The International Collaboration for Cancer Reporting

Tim Helliwell

International Collaboration for Cancer Reporting

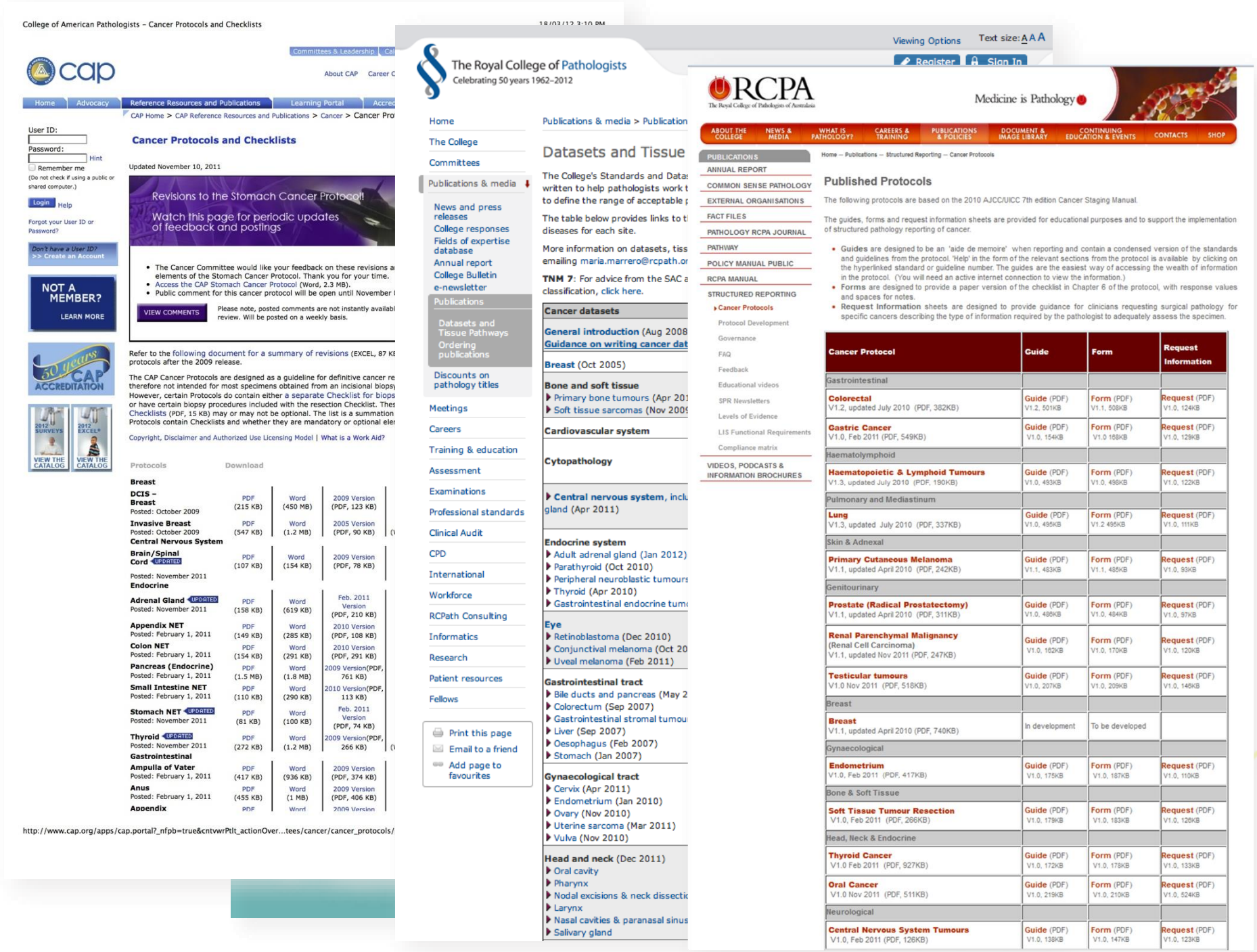
Vice-President Royal College of Pathologists

Consultant Histopathologist, Liverpool Clinical Laboratories

RCPath datasets meeting 2017

International Collaboration on Cancer Reporting

www.iccr-cancer.org



College of American Pathologists – Cancer Protocols and Checklists

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50 years CAP ACCREDITATION

2012 SURVEYS VIEW THE CATALOG
2012 EXCEL® VIEW THE CATALOG

Cancer Protocols and Checklists

Updated November 10, 2011

Revisions to the Stomach Cancer Protocol!
Watch this page for periodic updates of feedback and postings

- The Cancer Committee would like your feedback on these revisions a elements of the Stomach Cancer Protocol. Thank you for your time.
- Access the CAP Stomach Cancer Protocol (Word, 2.3 MB).
- Public comment for this cancer protocol will be open until November

VIEW COMMENTS

Please note, posted comments are not instantly availabl review. Will be posted on a weekly basis.

Refer to the following document for a summary of revisions (EXCEL, 87 KE protocols after the 2009 release.

The CAP Cancer Protocols are designed as a guideline for definitive cancer re therefore not intended for most specimens obtained from an incisional biopsy However, certain Protocols do contain either a separate Checklist for biops or have certain biopsy procedures included with the resection Checklist. Thes Checklists (PDF, 15 KB) may or may not be optional. The list is a summation Protocols contain Checklists and whether they are mandatory or optional ele

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Protocols	Download		
Breast			
DCIS – Breast Posted: October 2009	PDF (215 KB)	Word (450 MB)	2009 Version (PDF, 123 KB)
Invasive Breast Posted: October 2009	PDF (547 KB)	Word (1.2 MB)	2005 Version (PDF, 90 KB)
Central Nervous System			
Brain/Spinal Cord UPDATED Posted: November 2011	PDF (107 KB)	Word (154 KB)	2009 Version (PDF, 78 KB)
Endocrine			
Adrenal Gland UPDATED Posted: November 2011	PDF (158 KB)	Word (619 KB)	Feb. 2011 Version (PDF, 210 KB)
Appendix NET Posted: February 1, 2011	PDF (149 KB)	Word (285 KB)	2010 Version (PDF, 108 KB)
Colon NET Posted: February 1, 2011	PDF (154 KB)	Word (291 KB)	2010 Version (PDF, 291 KB)
Pancreas (Endocrine) Posted: February 1, 2011	PDF (1.5 MB)	Word (1.8 MB)	2009 Version(PDF, 761 KB)
Small Intestine NET Posted: February 1, 2011	PDF (110 KB)	Word (290 KB)	2010 Version(PDF, 113 KB)
Stomach NET UPDATED Posted: November 2011	PDF (81 KB)	Word (100 KB)	Feb. 2011 Version (PDF, 74 KB)
Thyroid UPDATED Posted: November 2011	PDF (272 KB)	Word (1.2 MB)	2009 Version(PDF, 266 KB)
Gastrointestinal			
Ampulla of Vater Posted: February 1, 2011	PDF (417 KB)	Word (936 KB)	2009 Version (PDF, 374 KB)
Anus Posted: February 1, 2011	PDF (455 KB)	Word (1 MB)	2009 Version (PDF, 406 KB)
Appendix	PDF	Word	2009 Version

http://www.cap.org/apps/cap.portal?_nfpb=true&cntvwrPtlt_actionOver...tees/cancer/cancer_protocols/

The Royal College of Pathologists
Celebrating 50 years 1962–2012

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Datasets and Tissue

The College's Standards and Datas written to help pathologists work t to define the range of acceptable p

The table below provides links to t diseases for each site.

More information on datasets, tiss emailing maria.marrero@rcpath.or

TNM 7: For advice from the SAC a classification, click here.

Cancer datasets

General introduction (Aug 2008
Guidance on writing cancer dat

Breast (Oct 2005)

Bone and soft tissue
- Primary bone tumours (Apr 201
- Soft tissue sarcomas (Nov 2009

Cardiovascular system

Cytopathology

- **Central nervous system**, inclu gland (Apr 2011)

Endocrine system
- Adult adrenal gland (Jan 2012)
- Parathyroid (Oct 2010)
- Peripheral neuroblastic tumours
- Thyroid (Apr 2010)
- Gastrointestinal endocrine tum

Eye
- Retinoblastoma (Dec 2010)
- Conjunctival melanoma (Oct 20
- Uveal melanoma (Feb 2011)

Gastrointestinal tract
- Bile ducts and pancreas (May 2
- Colorectum (Sep 2007)
- Gastrointestinal stromal tumou
- Liver (Sep 2007)
- Oesophagus (Feb 2007)
- Stomach (Jan 2007)

Gynaecological tract
- Cervix (Apr 2011)
- Endometrium (Jan 2010)
- Ovary (Nov 2010)
- Uterine sarcoma (Mar 2011)
- Vulva (Nov 2010)

Head and neck (Dec 2011)
- Oral cavity
- Pharynx
- Nodal excisions & neck dissecti
- Larynx
- Nasal cavities & paranasal sinus
- Salivary gland

RCPA
The Royal College of Pathologists of Australasia

Medicine is Pathology

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- COMMON SENSE PATHOLOGY
- EXTERNAL ORGANISATIONS
- FACT FILES
- PATHOLOGY RCPA JOURNAL
- PATHWAY
- POLICY MANUAL PUBLIC
- RCPA MANUAL
- STRUCTURED REPORTING
  - Cancer Protocols
  - Protocol Development
  - Governance
  - FAQ
  - Feedback
  - Educational videos
  - SPR Newsletters
  - Levels of Evidence
  - LIS Functional Requirements
  - Compliance matrix
- VIDEOS, PODCASTS & INFORMATION BROCHURES

Home – Publications – Structured Reporting – Cancer Protocols

Published Protocols

The following protocols are based on the 2010 AJCC/UICC 7th edition Cancer Staging Manual.

