly specify terms of usage of the data, with recognition being given to those from which the information was obtained. Any publications relying upon such data need to recognise issues such as personal effort and ownership-related issues. This presents as a potential barrier to the collection of staging data if the clinicians from whom the data are originally obtained have concerns about the uses to which such data might be put.

It might be asserted that primary medical information and, to at least some degree, derived information such as staging, properly belongs to the patients concerned, and not to any clinician or Registry, who act only as custodians. The WA Health Act, in this and other respects, does permit some exchange of personal information without individual consent, particularly for public health and health-administration-related purposes. There is an ongoing need for both clinicians and Government agencies to ensure the public are kept informed of such developments.

4.2.7 Specimens sent interstate

The recent expansion of pathology services which has seen large pathology corporations being established with branches both in the eastern states and Western Australia has an impact on the collection of staging data. In some instances, specimens will be sent interstate for pathological examination. Currently this appears to be occurring for skin specimens, however it needs to be considered as something that could occur with increasing regularity as large, multi-state pathology corporations become more established. The current legislation for the mandatory notification by pathologists, haematologist and radiation oncologists applies only to Western Australian clinicians. This legislation may need to be reviewed so that it can be applied to all clinicians throughout Australia.

4.2.8 Who should be responsible for staging?

Although not specifically a barrier, the issue of who should be responsible for staging cases would need to be decided upon before any staging collection system was implemented. This will vary between cancer types. For example breast cancer may be more easily staged from a pathology result, however stomach cancer could require a greater detail of clinical information.

One aspect of this question, is who should determine the actual stage, from the available information. Opinions varied between clinicians with regard to who should be responsible for the staging of cases. Some clinicians felt they should be responsible for staging, and forwarding the information on to the cancer registry, while others have felt it would be difficult to find the time for this extra paperwork and accepted the idea of Cancer Registry staff having access to their files to obtain such information. The divergence of opinions on this issue could be a possible barrier to the collection of staging data as it could be difficult to find one system that will satisfy everyone.

Whoever provides staging data, it will be incumbent on the WACR, who must record and report upon it, to be able to ensure compatibility of staging code systems and versions. Hence much more than a “stage” must be sought from external providers, to allow sufficient guarantees of information quality.

At another level, the question of who should assemble and collate staging information arises. A programme intended to collect population-based staging data should aim for a high level of completeness. If sufficient resourcing is unavailable and this cannot be achieved, it might be reasonable to suggest that the collection of such data, with other relevant clinical data, might better remain the task of the HBCRs (particularly if these can be extended into the private sector), than of the Western Australian Cancer Registry. The WACR is well-placed to support the HBCRs in terms of data linkage and outcome information.

4.3 Opportunities

The process of collecting staging data also allowed for the identification of several factors that could be considered as “opportunities” for assisting the collecting of staging at a population level.

4.3.1 Hospital Based Cancer Registries

Within the Perth metropolitan region there are 4 HBCRs. These are a valuable source of high-quality staging information. The Data Managers who manage the HBCRs are highly trained with particular expertise in staging. They are able to easily access medical records including reports from pathology and imaging reports, clinical examination notes and correspondence. In addition, they can access staging information directly from discussions or reports from interdisciplinary meetings. The outputs of HBCRs influence clinical care decision-making within individual hospitals.

Because HBCRs already collect high quality staging information, their continued operation is vital to the efficiency and cost-effectiveness of population-based collection of staging data. As can be seen from the results of this study, in cases where HBCRs covered a large proportion of the cancers seen in WA (for example the gynaecological cancers, or colorectal cancer), the proportion of cases stageable was high. In other cases, such as melanoma, for which no HBCR collects staging information, the proportion of stageable cases tended to be low. The extension

of support for HBCRs to private hospitals would further improve staging of all cancers. This would, of course, be dependent on funding availability and on satisfactory agreements regarding routine data exchange with the WACR.

Due to this project's small numbers, sampling requirements and chance, and the fact that some of the cases were very recent, the actual proportions of sample cases staged at HBCRs appears to have been lower than one might usually expect. On the basis of full data collection efforts, and with marginally less stringent timeliness requirements, the proportions of cases for which HBCRs are able to supply data would be expected to be higher than those presented in the individual tables for each cancer type. Details of the possible proportion of cases load seen by 3 HBCRs for lung, breast and colorectal can be found in Appendix E (Table E4).

4.3.2 Synoptic reports

Synoptic pathology reports have been produced by multidisciplinary groups for lung, breast and colorectal cancer. These contain information on both clinical and pathological staging in an agreed format between laboratories. There may also be scope for these reports to also contain radiological information which would be of benefit to any staging collection system. There is a need for education and cooperation to encourage requesting clinicians to include relevant clinical details in requests, and for pathologists to ensure that these are included in the pathology reports. The success of the HBCRs are a good example of such cooperation.

4.3.3 Current follow-up by WACR staff

As has been mentioned, staff at the WACR already routinely visit hospitals to obtain more information on cases, to enable them to code cancer cases. The extra information they routinely collect contributes to the existing pool of staging data available from the WACR. Increased familiarity of hospital clinicians and administration staff with the aims, needs and ethical concerns of the Registry can be expected to further facilitate such access.

4.3.4 Public support for cancer research

The enhancement of cancer information systems and, further, their use in ongoing research, does represent an important opportunity to provide more useful information to health care consumers, and to improve the participation rates when their involvement in epidemiological studies is sought.

4.3.5 Less use of cross border health services, and net inward migration

During the years 1992 – 1999 Western Australia recorded a positive population growth due to net inward interstate migration. However, since 2000 there has been a consistent nett loss of WA residents to other states.¹⁹ An increase in the loss of population to other states might have an impact on the collection of staging data, however this percentage remains small at present (0.2% in 2002). For people who move interstate, staging data might become more difficult to trace. However, the impact on cost might be more significant for other states who experience a larger nett outward interstate migration. There is less use of cross border health services in Western Australia than experienced in the Eastern states, hence data on Western Australian patients should be readily available.

4.3.6 Unique characteristics of WACR

As one of the few remaining Australian population-based cancer registries to continue to operate wholly within the Government, WACR has advantages in terms of access to other information sources within the public sector. In addition, the operation is small enough that it is centralized within one small area of one building. Current records and records for persons deceased within 2 years are all stored in filing cabinets and records for persons deceased within the last 3-5 years are also easily accessible. Staff have on-screen access to the (public hospital) Patient Master Index and fully-linked cancer-related hospitalization records back to 1980, to aid assessment of where staging information can be sought.

This access to other data sources allows data entry to keep pace with the inflow, and time delays in case registration are negligible for all cancer types. Staging data collection would take significantly more time if the data access and physical convenience of the centralized office environment were compromised.

Cancer Registry data are continually updated in the light of new information, and this would extend also to staging information that was thought to be relevant to the stage at diagnosis.

4.3.7 Existence of the West Australian Clinical Oncology Group

The WA Clinical Oncology Group (WACOG) was formed in early 1997 to advise the Cancer Foundation of Western Australia and the Health Department of Western Australia on all aspects of cancer, and in particular on research, prevention, screening, diagnosis, treatment, palliative medicine, and professional education. WACOG also aims to promote, facilitate and co-ordinate co-operative studies on all aspects of cancer. The existence of WACOG provides a useful tool to help facilitate the collection of staging data.

WACOG is already involved in the support and running of various organ specific multidisciplinary groups, such as the Lung Cancer Advisory Committee. These groups already assist the collection of staging data by promoting and initiating the use of synoptic pathology reports. They are also in a position to offer annual updates on what data to collect, what reports they would like produced, evaluation etc. This would ensure that the clinicians are obtaining the maximum benefit from the data collection.

4.3.8 Uses of databases in the public and private sectors

Apart from the availability of staging data from HBCRs, there are also in existence several large research databases in various public and private institutions. These databases could be useful sources of staging data. One needs to bear in mind that these databases may only be in existence in the short-term and thus may not represent an ongoing source of staging information. In the short-term however, they may prove to be quite useful.

4.3.9 Access to WA health services and data collections

Western Australia's population density is low, with most people living near the coast and medical services are geographically concentrated, mostly in the Perth metropolitan area, but also in the larger coastal centres of Bunbury and Geraldton in particular. There are thus relatively few persons and institutions with which communication must be established and maintained, and the bulk of hospital-record based work can be done in person.

4.4 Cost estimates for adding staging data to WACR

Here, we present a summary of the costs involved in adding staging data to the WACR. As discussed previously, this feasibility study has concluded that whether staging information can be added to the WACR is highly dependent on the cancer type. Resource needs have been assessed with reference to the cancer-type groups of Table 20, summarized below.

Group	Status	Cancer types
A	Could be staged now	cervix, ovary and uterus
B	Could be staged now, making MX=M0 assumption	breast and colorectal
C	Could be staged now making MX=M0 and NX=N0 assumption	prostate and melanoma
D	Could be started now, but long term collection requires system changes	lung, stomach, thyroid, testis, pancreas and kidney
E	Staging not feasible at present	lip, bladder, oesophagus, brain, lymphoma, leukaemia, myeloma

A full description of the calculations and assumptions making up these cost estimates are available in Appendix F. For each cancer type, actual times from the feasibility study were extrapolated to costs based on a whole year's collection. Tasks contributing to this time included: reviewing pathology reports; looking at electronic files at WACR; examining case notes at hospital medical records departments or doctors' rooms; writing enquiry letters to hospitals or doctors, and reviewing replies; writing follow-up enquiry letters to hospitals or doctors, and reviewing replies. To this were added "general" costs, such a mileage and driving time; time spent liaising with data holders; training time; annual and sick leave; general office duties; and delays due to the competing priorities of hospital and other non-WACR staff.

Although we have included an estimate of Group D costs it would be important to receive considerable clinical input to make this option cost-effective. Currently, kidney staging data would not be collected as the percentage staged would still too low to be of any clinical or statistical value.

Table 21. Annual cost estimates for staging data collection (based on preliminary 2002 data)

Groups included	Estimated time (hrs)	Estimated time (FTE)	\$ (approx.)	Assumptions	Estimated completeness
A	61	<0.1	2,000	HBCRs continue operation	100% cervix 100% ovary 95% uterus
+ B	939	0.5	24,000	MX=M0	+ 95% breast 92% colorectal
+C	1917	1.0	53,000	NX=N0 & MX=M0	+100% melanoma 97% prostate
+D	2667	1.5	69,000	MX=M0	+ 95% stomach 86% lung 80% pancreas 79% thyroid 75% testis 70% kidney