The guides, forms and request information sheets are provided for educational purposes and to support the implementation of structured pathology reporting of cancer.

- **Guides** are designed to be an 'aide de memoire' when reporting and contain a condensed version of the standards and guidelines from the protocol. 'Help' in the form of the relevant sections from the protocol is available by clicking on the hyperlinked standard or guideline number. The guides are the easiest way of accessing the wealth of information in the protocol. (You will need an active internet connection to view the information.)
- **Forms** are designed to provide a paper version of the checklist in Chapter 6 of the protocol, with response values and spaces for notes.
- **Request Information** sheets are designed to provide guidance for clinicians requesting surgical pathology for specific cancers describing the type of information required by the pathologist to adequately assess the specimen.

Cancer Protocol	Guide	Form	Request Information
Gastrointestinal			
Colorectal V1.2, updated July 2010 (PDF, 382KB)	Guide (PDF) V1.2, 501KB	Form (PDF) V1.1, 508KB	Request (PDF) V1.0, 124KB
Gastric Cancer V1.0, Feb 2011 (PDF, 549KB)	Guide (PDF) V1.0, 154KB	Form (PDF) V1.0 168KB	Request (PDF) V1.0, 129KB
Haematolymphoid			
Haematopoietic & Lymphoid Tumours V1.3, updated July 2010 (PDF, 190KB)	Guide (PDF) V1.0, 493KB	Form (PDF) V1.0, 498KB	Request (PDF) V1.0, 122KB
Pulmonary and Mediastinum			
Lung V1.3, updated July 2010 (PDF, 337KB)	Guide (PDF) V1.0, 495KB	Form (PDF) V1.2 495KB	Request (PDF) V1.0, 111KB
Skin & Adnexal			
Primary Cutaneous Melanoma V1.1, updated April 2010 (PDF, 242KB)	Guide (PDF) V1.1, 483KB	Form (PDF) V1.1, 485KB	Request (PDF) V1.0, 93KB
Genitourinary			
Prostate (Radical Prostatectomy) V1.1, updated April 2010 (PDF, 311KB)	Guide (PDF) V1.0, 486KB	Form (PDF) V1.0, 484KB	Request (PDF) V1.0, 97KB
Renal Parenchymal Malignancy (Renal Cell Carcinoma) V1.1, updated Nov 2011 (PDF, 247KB)	Guide (PDF) V1.0, 162KB	Form (PDF) V1.0, 170KB	Request (PDF) V1.0, 120KB
Testicular tumours V1.0 Nov 2011 (PDF, 518KB)	Guide (PDF) V1.0, 207KB	Form (PDF) V1.0, 209KB	Request (PDF) V1.0, 146KB
Breast			
Breast V1.1, updated April 2010 (PDF, 740KB)	In development	To be developed	
Gynaecological			
Endometrium V1.0, Feb 2011 (PDF, 417KB)	Guide (PDF) V1.0, 175KB	Form (PDF) V1.0, 187KB	Request (PDF) V1.0, 110KB
Bone & Soft Tissue			
Soft Tissue Tumour Resection V1.0, Feb 2011 (PDF, 266KB)	Guide (PDF) V1.0, 179KB	Form (PDF) V1.0, 183KB	Request (PDF) V1.0, 126KB
Head, Neck & Endocrine			
Thyroid Cancer V1.0 Feb 2011 (PDF, 927KB)	Guide (PDF) V1.0, 172KB	Form (PDF) V1.0, 178KB	Request (PDF) V1.0, 133KB
Oral Cancer V1.0 Nov 2011 (PDF, 511KB)	Guide (PDF) V1.0, 219KB	Form (PDF) V1.0, 210KB	Request (PDF) V1.0, 524KB
Neurological			
Central Nervous System Tumours V1.0, Feb 2011 (PDF, 126KB)	Guide (PDF) V1.0, 138KB	Form (PDF) V1.0, 147KB	Request (PDF) V1.0, 123KB