5. CONCLUSIONS

1. Adding stage to the WA Cancer Registry routinely collected information is possible for many cancer types.
2. Good staging information can be obtained with relatively minimal effort, for the following cancers - if specialized gynaecological hospital-based cancer registries continue to operate: **cervix, ovary and uterus.**
3. Making the assumption that MX=M0 for all cancers with N0; reasonable staging information (>75% complete) can be obtained for the following cancers: **breast and colorectal.**
4. Making the assumption that MX=M0 and NX=N0, reasonable staging information (>75% complete) can be obtained for the following cancers: **prostate and melanoma.** However, for both these cancers, considerable improvement of the completeness and accuracy of the staging information would be possible if routine histopathology referral forms for melanoma and prostate cancer could include tick boxes for the clinician to indicate whether there were clinically involved regional nodes or distant metastases.
5. Further work is needed to improve the staging data availability and systems for cancers of the lung, stomach, thyroid, testis, pancreas and kidney. In particular, the acceptability of an MX=M0 assumption for lung cancer, needs to be debated with local clinicians.
6. Staging of brain cancer should not be considered further at the moment, as no accepted staging system exists.
7. At the moment it is not possible to stage oesophageal, bladder or lip cancers, lymphoma, myeloma or leukaemia with reasonable effort.
8. The time taken to stage cancers received previously is very similar to the time taken to stage cancers as they are received. This result should, however, be treated with caution – once case notes for deceased patients are archived, retrieval becomes impossible or excessively time-consuming, and it is not expected that retrospective data collection would be feasible for cases diagnosed more than four years in the past.
9. These conclusions should be generalizable to most cancer registries in Australia.

6. RECOMMENDATIONS

1. Adding stage to the WA Cancer Registry routinely collected information should be started for the following cancers as soon as funding can be made available:
 - Cervix
 - Ovary
 - Uterus
 - Colorectal
 - Breast
 - Prostate
 - Melanoma
2. Urgent further discussions with pathologists and relevant clinicians should be held to determine whether routine histopathology referral forms could include “tick boxes” for the clinician to indicate whether there were thought to be cancer-affected regional lymph nodes or distant metastases.
3. Further work is needed in the near future to improve the staging data availability and systems for cancers of the lung, stomach, thyroid, testis, pancreas, and kidney.
4. Staging of lip, oesophagus, bladder and brain cancers and lymphoma, myeloma and leukaemia are not possible at the moment, but this conclusion should be reviewed regularly to determine whether circumstances have changed so as to make staging of these cancers feasible.
5. A special project should be funded to add staging to the data for cancers held by the WA Cancer Registry from 1998 onwards.
6. The HBCRs should continue to be funded, on the condition that regular and timely data exchange with the WA Cancer Registry occurs, to facilitate the availability of population-based staging information. Extending coverage to private hospitals should also be considered.
7. Any long term moves towards registration of “cancer treatment centres” should include a requirement that all cancers are staged and that such information is passed on to the WA Cancer Registry.

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APPENDIX A

Degree of spread of cancer

(now accepted for Australian National Health Data Dictionary; based on a proposal from NSW Central Cancer Registry, 2003.)

Admin. status: DRAFT

Identifying and definitional attributes

NHIK identifier:

Data element type: DATA ELEMENT

Definition: Degree of spread of cancer is a measure of the progression/extent of cancer at the time of diagnosis.

Context: This information is collected for the purpose of:

- Determining what proportion of cancers are localised to the site of the primary cancer at the time of diagnosis.
- Indicating the extent of disease at the time of diagnosis.
- For previously diagnosed cancers, the degree of spread may be updated to track the progression of the cancer.
- Assessing how early in its course the cancer was diagnosed (used to assess impact of early diagnosis measure).
- Estimating severity by degree of spread (used for comparing survival after adjusting for degree of spread).

Note: This categorisation of degree of spread of cancer is currently used by major Cancer Registries world wide.

Relational and representational attributes

Datatype: Numeric *Representational form*

Field size: Min. 1 Max. 1 *Representational layout:* N

Data domain: Degree of Spread of Cancer:

- 1 - Localised to the Tissue of Origin
- 2 - Invasion of Adjacent Tissue or Organs
- 3 - Regional Lymph Nodes
- 4 - Distant Metastases
- 5 - Not Applicable
- 9 - Unknown

Guide for use: To code degree of spread, the valid values for each data domain code are listed below.

- 1 - Localised to the tissue of origin: Includes a primary cancer where the spread

is contained within the organ of origin

Note: (this includes in situ breast (D05.0-D05.9) and in situ melanoma (D03.0 – D03.9))

Guide for use

Example 1: For colon cancer, the cancer has not progressed into the adventitia (peritoneal layer) surrounding the colon).

Example 2: For breast cancer, the cancer has not progressed into the underlying muscle layer (pectoral) or externally to the skin.

Example 3: For melanoma of the skin, the cancer has not invaded the subcutaneous fat layer (that is, it is contained within the dermis and epidermis).

Example 4: For lung cancer, the cancer has not invaded the pleura.

2 - Invasion of adjacent tissue or organs: A primary cancer has spread to adjacent organs or tissue not forming part of the organ of origin. This category includes sub-cutaneous fat or muscle and organs adjacent to the primary cancer site.

Example 1: For colon cancer, the cancer has progressed into the adventitia (peritoneal layer) surrounding the colon.

Example 2: For breast cancer, the degree of spread has progressed into the underlying muscle layer (pectoral) or externally into the skin.

Example 3: For melanoma of the skin, the cancer has invaded into subcutaneous fat or muscle.

Example 4: For lung cancer, the cancer has invaded the pleura or tissues of the mediastinum.

3 - Regional Lymph Nodes: The primary cancer has metastasised to the near by draining lymph nodes.

The list below shows the regional lymph nodes by site of primary cancer (International Union Against Cancer's definition).