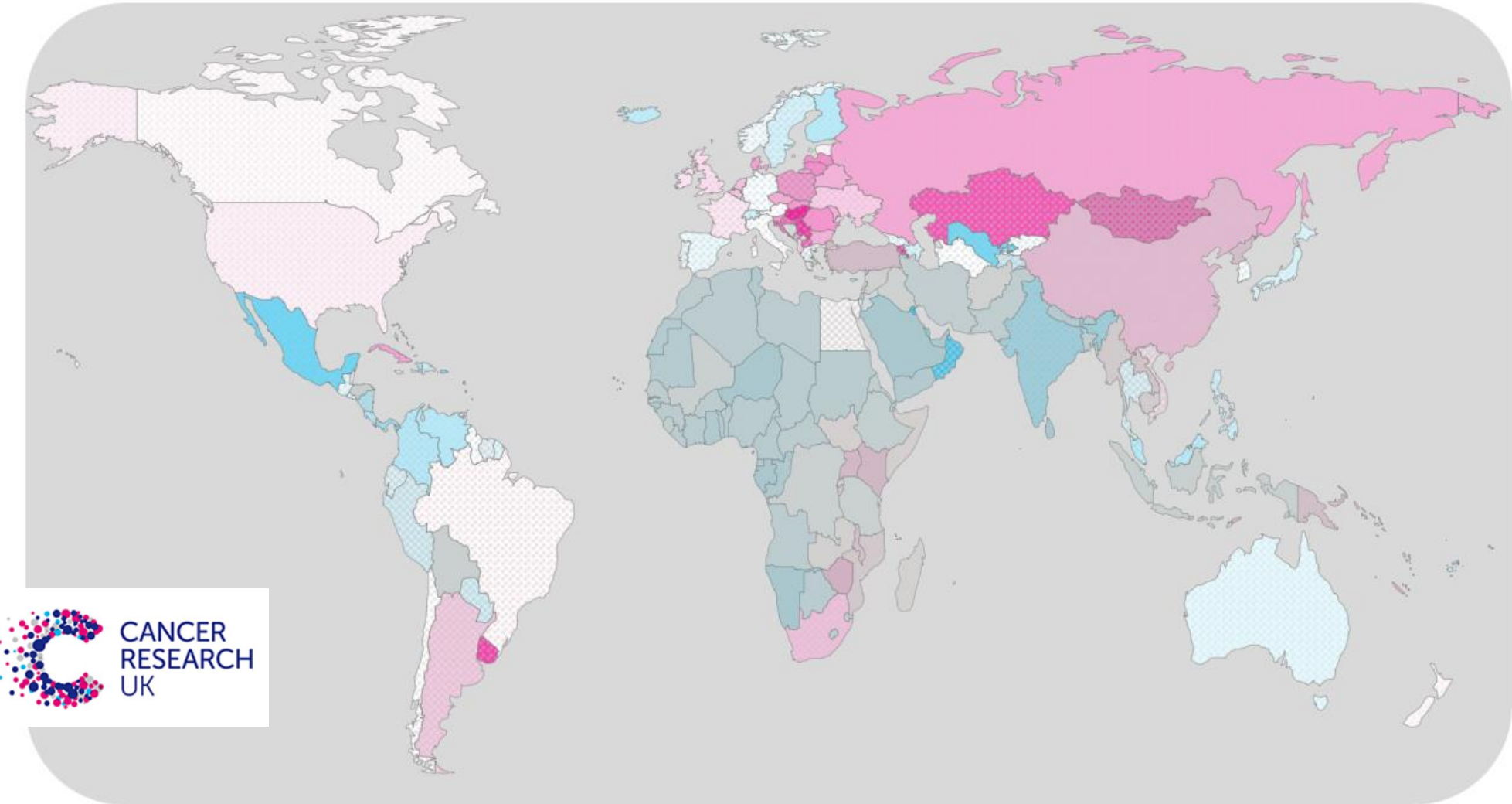
Aggregated Pathology Cancer Data

- Data duplication
- Interoperability compromised or precluded

No Data

Interactive Map of Cancer Mortality, World, 2012 Estimates

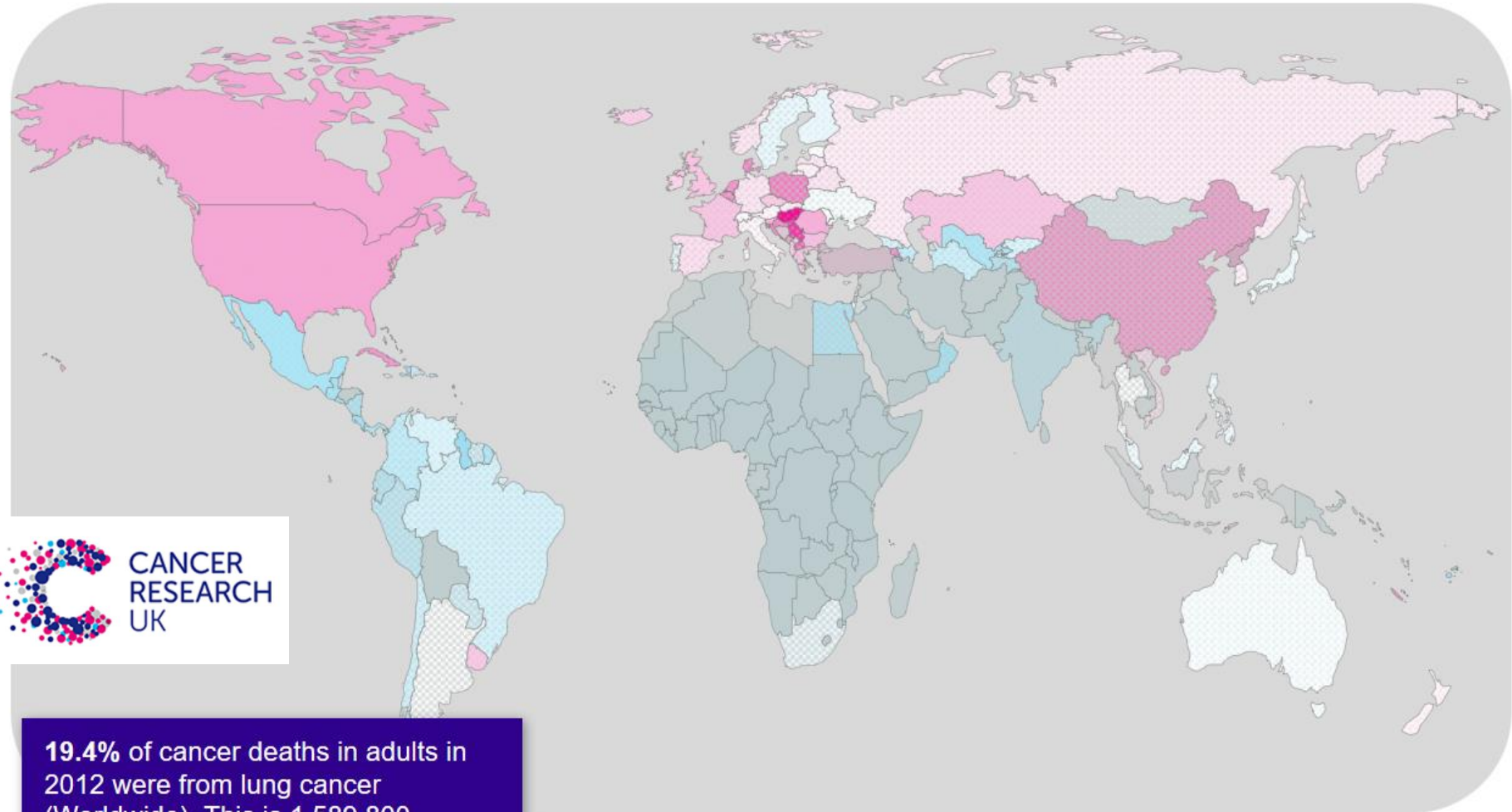
Cancer mortality — Worldwide



Worldwide cancer mortality — 8,201,030 cancer deaths per year:

Interactive Map of Cancer Mortality, World, 2012 Estimates

Lung cancer mortality — Worldwide

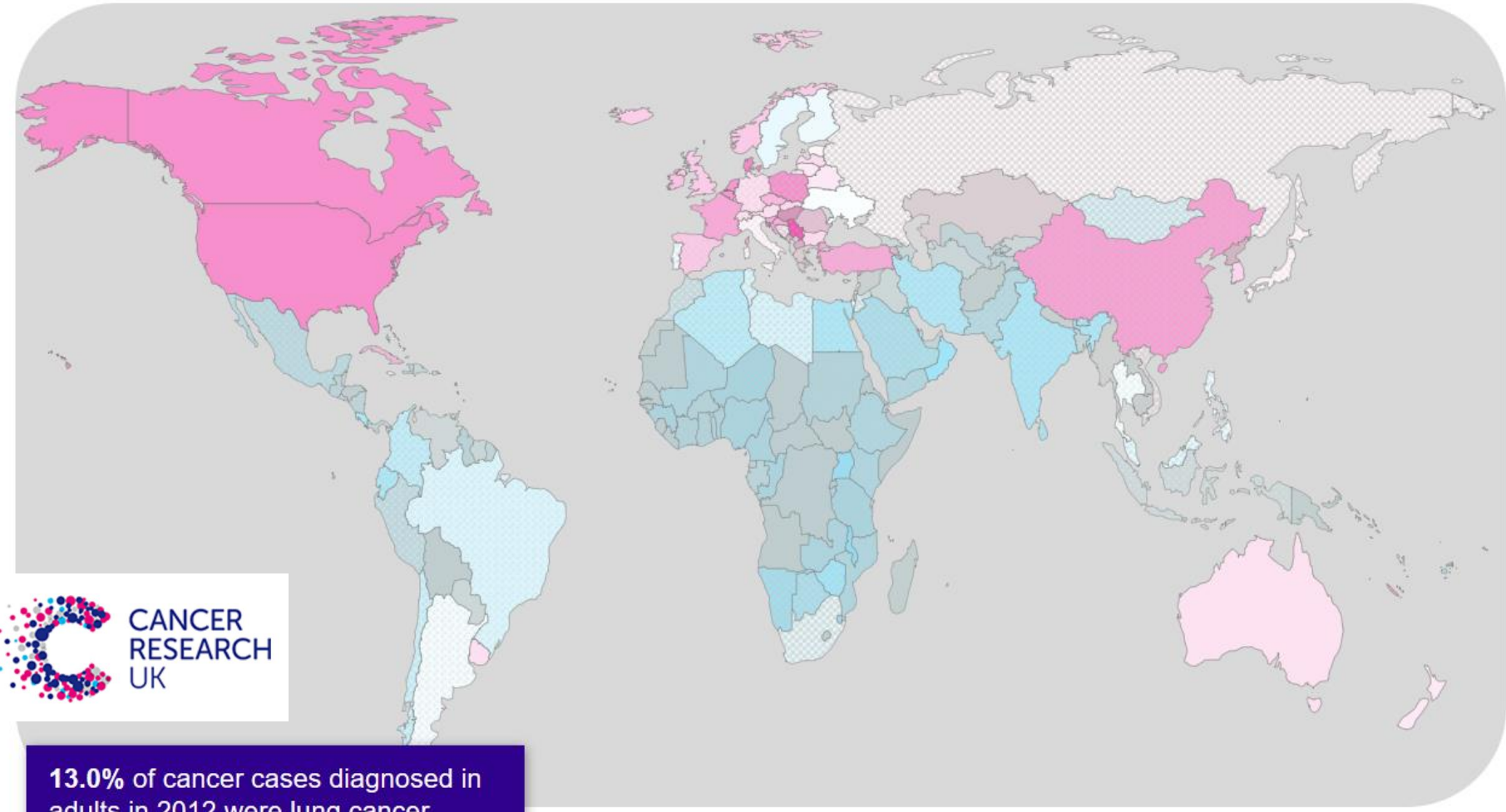


cer mortality — 8,201,030 cancer deaths per year:

Lung	Stomach	Oesophagus	Leukaemia	Kidney	Nas…	KS

Interactive Map of Cancer Incidence, World, 2012 Estimates

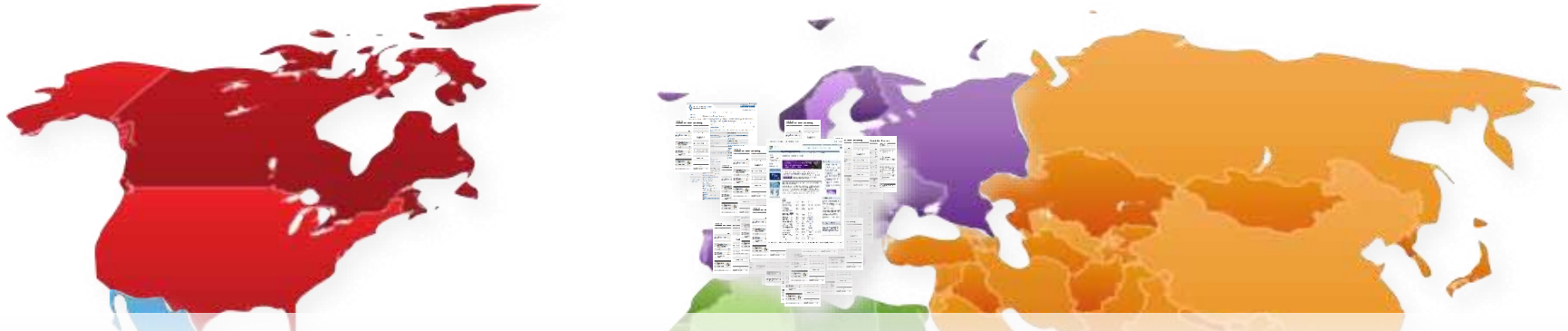
Lung cancer incidence — Worldwide



incidence — 14,090,149 new cancer cases per year:

Lung	Bowel	Liver	NHL	Thyroid	My…	HL

Incompatible datasets

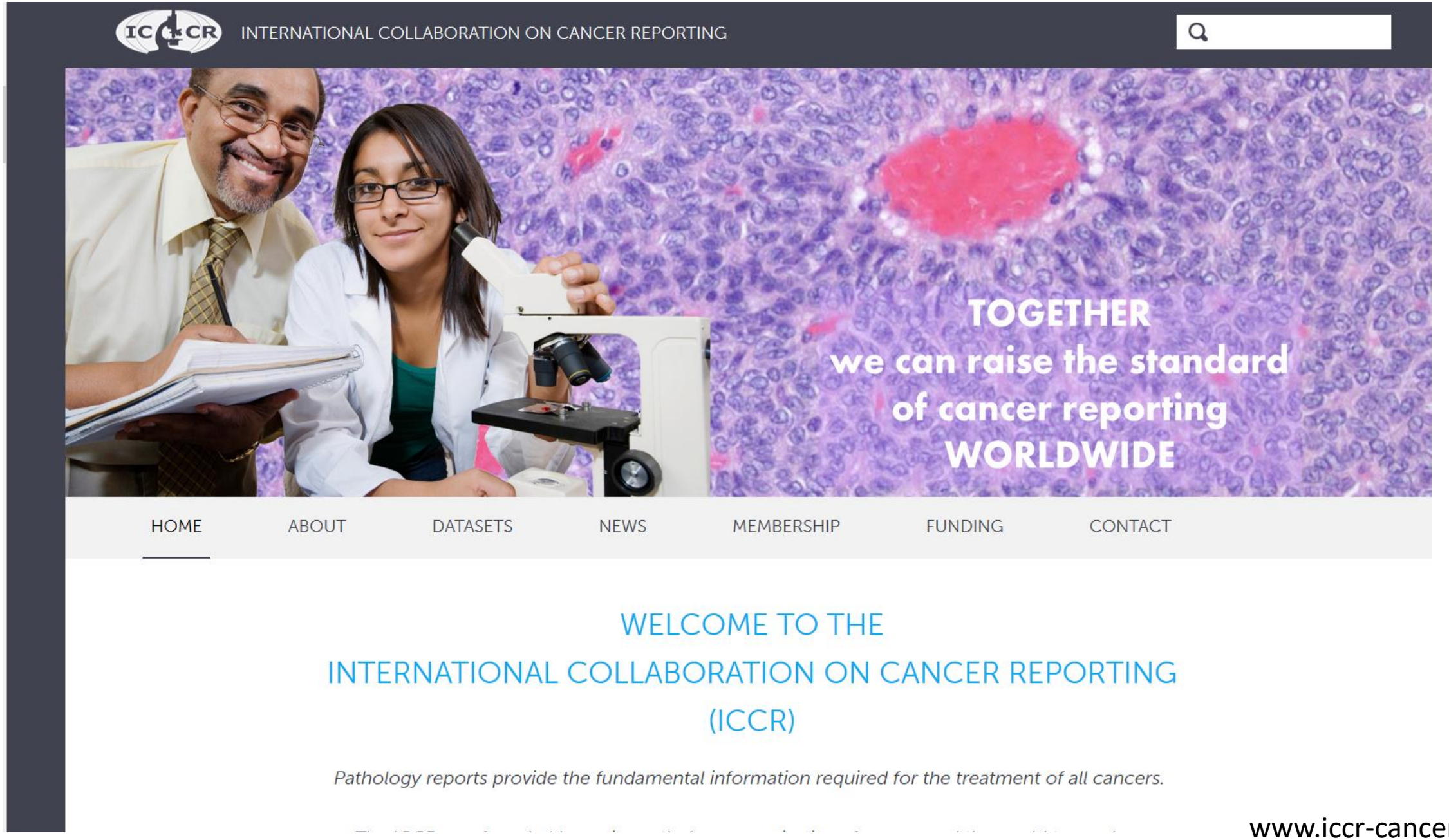


Need:

Standardised, internationally accessible datasets

- Data Elements:
  - Naming conventions
  - Value lists
  - Units and methods of measurement

- *and* explanatory text



www.iccr-cancer.org

INTERNATIONAL COLLABORATION ON CANCER REPORTING

HOME ABOUT DATASETS NEWS MEMBERSHIP FUNDING CONTACT

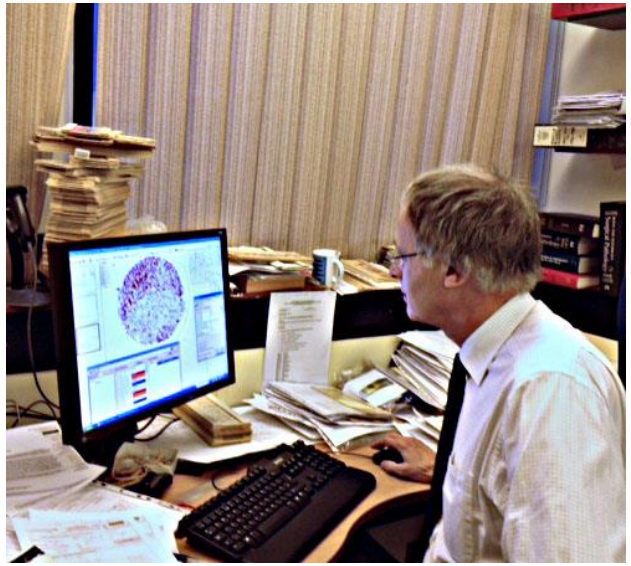
WELCOME TO THE INTERNATIONAL COLLABORATION ON CANCER REPORTING (ICCR)

Pathology reports provide the fundamental information required for the treatment of all cancers.

www.iccr-cancer.org

What does ICCR do?

- Publication of evidence based protocols for the pathology reporting of cancers as structured data
  - Improves clinical practice.
  - Ensures ‘buy in’ from pathologists
  - Quality assurance at this stage underpins everything else



Why does ICCR do this?

- Electronic implementation of these protocols as discrete data across large populations enables:
  - aggregation and automated analysis of data in real time
  - epidemiological and other research
  - quality indicators
  - public health management

International Collaboration on Cancer Reporting

Proposed Benefits

- **Worlds best expertise:**
  - ✓Domain knowledge
  - ✓Credibility
- **One world resource:**
  - ✓Dramatically reduced cost
  - ✓Burden on expert resources shared
  - ✓Developing countries have access
- **Universality means:**
  - ✓Simplified IT implementation in the laboratory
  - ✓Simplified IT implementation in eHealth:
    - ✓ Terminology binding
    - ✓ eMessaging
  - ✓Interoperability of health data internationally