Head and neck - Cervical Nodes

Larynx - Cervical Nodes

Thyroid - Cervical and Upper Mediastinal Nodes

Stomach - Perigastric nodes along the lesser and greater curvatures

Colon and Rectum - Pericolonic, perirectal, and those located along the ileocolic, right colic, middle colic, left colic, inferior mesenteric and superior rectal

Anal - Perirectal, internal iliac, and inguinal lymph nodes

Liver - Hilar nodes eg the hepatoduodenal ligament

Pancreas - Peripancreatic nodes

Lung - Intrathoracic, scalene and supraclavicular

Breast - Axillary, interpectoral, internal mammary

Cervix - Paracervical, parametrial, hypogastric, common, internal and external iliac, presacral and sacral

Ovary - Hypogastric(obturator), common iliac, external iliac, lateral, sacral, paraortic and inguinal

Prostate and bladder - Pelvic nodes below the bifurcation of the common iliac arteries

Testes – Abdominal, para-aortic and paracaval nodes, the intrapelvic and inguinal nodes

Kidney - Hilar, abdominal, para–aortic or paracaval

4 - Distant Metastases: The primary cancer has spread to sites distant to the primary site, for example liver and lung and bone, or any lymph nodes not stated as regional to the site (see “3 – Regional Lymph Nodes” above).

5 - Not Applicable: This category applies for lymphatic and haematopoietic cancers eg myelomas, leukaemias and lymphomas (C81.0 – C96.9) only.

9 - Unknown: No information is available on the degree of spread at this episode or the available information is insufficient to allow classification into one of the preceding categories

Related data:

Administrative attributes

Source document: International Classification of Diseases for Oncology, Second Edition (ICD-O-2)
NSW Inpatient Statistics Collection Manual–2000/2001

Source organisation: World Health Organization
NSW Health Department

National minimum data sets:

Comments:

APPENDIX B

Extent of Disease codes, New Zealand Cancer Registry

NZCR Data Dictionary Cancer Detail table

Reference ID: A0121 **Version:** 1.0 **Version date:** 01-Jan-2003

Extent of disease code

Element type: Data element

Definition: A code that describes the stage of development that a registrable tumour has reached at the time of diagnosis.

Context:

Data type: char **Field size:** 1 **Layout:** N

Data domain: A In situ

B Localised to organ of origin

C Invasion of adjacent tissue or organ

D Regional lymph nodes

E Distant

F Not known

G Not applicable

Guide for use: This field is not always reliable.

Numeric extent of disease codes were used for registrations up to and including 1998, and are stored as numeric in the new database. For registrations from 1 January 1999, alpha codes are used. The current codes 'C' and 'D' replace the single numeric code '2' so these cannot be mapped one-to-one forwards. (See Collection method below.)

From 1999 (Registration year), the Extent of disease code was applied in a standardised way, using the SEER (Surveillance, Epidemiology and End Results) Guide to Summary Staging. At the end of 2002, NZHIS adopted the updated SEER Guide (extended version).

Verification rules: Mandatory on registration.

On registration, this is validated against the values in the Stage to Basis and Site to Stage tables. All values that exist in the Stage to Basis code tables but do not have an equivalent Basis are considered invalid and hence will generate warning messages and set the Warnings overridden status code to 'S', e.g., Extent of disease code 'A' (In situ) is not valid with Basis '1', '2' or '3' (Clinical). If the record has no values, then the system will default this field to null.

Collection method: The Extent of disease code is allocated by the cancer registrars.

'A' (In situ) – in situ where there is no penetration of the basement membrane or invasion of supporting structures; maps to numeric code '0'

'B' (Localised to organ of origin) – localised and confined to organ of origin without evidence of spread; maps to numeric code '1'

'C' (Invasion of adjacent tissue or organ) – infiltration beyond the organ of origin into adjacent organ(s) or tissues but not into lymph nodes; maps to numeric code '2'

'D' (Regional lymph nodes) – the tumour is identified in regional lymph node; maps to numeric code '2'

'E' (Distant) – distant metastases and lymph nodes; maps to numeric code '3'

'F' (Not known) – maps to numeric code '5'

'G' (Not applicable) – lymphoma, myeloma, leukaemia; maps to numeric code '6'

Related data:

Administrative status

Identifying and defining attributes

Name: Extent of disease code

Other names: Stage of disease, Extent of disease (stage) code, Stage

Relational and representational attributes

Name in database: stage_code

Mandatory

Page 38 NZHIS Version: 1.0

June 2003

NZCR Data Dictionary Cancer Detail table

Source document: SEER Summary Staging Manual

Source organisation: SEER Programme, World Health Organization

Administrative attributes

APPENDIX C

Data entry forms

NCCI Data Entry Form : Form

WA Cancer Staging Project (A pilot study)

Search CRN Search UMRN Open WACR Form

CRN: PATHNO: UMRN: CANCER TYPE:

SURNAME: FORENAME MIDNAME: DOB: SEX:

DOD: ADDRESS: TOWN: POSTCODE:

TNM Prognostic Factors Procedure WACR Prognostic Factors

TNM classification of Malignant Tumours UICC 6th Edition)

CLIN_T
CLIN_N
CLIN_M
PATH_T
PATH_N
PATH_M

Record: 1 of 1372

Procedure of Data Collection

Caselist Extra_Followup_Type

TimeWACR Extra_Followup_Time

Infor_Source Sent_Date

Follow_Place Received_Date

Exchange Received_Data

Exchange_Place: Follow up_Level

TimeHBCR Difficult_Source

TimeMR Second_RECE_DATE:

Further_Follow up Second_RECE_DATA:

At_WACR: At_MRHOS:

At_HBCR: At_Letters:

Record: 1 of 1372

APPENDIX D

Cancer Staging information request letter



WA Cancer Staging Project
(A collaboration of UWA, DOH, WACOG & NCCI)
1st Floor C Block, 189 Royal St
East Perth WA 6004
Phone: 08 9222 2075 or 9222 4022
Fax: 08 9222 4236
Email: WACANREG@health.wa.gov.au

Dear Dr _____

The W.A. Cancer Registry is currently undertaking a study in conjunction with the UWA Centre for Health Services Research and the WA Clinical Oncology Group (Cancer Foundation of WA), funded by the National Cancer Control Initiative. The one-year project aims to assess the requirements for the routine collection of cancer staging data by the Registry

Western Australian health service providers play a major role in this project, as the information you may have goes well beyond what appears on most pathology reports. I am writing to seek your support for this project, and ask that you provide **the additional information which is highlighted** on the attached table for (patient's name and DOB), **(please tick the relevant boxes on the attached table)**.

If you are aware of an alternative source for such information, your advice would be appreciated.

.....
Thank you for your support.

Yours sincerely,

Dr T J Threlfall
Principal Medical Officer

Padabphet (Noy) Boutdara
Project officer

Jana Wittorff
Project Coordinator



Western Australian Cancer Registry
Health Information Centre



THE UNIVERSITY OF
WESTERN AUSTRALIA



NATIONAL
CANCER
CONTROL
INITIATIVE

Example of TNM table - Lung Cancer

Doctor was asked to indicate T, N and M status in the right hand column.

<u>Tumour</u>	Primary tumour cannot be assessed, <i>or</i> tumour proven by the presence of malignant cells in sputum or bronchial washings but not visualised by imaging or bronchoscopy	TX	
	No evidence of primary tumour	T0	
	Carcinoma in situ	Tis	
	Tumour 3cm or less in greatest dimension, surrounded by lung or visceral pleura, without bronchoscopic evidence of invasion more proximal than the lobar bronchus (ie: not in the main bronchus)	T1	
	Tumour with <i>any</i> of the following features of size or extent <ul style="list-style-type: none"> • More than 3cm in greatest dimension • Involves main bronchus, 2cm or more distal to the carina • Invades visceral pleura • Associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung 	T2	
	Tumour of any size that directly invades any of the following: chest wall (including superior sulcus tumours), diaphragm, mediastinal pleura, parietal pericardium; <i>or</i> tumour in the main bronchus less than 2cm distal to the carina but without involvement of the carina; <i>or</i> associated atelectasis or obstructive pneumonitis of the entire lung	T3	
	Tumour of any size that invades any of the following: mediastinum, heart, great vessels, trachea, oesophagus, vertebral body, carina; separate tumour nodule(s) in the same lobe; tumour with malignant pleural effusion	T4	
<u>Regional Lymph nodes</u>	Regional lymph nodes cannot be assessed	NX	
	No regional lymph node metastasis	N0	
	Metastasis in ipsilateral peribronchial and/or ipsilateral hilar lymph nodes and intrapulmonary nodes, including involvement by direct extension	N1	
	Metastasis in ipsilateral mediastinal and/or subcarinal lymph node(s)	N2	
	Metastasis in contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene, or supraclavicular lymph nodes	N3	
<u>Distant Metastasis</u>	Distant metastasis cannot be assessed	MX	
	No distant metastasis	M0	
	Distant metastasis, include separate tumour nodule(s) in a different lobe (ipsilateral or contralateral)	M1	

APPENDIX E

Additional information from WACR and HBCR databases

Under-staging of cases as result of making MX=M0 assumption

This information is based on further work after data collection for the study sample cases. Tables E1-E3 are presented to illustrate that the MX=M0 assumption could result in considerable “under-staging” of cases if either T or N stage is high, but may be acceptable for early T stage cancers, especially if N stage is 0.
if N stage is 0.

Table E1: Proportion of lung cancer cases under-staged if “MX=M0” assumed.

Lung TN status	No of cases	%	No. of cases with M0	No. of cases with M1	%Under-Staged if MX=M0
T1N0	144	21.0	138	6	4.2
T2N0	169	24.6	156	13	7.7
T3N0	44	6.4	43	1	2.3
T4N0	41	6.0	26	15	36.6
T1N1	24	3.5	21	3	12.5
T2N1	81	11.8	72	9	11.1
T3N1	29	4.2	22	7	24.1
T4N1	16	2.3	10	6	37.5
T1N2	14	2.0	10	4	28.6
T2N2	45	6.6	34	11	24.4
T3N2	18	2.8	15	3	16.7
T4N2	20	2.9	13	7	35.0
T1N3	6	0.9	2	4	66.7
T2N3	12	1.7	3	9	75.0
T3N3	5	0.7	3	2	40.0
T4N3	18	2.6	4	14	77.8
Total	686	100.0			

Table E2: Proportion of breast cancer cases under-staged if MX=M0 assumed.