2011 Four Pilot Protocols Started

CAP: Lung Cancer *Arch Path Lab Med*

RCPath: Endometrial Cancer *Int J Gynae Path*

CPAC: Prostate Cancer *Histopathology*

RCPA: Melanoma *Am J Surg Path*


IC CR

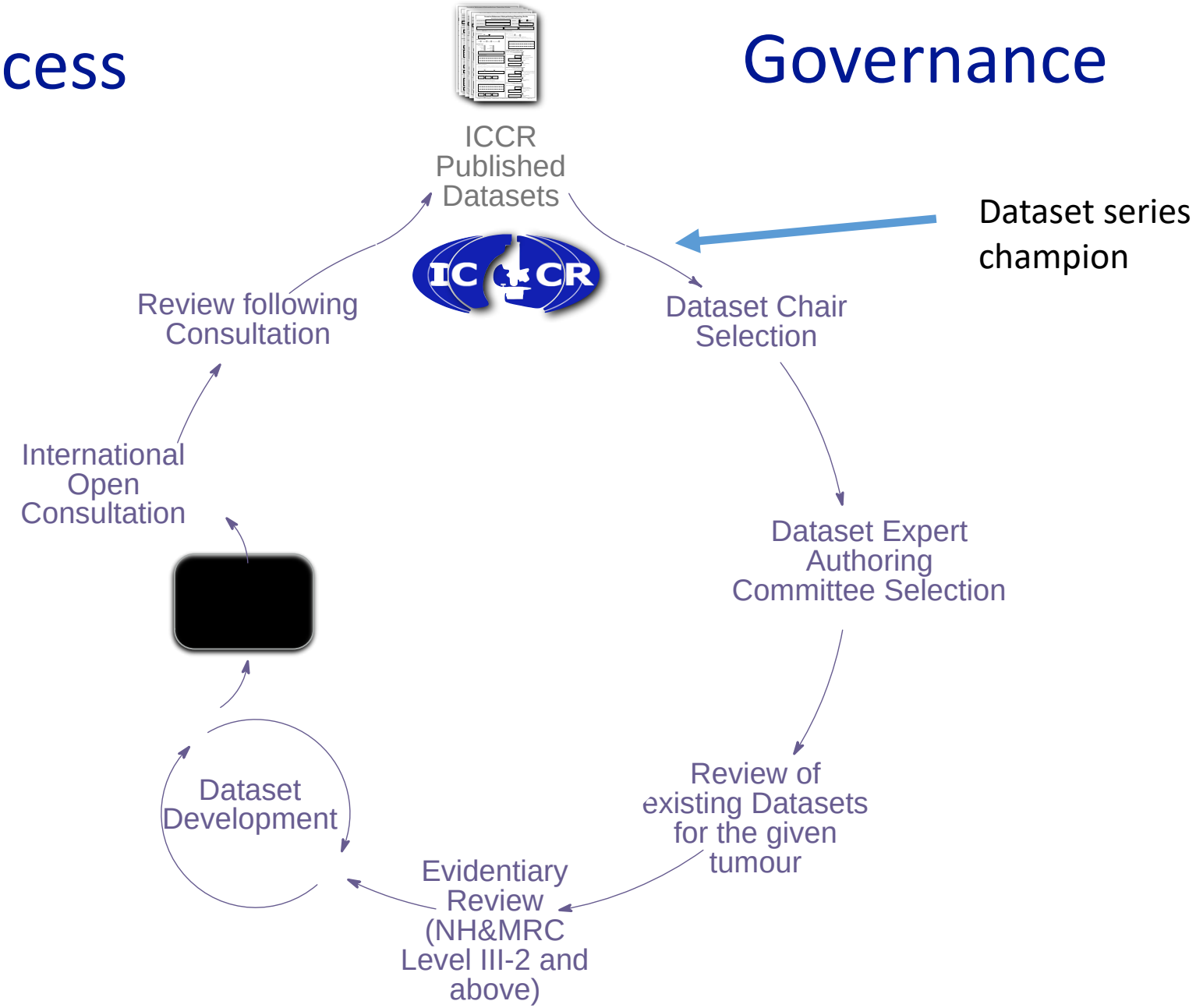
2011 - Four Pilot Protocols

Findings

- All protocols completed successfully within 4 months
- Collaborative Paradox:
  - Enthusiastic and productive collaboration
  - Easier Internationally > National > Institutional
- All reduced the number of mandatory items (118 to 66)
- Agreed naming conventions value lists & units
- The importance of a Project Manager was recognised

Process

Governance



Governance

Constitution

Dated

Constitution of International Collaboration on Cancer Reporting (ICCR)

(Draft dated 16 May 2013)

Richard Fogl
Norton Rose Australia
Grosvenor Place, 225 George Street
Sydney NSW 2000
Tel: +61 (2) 9330 8484
www.nortonrose.com
Our ref: 2782357

Board

International Collaboration on Cancer Reporting

ICCR Board of Directors Tasks

In order to achieve its objectives the ICCR Board will need to undertake the following tasks:

1. Administration
   - Buy or rent premises/equipment as required
   - Employ staff as required
   - Appoint a company secretary
   - Maintain a stakeholder database
   - Maintain a conflict of interest register
   - Maintain a website
   - Organise an annual general meeting which includes:
     - Annual financial report, directors' report and auditor's report,
     - The election of directors,
     - The appointment of an auditor, and determination of auditor's remuneration
     - Other business
2. Membership
   - Recruit ICCR members
   - Approve membership applications
   - Determine membership categories and set the fee structure for membership, including any discounts (part year membership/low income applicants)
   - Maintain a member database
     - Member name and contact details
     - Membership category and financial status of membership
     - Date of admission (and cessation) of membership
     - In the case of a corporate members, the name, and contact details of its nominated representative
3. Oversight
   - Monitor the progress of the ICCR Steering Committee in the development and publication of cancer datasets
4. Financial
   - Seek sponsorship for dataset development
   - Appoint an auditor
   - Maintain a budget and produce regular financial statements
   - Administer membership fees
   - Seek funding opportunities
5. Communication/Promotion
   - Organise promotional activities eg conference presentations/posters
   - Develop and publish ICCR newsletter
6. Relationships
   - Identify partner organisations and maintain partner relationships
7. Education
   - Organise educational opportunities for ICCR datasets
   - Investigate translation of published datasets into different languages
8. Implementation

ICCR BOARD OF DIRECTORS — Page 4

DSC

International Collaboration on Cancer Reporting

Terms of Reference of

ICCR STEERING COMMITTEE

Version: 0.1: DRAFT

Edit. Review Comm.

International Collaboration on Cancer Reporting

ICCR Board of Directors Tasks

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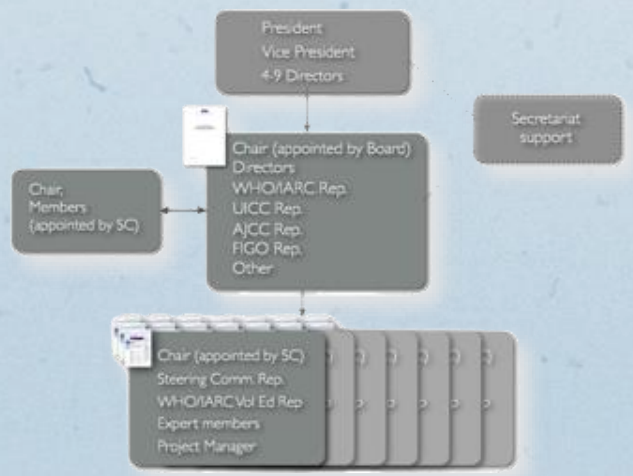
ICCR BOARD OF DIRECTORS — Page 4

Conflict of Interest



Dataset Framework

International Collaboration on Cancer Reporting

Guidelines for the Development of Cancer Datasets

Version: 0.6 DRAFT

GUIDELINES FOR CANCER DATASET DEVELOPMENT Page 1

International Collaboration on Cancer Reporting

Roles and Responsibilities ICCR Dataset Writing Committee

Version: 0.6 DRAFT

GUIDELINES FOR CANCER DATASET DEVELOPMENT Page 1

International Collaboration on Cancer Reporting

Project Manager Toolkit

Version: 0.6 DRAFT

GUIDELINES FOR CANCER DATASET DEVELOPMENT Page 1

International Collaboration on Cancer Reporting

ICCR Harmonisation Guidelines

Version: 0.1

uicc global cancer control WORLD CANCER CONGRESS

Lexicon Project

Levels of evidence

...an evidence hierarchy to include topics other than treatment: revising the Australian 'levels of evidence'. BMC Medical Research Methodology, 2009

Additional File 1 **NHMRC Evidence Hierarchy: designations of 'levels of evidence' according to type of research question** (including explanatory notes)

Level	Intervention [1]	Diagnostic accuracy [2]	Prognosis	Aetiology [3]	Screening Intervention
I [4]	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies
II	A randomised controlled trial	A study of test accuracy with: an independent, blinded comparison with a valid reference standard,[5] among consecutive persons with a defined clinical presentation[6]	A prospective cohort study[7]	A prospective cohort study	A randomised controlled trial
III-1	A pseudorandomised controlled trial (i.e. alternate allocation or some other method)	A study of test accuracy with: an independent, blinded comparison with a valid reference standard,[5] among non-consecutive persons with a defined clinical presentation[6]	All or none[8]	All or none[8]	A pseudorandomised controlled trial (i.e. alternate allocation or some other method)
	▯ Case-control study ▯ Interrupted time series with a control group	A comparison with reference standard that does not meet the criteria required for level II and III-1 evidence	Analysis of prognostic factors amongst persons in a single arm of a randomised controlled trial	A retrospective cohort study	A comparative study with concurrent controls: ▯ Non-randomised, experimental trial ▯ Cohort study ▯ Case-control study
III-3	A comparative study without	Diagnostic case-control	A retrospective cohort study	A case-control study	A comparative study without concurrent controls: ▯ Historical control study ▯ Two or more single arm study
			...s, or cohort study of different stages of disease	A cross-sectional study or case series	Case series

Core **ired**

Non-core **nded**

Key ICCR dataset development points

Definitions – CORE (REQUIRED) elements

- Core elements - essential for staging, clinical management, or prognosis of the cancer.
- These elements will either have evidentiary support at Level III-2 or above (based on prognostic factors in the NHMRC levels of evidence[1] document – "Analysis of prognostic factors amongst persons in a single arm of a randomised controlled trial").
- In rare circumstances, where level III-2 evidence is not available an element may be Core where there is unanimous agreement in the expert committee. An appropriate staging system eg Pathological TNM staging would normally be included as a required element.
- The summation of all CORE elements is considered to be the minimum reporting standard for a specific cancer.

Key ICCR dataset development points

Definitions – NON-CORE (RECOMMENDED) elements

- Non-core elements - unanimously agreed should be included in the dataset but are not supported by level III-2 evidence.
- These elements may be clinically important and recommended as good practice but are not yet validated or regularly used in patient management.
- Key information other than that which is essential for staging, clinical management or prognosis which are fundamental to the histological diagnosis and conclusion
  - e.g. macroscopic observations and interpretation, block identification key,
  - May be included as either core or non-core elements by consensus of the expert panel.