Breast TN status	No of cases	%	No. of cases with M0	No. of cases with M1	%Under-Staged if MX=M0
T1N0	1538	48.1	1534	4	0.3
T2N0	430	13.5	429	1	0.2
T3N0	47	1.5	45	2	4.3
T4N0	11	0.3	9	2	18.2
T1N1	489	15.3	482	7	1.4
T2N1	502	15.7	494	8	1.6
T3N1	106	3.3	97	9	8.5
T4N1	32	1.0	25	7	21.9
T1N2	10	0.3	9	1	10.0
T2N2	14	0.4	11	3	21.4
T3N2	7	0.2	6	1	14.3
T4N2	4	0.1	1	3	75.0
T1N3	0	0.0	0	0	NA
T2N3	5	0.2	5	0	0.0
T3N3	0	0.0	0	0	NA
T4N3	1	0.0	0	1	100.0
Total	319	100.0			

Table E3. Proportion of colorectal cancer cases under-staged if MX=M0 assumed.

CRC TN status	No of cases	%	No of cases with M0	No of cases with M1	%under staged
T1N0	121	7.7	117	4	3.3
T2N0	136	8.6	132	4	2.9
T3N0	424	26.8	393	31	7.3
T4N0	75	4.7	51	24	32.0
T1N1	13	0.8	13	0	0.0
T2N1	63	4.0	56	7	11.1
T3N1	338	21.4	274	64	18.9
T4N1	80	5.1	48	32	40.0
T1N2	1	0.1	1	0	0.0
T2N2	19	1.2	17	2	10.5
T3N2	233	14.7	159	74	31.8
T4N2	77	4.9	40	37	48.1
Total	1580	100.0			

Proportions of cancers recorded at HBCRs.

This information is presented to illustrate that the proportions of cases for which data might be available from HBCRs are considerable, but vary with cancer type, and in general have improved with time. This situation will be affected by any changes in levels of support for HBCRs and, unless HBCRs can be introduced into private hospitals, by any changes in the distribution of private vs public medical practice.

Table E4. Proportion of lung, breast and colorectal cancers seen by HBCRs at the three major teaching hospitals treating these cancers

Cancer type	1998	1999	2000
Lung			
Total number of cases seen by 3 HBCRs	452	485	487
Total cases registered at WACR	716	758	735
% seen by 3 HBCRs (Lung)	63	64	66
Breast			
Total number of cases seen by 3 HBCRs	596	716	787
Total cases registered at WACR	925	1025	1010
% seen by 3 HBCRs (Breast)	64	70	78
Colorectal			
Total number of cases seen by 3 HBCRs	415	432	426
Total cases registered at WACR	937	943	1053
% seen by 3 HBCRs (Colorectal)	44	46	40

APPENDIX F

Methods and details of costing estimates

In Table F1 below, are shown several different combinations of cancer types which can be staged, with varying levels of difficulty, success, and expense. The easiest option is to only stage for cancers of the cervix, ovary and uterus as HBCRs currently collect close to 100% of these cases and these cancers can be staged with relatively little additional resourcing required. Progressing from top to bottom of Table 20, the combinations of cancer types become increasingly difficult and expensive to stage, and for the group at the bottom of the table, staging is simply not possible at present.

F.1 The “cancer staging budget” process.

F.1.1 Cost estimates: Overview

For each cancer type, actual times used in various kinds of research work for the project sample cases were extrapolated to estimate costs based on a whole year's collection, using a draft 2002 data extraction from the WACR as a guide.

To this, for each possible scenario (i.e. combination of cancer types to be staged) were added "general" costs, such as mileage and driving time, which are rather more difficult to determine on the basis of cancer type.

The dollar costs in this Appendix have been calculated based on a salary of \$40,000 and estimated “on costs” figure taking the estimated cost for 1.0 full-time-equivalent (fte) to \$45,000 per year.

F.1.2 Cost estimates: Resources not included

- Telephone calls (60) and email messages (100) generated by the Project Officer have not been apportioned among the cancer types studies. Some such messages were directed towards the establishment of data-exchange routines (a need which might diminish with time), and some were concerned with individual cases. Access to e-mail and State-wide/mobile telephone facilities is seen to be a necessary part of any budget for on-going collection of staging data.

F.1.3 Cost estimates: General costs, not apportioned on basis of particular tumour types

- Time spent in travel to hospitals and doctors' rooms for the collection of information, at an estimated average speed of 35 km/h for an estimated 2 trips per week (but ONLY included in calculations if external work were required for one or more of the chosen cancer type/s). Mileage costs also included, averaged at 16km per trip.
- Time spent in liaison concerning establishment and maintenance of communication channels, based on an estimated 90-minute meeting every 4 weeks or so in the course of a usual year.
- Estimated costs of 2% in each year, in recognition of the need for new staff to spend an estimated 2-3 months learning staging processes and becoming familiar with relevant persons and institutions, and remaining in the job for an estimated 3 years (10%); and for having 4 weeks annual leave and 2 weeks sick leave in each year (13%).
- Additional costs including public holidays and pro-rata long service leave, which can vary more with individual arrangements, are accounted for by assuming a “year” is 37.5 hours per week for 48 weeks a year, in calculating the f.t.e. required from the hours shown.

F.1.4 Cost estimates: Costs apportioned on basis of records for particular tumour types

The possible types of work, recorded by cancer type and included in the projected costings where relevant, were:

- Time spent reviewing pathology reports and other records at WACR. (*Mean 5 to 12 minutes per case depending on cancer type*).
- Time spent looking at HBCR-sourced stage information in electronic files at WACR. (*Mean 3 minutes per case*)
- Time spent examining case notes at hospital medical records departments or doctors' rooms. (*Mean 5 to 12 minutes per case depending on cancer type*)
- Time spent in writing enquiry letters to hospitals or doctors, and in reviewing replies. (*Estimated at 7 minutes per letter and 5 minutes for each response*)
- Time spent in writing follow-up enquiry letters to hospitals or doctors, and in reviewing replies. (*Same times per letter, but using the response rate for melanoma follow-up letters as a guide*).