Key ICCR dataset development points

***Commentary* on data items**

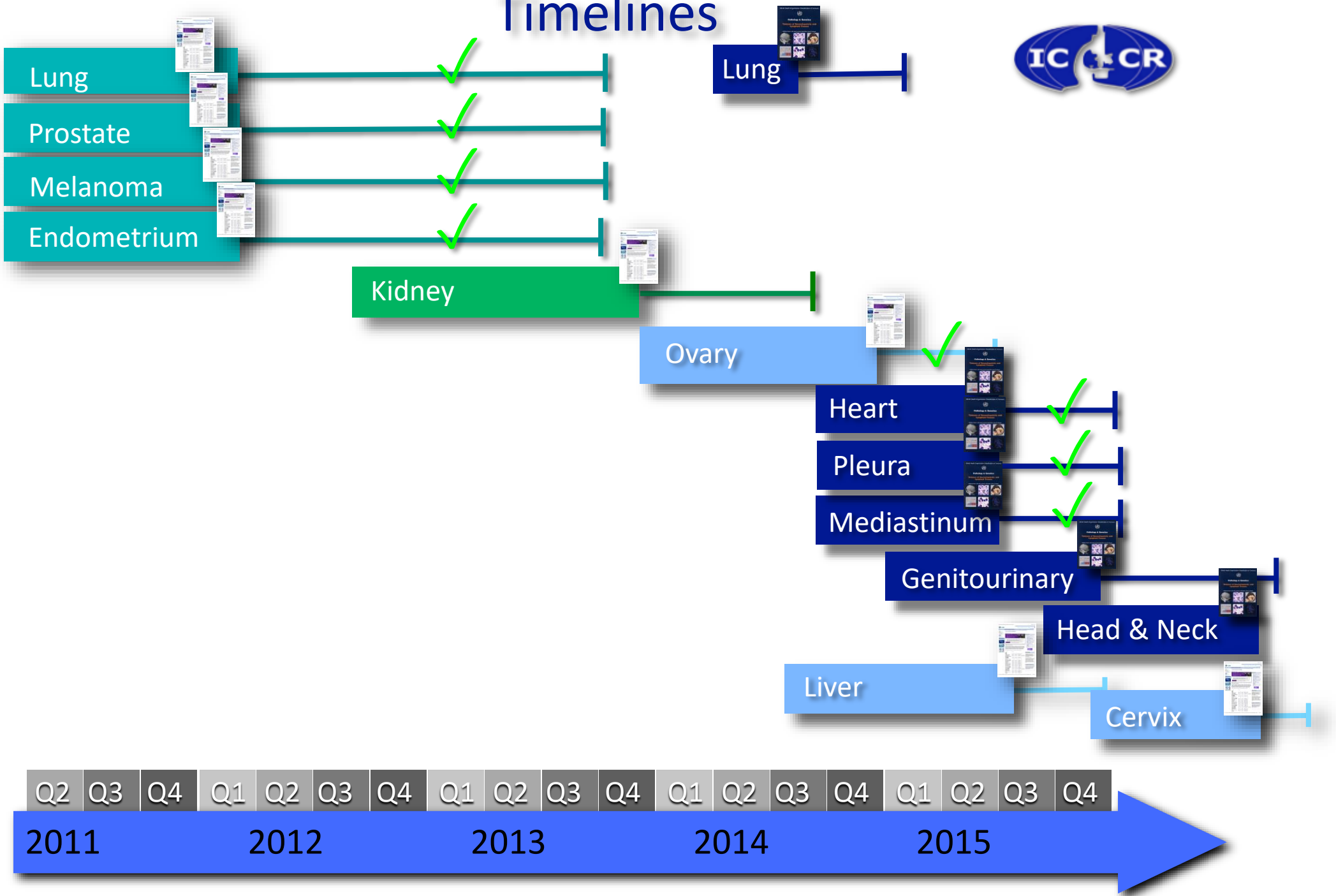
- Commentary is explanatory text, diagrams or tables that clarify the elements used to:
  - defines the way an item should be reported, to ensure clarity and conformity
  - explains why an item is included (e.g. how does the item assist with clinical management or prognosis of the specific cancer)
  - cites published evidence in support of the element
  - states any exceptions or issues
- Commentary provides contextual guidance to the reporting pathologist.

Key ICCR dataset development points

Breadth of the ICCR datasets

- The goal of the ICCR is to develop a set of data elements which will form the core of any pathology report on the specific cancer around the world.
- Debate: how to provide datasets that work well in resource-rich and resource poor countries? Working on layered datasets to allow combination of morphological and molecular items
- Pathologists may add other elements etc when implementing or reporting. The intention is not to restrict them from adding in items they feel are important to fit in with local practice.

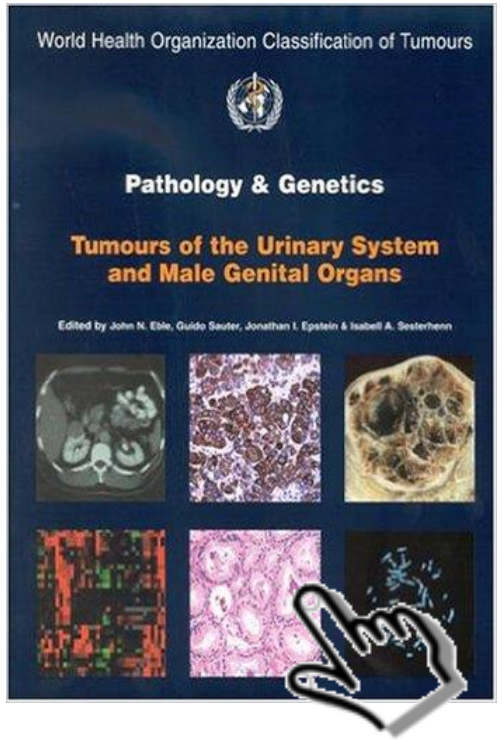
Timelines


Lung
Prostate
Melanoma
Endometrium
Lung
Kidney
Ovary
Heart
Pleura
Mediastinum
Genitourinary
Head & Neck
Liver
Cervix
Q2 Q3 Q4 Q1 Q2 Q3 Q4 Q1 Q2 Q3 Q4 Q1 Q2 Q3 Q4 Q1 Q2 Q3 Q4
2011
2012
2013
2014
2015

IC CR

European Society of Pathology

International Society of Urological Pathology



- Kidney
- Kidney core
- Bladder Bx TUR
- Bladder Resect
- Urethrectomy
- Nephro-urethra
- Prostate Rad
- Prostate Core
- TUR
- Testis

Genitourinary

- RPLND
- Penis
- Wilms

Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
2011			2012				2013				2014				2015			

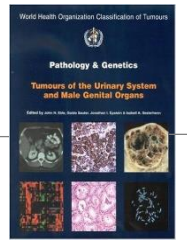
Timelines

H & N
Endocrine

Skin
Haem
CNS

Eye

4th Ed



5th Ed

CNS
GIT

Breast
Soft Tissue
Bone

uicc
global cancer control

8th Ed TNM

H & N
Endocrine

Cervix

Skin
Haem
CNS

Eye

Colorectal
Breast

UPDATE
ALL EXISTING
TO 8th Ed. TNM

GIT suite

Breast
Soft Tissue
Bone

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2016 2017 2018 2019 2020

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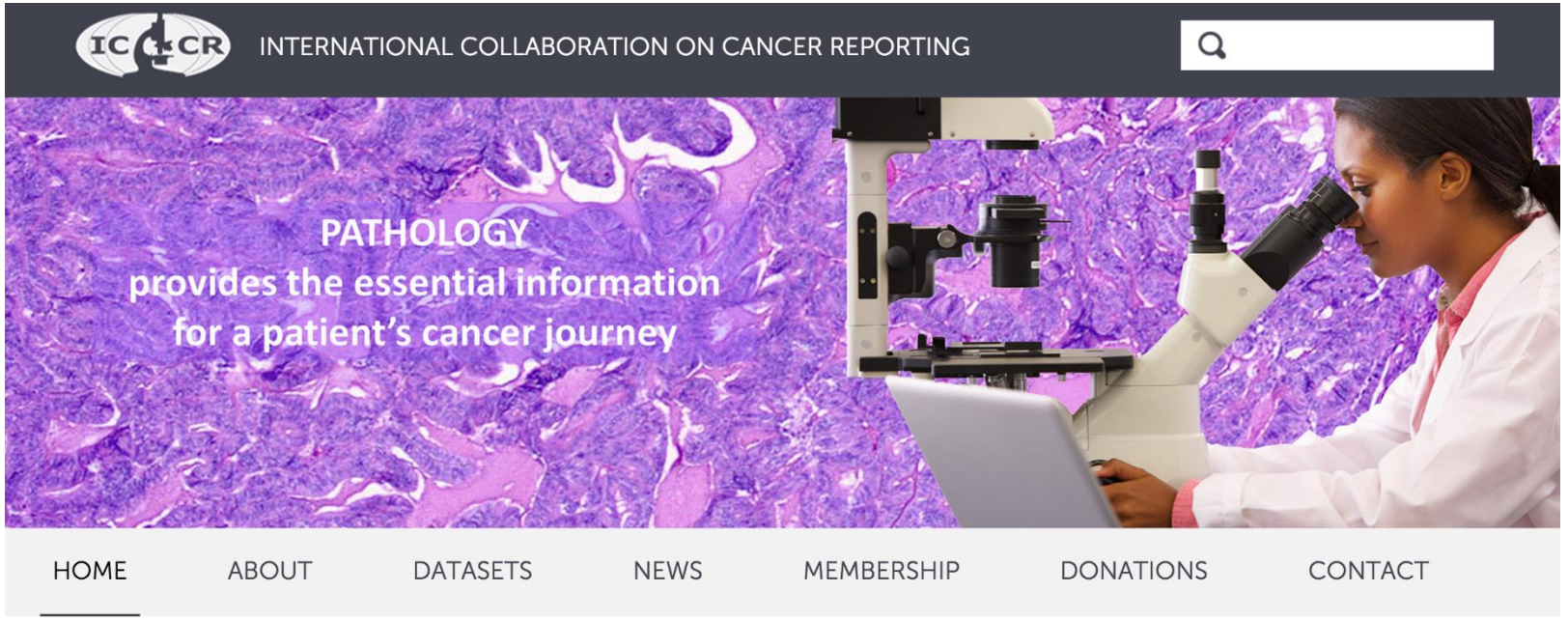
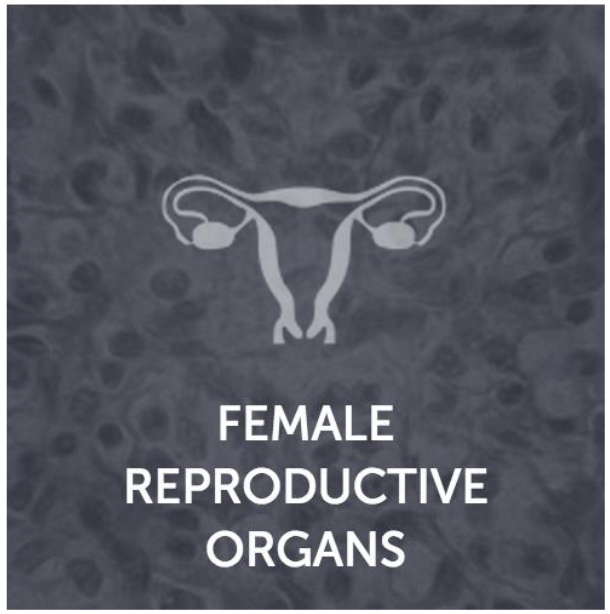