F.1.5 Cost estimates: “Lost time” corrections

To these tumour-specific costs, have been added two types of "lost time" correction, one for work outside the WACR "base", and one for all work conducted within the WACR.

The internal-work correction is applied in order to ensure that required workloads can be handled, given the need for any person working in an office environment to spend unproductive time in answering telephone calls, monitoring unsolicited Global Message emails, attending staff meetings, completing timesheets, writing reports, participating in evacuation drills, walking to the tearoom and so on.

The correction factor for external work accounts for similar issues, and for additional delays due to the competing priorities of hospital and other staff not under WACR control, and repeat visits/extra time in viewing records that cannot be found where initially expected. The data recorded for breast cancer are indicative - 23% of time spent in the hospitals was not spent actually looking at clinical notes.

These “lost-time factors” are estimated at 20% for WACR-based work, and 25% for external work.

F.2 Cost estimates for combinations of cancer types

F.2.1 Scenario 1: Only Group A from Table F1.

Estimate - 61 hours.

- Add 24 hr / 200km for liaison and establishment of communications.
- No follow-up letters or external case note review required.
- Totally-dependent on continued operation and timeliness of HBCR at KEMH, and inclusion, in that database, of privately-funded cases from key surgeons.

Estimated completeness of staging - 100% for cervix and ovarian, 95% for uterine cancer.

Cost - \$2000.

F.2.2 Scenario 2: Groups A and B from Table F1.

Estimate - $61+816 = 877$ hours.

- Add 24 hr / 200km for liaison and establishment of communications.
- Add 38 hr / 1300km for external data collection travel time/distance.
- Total - 939 hrs = 25 weeks i.e. 0.5 FTE.

- Requires MX=M0 assumption for colorectal and breast cancers for adequate staging percentages.

Estimated completeness of staging - 100% cervix and ovarian, 95% uterine cancer, 95% breast, 92% colorectal cancer.

Cost - \$22,500.

F.2.3 Scenario 2a: As for Scenario 2, but with use of reminder letters

Add 63 hours.

Estimated completeness of staging - 100% cervix and ovarian, 95% uterine cancer, 100% breast, 98% colorectal cancer.

Cost - \$24,000.

F.2.4 Scenario 3: Groups A, B and C from Table F1.

Estimate - 61+816+978 hours = **1855 hr.**

Add 24 hr / 200km for liaison and establishment of communications.

Add 38 hr / 1300km for external data collection travel time/distance.

Total = 1917 hrs = 51 weeks, or 1.1 FTE.

Estimated completeness of staging - 100% cervix and ovarian, 95% uterine cancer, 95% breast, 92% colorectal cancer. With additional NX=N0 assumption, 92% prostate, 97% melanoma.

Cost - \$49,500.

F.2.5 Scenario 3a: As for Scenario 3, but with use of reminder letters

Add 125 hours.

Estimated completeness of staging - 100% cervix and ovarian, 95% uterine cancer, 100% breast, 98% colorectal cancer. With additional NX=N0 assumption, 92% prostate, 97% melanoma.

Cost - \$52,800.

F.2.6 Scenario 4: Groups A, B, C and D from Table F1.

Estimate - 61+816+978+651 hours.

Add 24 hr / 200km for liaison and establishment of communications.

Add 38 hr / 1300km for external data collection travel time/distance.

Total 2568 hours = 68.5weeks or 1.4 f.t.e.

Estimated completeness of staging - 100% cervix and ovarian, 95% uterine cancer, 95% breast, 92% colorectal cancer. With additional NX=N0 assumption, 92% prostate, 97% melanoma. Also - lung 84%, stomach 95%, thyroid 79%, testis 79%, pancreas 80%, kidney 70%.

Cost - \$64,200

F.2.7 Scenario 4a: Groups A, B, C and D from Table F1, with reminder letters

Add 263 hours.

Cost - \$68,480.

F.2.8 The value of “reminder letters” for un-answered queries

The writing of “reminder” letters to clinicians is an important part of existing WACR data-enhancement routines, and is a relatively-efficient process using the computerized enquiry database that has been used for the last five years. It plays an important role in maintaining an awareness among clinicians of the importance of WACR operations and completeness of data, and provides an avenue for enhancing awareness of Registry roles, and the legal rights and responsibilities of data providers. It would be unrealistic to continue to use this process to

follow up issues such as undetermined primary sites of cancers, while not resorting to such a step for the purposes of collecting staging information. Table F1 shows the estimated improvement in completeness of staging information, by cancer type, and it can be seen that for melanoma in particular, such follow-up of un-answered enquiry letters may be very important.

Table F1. Improvement in staging completeness, if reminder letters used

Cancer type	Base %	% after reminders	Improvement, % points
Colorectal	92	98	6
Breast	95	101	6
Melanoma	49	68	19
Prostate	39	48	9
Lung	84	91	7
Stomach**	95	98	3
Thyroid**	78	84	6
Pancreas	75	83	8
Testis**	75	83	8
Kidney**	65	78	13
Bladder**	50	65	15
Lip	42	61	19
Oesophagus**	65	80	15

The remainder of this Appendix, Table F.2, presents further details of the resources used, in terms of hours of effort for the study, and for the estimated annual caseload in 2002.

Notes regarding Table F2.