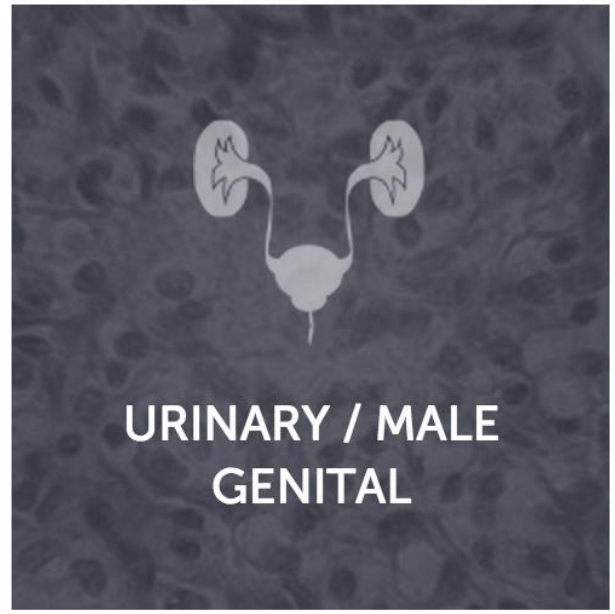
WELCOME TO THE
INTERNATIONAL COLLABORATION ON CANCER REPORTING

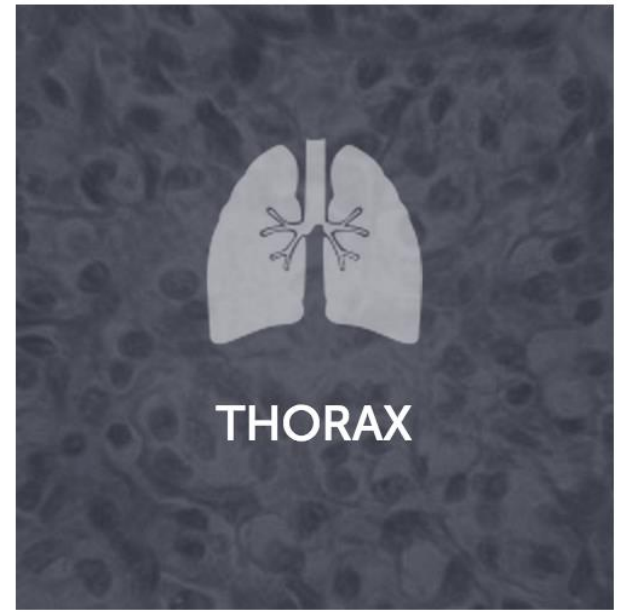
ICCR DATASETS
Internationally agreed cancer datasets for many major cancers

PUBLICATIONS
Publications on structured pathology reporting of cancer.

NEWS
Updates on international structured pathology reporting of cancer


FEMALE
REPRODUCTIVE
ORGANS


URINARY / MALE
GENITAL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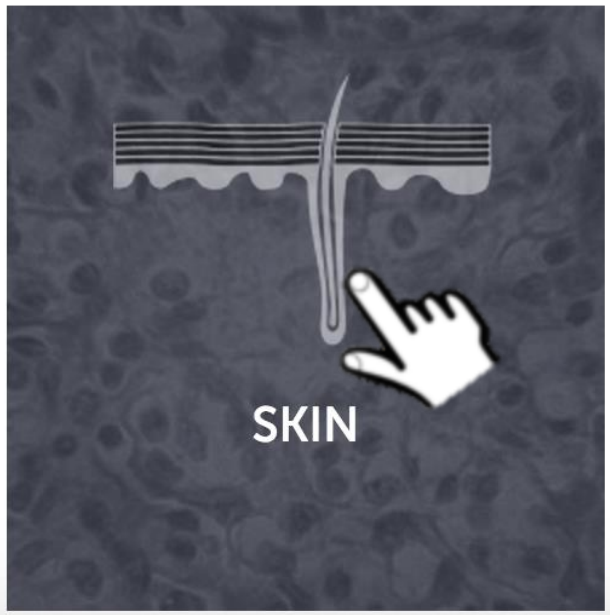
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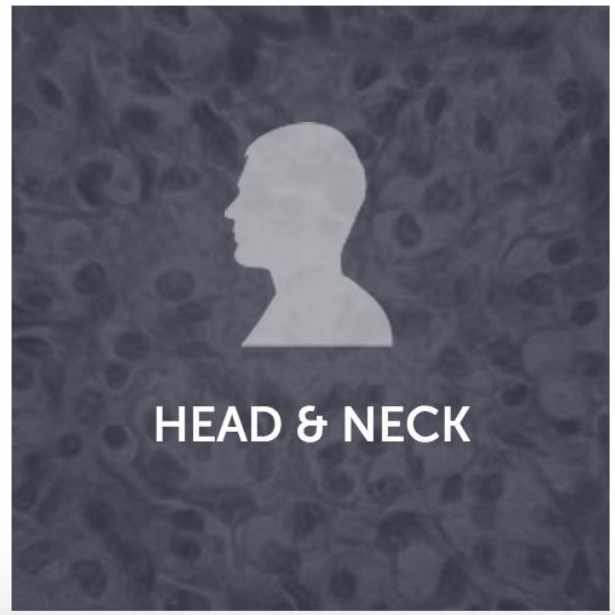
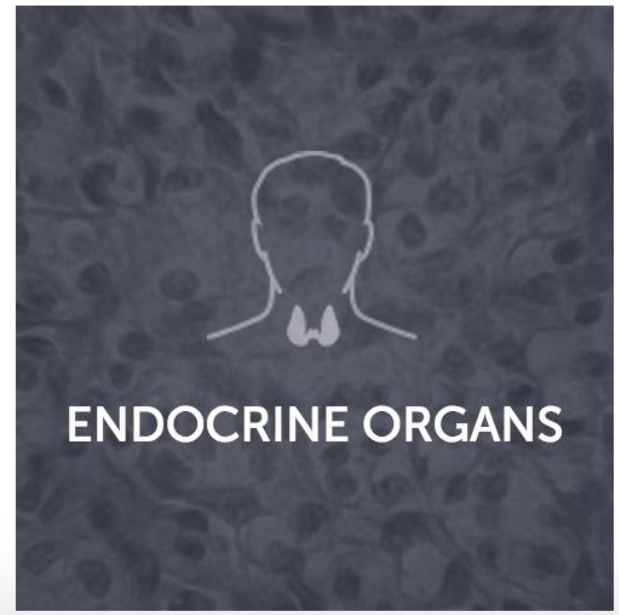
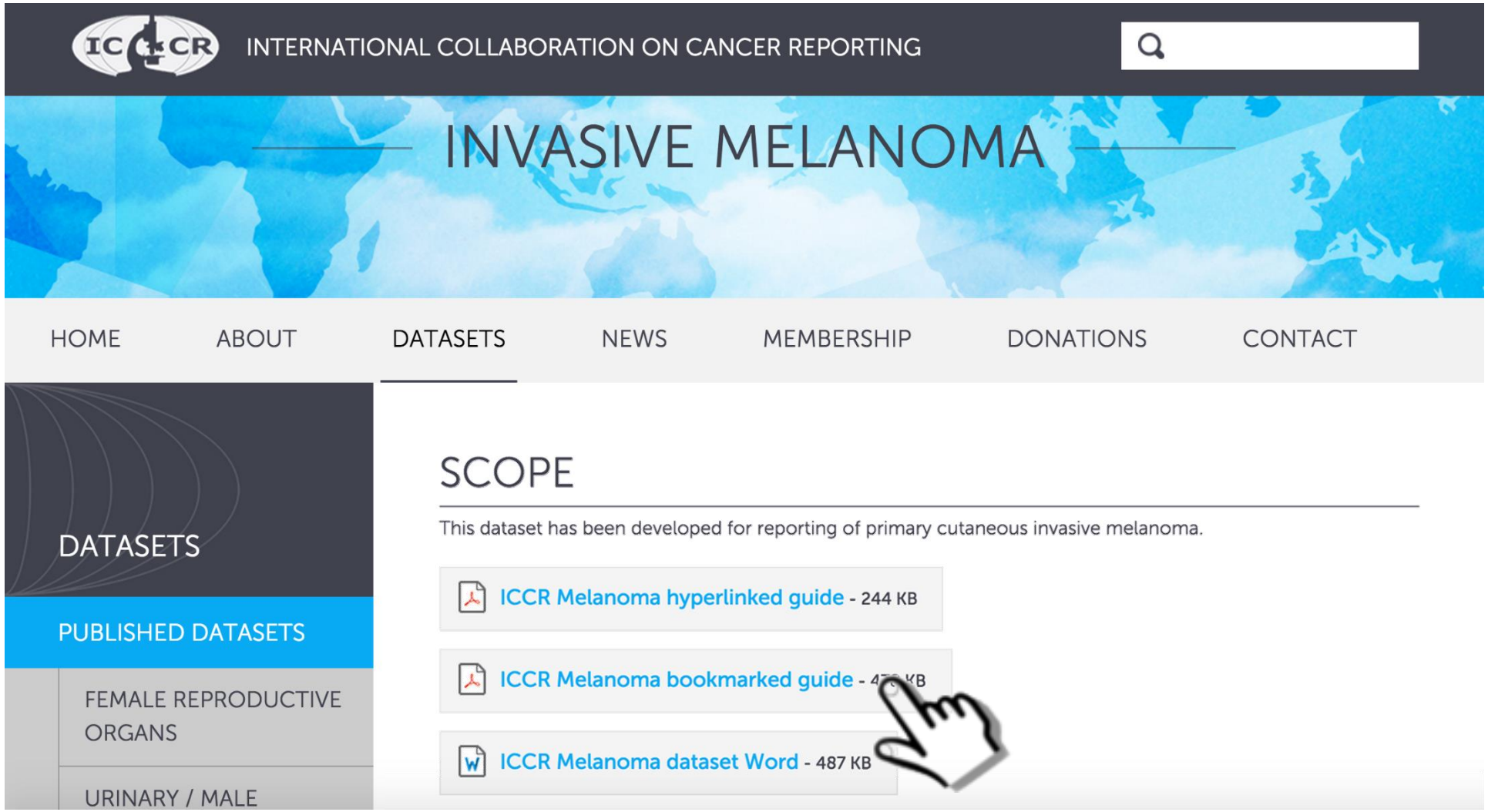

HEAD & NECK


ENDOCRINE ORGANS


INTERNATIONAL COLLABORATION ON CANCER REPORTING
INVASIVE MELANOMA
HOME
ABOUT
DATASETS
NEWS
MEMBERSHIP
DONATIONS
CONTACT
DATASETS
PUBLISHED DATASETS
FEMALE REPRODUCTIVE ORGANS
URINARY / MALE
SCOPE
This dataset has been developed for reporting of primary cutaneous invasive melanoma.
ICCR Melanoma hyperlinked guide - 244 KB
ICCR Melanoma bookmarked guide -
ICCR Melanoma dataset Word - 487 KB

Tumour regression (intermediate and late)

Notes

A host immunologic response may be directed against melanoma and may result in elimination of part or all of the melanoma; this is termed regression. This phenomenon may be categorized into three temporal stages: early, intermediate and late. Early regression is signified by the presence of tumor-infiltrating lymphocytes (TILs). Intermediate and late regression result in partial or complete loss of melanoma and are characterized by immature (intermediate) and mature (late) dermal fibrosis, often accompanied by the presence of melanophages and flattening of the epidermis (with loss of rete ridges). In most reports assessing the prognostic significance of regression, intermediate and late regression have not been differentiated or separately analysed.

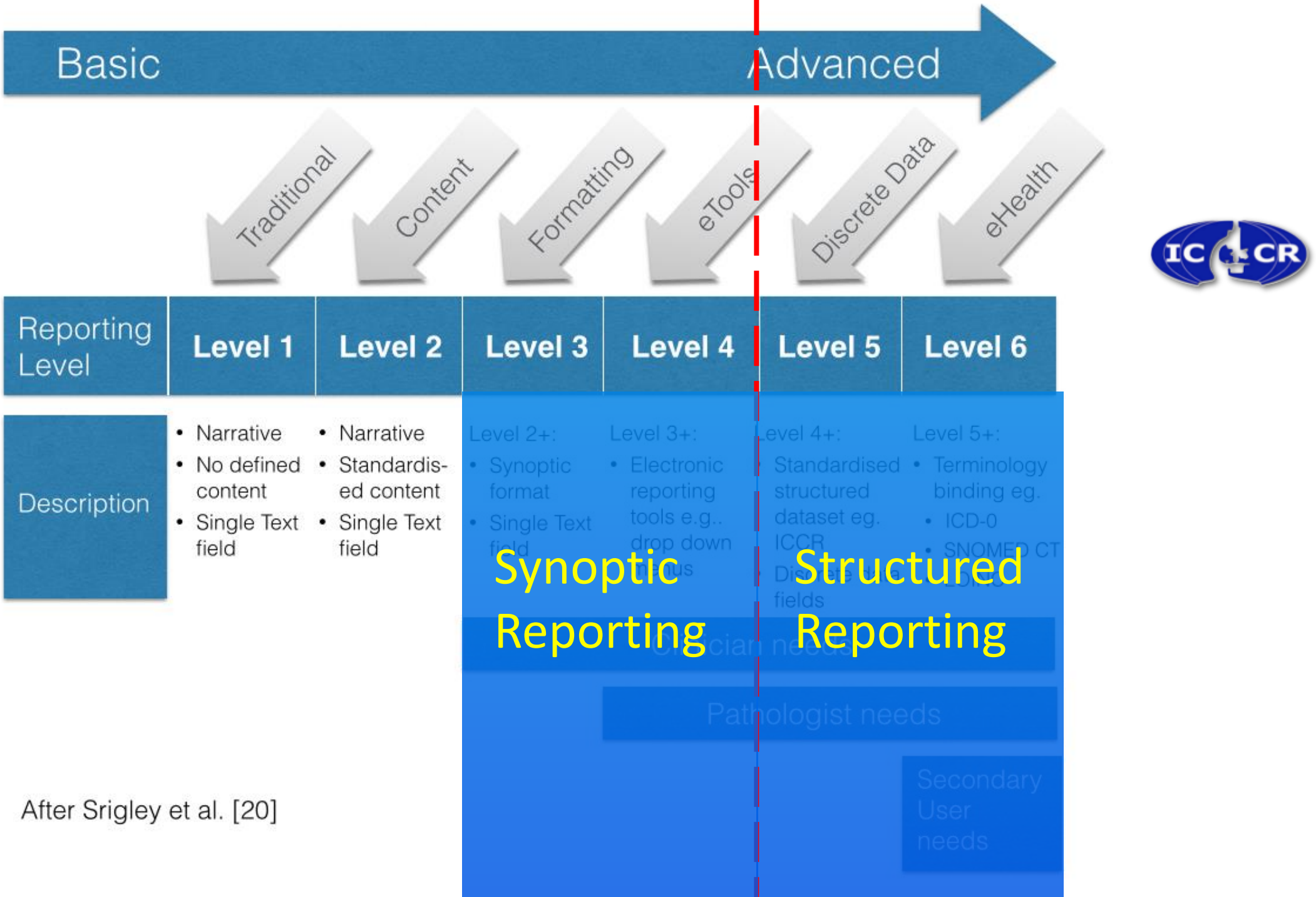
Evidentiary Support

The prognostic significance of (intermediate and late) regression is controversial.[1] Some studies report that it portends a worse prognosis (particularly in thin melanomas),[2] whereas others report that it is associated with a more favourable outcome.[1] Difficulties in interpreting such studies include lack of a standardised definition or criteria for its diagnosis, and poor interobserver reproducibility.

References

1 Scolyer RA, Mihm Jr MC, Cochran AJ, Busam KJ and McCarthy SW (2009). Pathology of melanoma. In: *Cutaneous Melano* CM, Houghton Jr A, Sober A and Soong SJ (eds), Quality Medical Publishing, St. Lou , 205–248.

2 Cook MG, Spatz A, Brocker EB and Ruite DJ (2002). Identification of histological features associated with metastatic potential in thin (<1.0 mm) cutaneous melanoma with metastases. A study on behalf of the EORTC Melanoma Group. *Journal of Pathology* 197:188–193.


Basic
Advanced
Traditional
Content
Formatting
eTools
Discrete Data
eHealth
Reporting Level
Level 1
Level 2
Level 3
Level 4
Level 5
Level 6
Description
• Narrative
• No defined content
• Single Text field
• Narrative
• Standardis-ed content
• Single Text field
Level 2+:
• Synoptic format
• Single Text field
Level 3+:
• Electronic reporting tools e.g.. drop down menus
Level 4+:
• Standardised structured dataset eg. ICCR
Level 5+:
• Terminology binding eg.
• ICD-0
Synoptic Reporting
Structured Reporting
Pathologist needs
Secondary User needs
After Srigley et al. [20]

Success will be:

- Unified global language for reporting all cancers (50+ datasets)
- Improved consistency/quality of reports
- Improved patient management and outcomes
- Demonstrated by:
  - International audits of pathology practice
  - Adoption of ICCR pathology datasets by national oncology teams
  - Genuinely comparative data on cancer incidence and outcomes