Abbreviations in column headings include –

- Hosp time - times spent in assessing hospital case notes.
- WACR time - time spent in assessing record held at WACR
- HBCR file time - time spent in assessing HBCR data files and notes
- 1st Letter time - time spent in creating enquiry letters and assessing replies
- Reminder time - time spent in generation reminders for all non-replies

Times shown are all in hours. The times shown for 2002 include process-specific corrections for "lost time" as detailed in the text.

Table F2. Components of costing estimates, by cancer type and group.

Cancer type and group (Table 20)	Sample cases	Est. cases 2002	WACR time each	WACR cases	WACR 2002 time	Hosp time each	Hosp cases	Hosp time 2002	HBCR file time each	HBCR file cases	HBCR file time 2002	1st Letter cases	1 st Letter replies	1st Letter time 2002	Reminder cases	Reminder replies	Reminder time sample	Reminder time 2002	Total 2002 w/o reminders	Total 2002 with reminders
Group A: Could be staged now																				
Ovary	20	105	0.12	12	8.8			0.0	0.05	20	6.3	0	0	0.0	0	0	0.0	0.0	15.1	15.1
Cervix	19	79	0.10	4	2.0			0.0	0.05	19	4.7	1	1	1.0	0	0	0.0	0.0	7.7	7.7
Uterus	20	146	0.11	13	12.3			0.0	0.05	20	8.8	3	3	5.3	0	0	0.0	0.0	26.4	26.4
TOTAL FOR GROUP																			49.2	49.2
TOTAL FOR GROUP with training/leave correction 24%																			61.0	61.0
Group B: Could be staged now, with MX=M0 assumption																				
Colorectal	60	1000	0.10	44	88.0	0.08	4	6.9	0.05	34	34.0	21	13	70.7	8	4	1.3	25.3	199.6	224.9
Breast	60	1139	0.13	60	182.2	0.08	42	83.1	0.05	13	14.8	42	35	178.1	7	4	1.1	25.2	458.2	483.4
TOTAL FOR GROUP																			657.8	708.4
TOTAL FOR GROUP with training/leave correction 24%																			815.6	878.4
Group C: Could be staged now, with both NX=N0 and MX=M0 assumptions																				
Melanoma	60	1045	0.13	60	156.8	0.00	0	0.0	0.05	0	0.0	58	34	200.6	24	11	3.7	77.7	357.4	435.1
Prostate	60	1197	0.08	60	119.7	0.10	31	77.3	0.05	2	2.4	53	42	231.8	11	6	1.7	41.7	431.2	472.9
TOTAL FOR GROUP																			788.6	908.0
TOTAL FOR GROUP with training/leave correction 24%																			977.9	1125.9

Table F2 (continued) Components of costing estimates, by cancer type and group.

Cancer type and group (Table 20)	Sample cases	Est. cases 2002	WACR time each	WACR cases	WACR 2002 time	Hosp time each	Hosp cases	Hosp time 2002	HBCR file time each	HBCR file cases	HBCR file time 2002	1st Letter cases	1st Letter replies	1st Letter time 2002	Reminder cases	Reminder replies	Reminder time sample	Reminder time 2002	Total 2002 w/o reminders	Total 2002 with reminders
Group D: Could be commenced, but system change required to make economical																				
Lung	60	792	0.15	60	142.6	0.13	40	88.0	0.05	12	9.5	19	10	48.3	9	5	1.4	22.6	288.4	310.9
Stomach**	20	141	0.15	20	25.4	0.13	9	10.6	0.05	0	0.0	10	9	16.2	1	1	0.2	1.3	52.2	53.5
Thyroid**	19	108	0.13	18	16.4	0.08	8	4.7	0.05	0	0.0	13	11	16.6	2	1	0.3	2.2	37.7	39.9
Pancreas	20	157	0.15	20	28.3	0.12	10	11.4	0.05	0	0.0	8	5	12.7	3	2	0.5	4.5	52.4	56.9
Testis**	20	64	0.10	20	7.7	0.13	8	4.3	0.05	0	0.0	14	11	9.8	3	2	0.5	1.8	21.7	23.6
Kidney**	20	203	0.10	20	24.4	0.12	14	20.7	0.05	1	0.6	13	8	26.6	5	3	0.8	9.6	72.3	81.9
TOTAL FOR GROUP																			524.7	566.7
TOTAL FOR GROUP with training/leave correction 24%																			650.7	702.7
Group E: Staging not feasible																				
Bladder**	20	182	0.17	20	36.4	0.12	14	18.6	0.05	0	0.0	14	8	25.1	6	3	1.0	10.4	80.1	90.5
Lip	19	130	0.08	19	13.0	0.12	2	2.0	0.05	0	0.0	18	11	24.8	7	4	1.1	9.1	39.8	48.9
Oesophagus**	20	106	0.12	20	14.8	0.17	15	16.6	0.05	0	0.0	15	9	15.9	6	3	1.0	6.0	47.3	53.3
Brain	20	132	0.07	20	10.6	0.00	0	0.0	0.05	0	0.0	0	0	0.0	0	0	0.0	0.0	10.6	10.6
Lymphoma	18	389	0.10	18	46.7	0.00		0.0	0.05	0	0.0	0	0	0.0	0	0	0.0	0.0	46.7	46.7
Myeloma	20	75	0.10	20	9.0	0.00		0.0	0.05	0	0.0	0	0	0.0	0	0	0.0	0.0	9.0	9.0
Leukaemia	20	227	0.10	20	27.2	0.00		0.0	0.05	0	0.0	0	0	0.0	0	0	0.0	0.0	27.2	27.2
																			(260.6)	(285.9)
																			(323.2)	(354.9)

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