

# International Collaboration on Cancer Reporting

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# ANNUAL REPORT 2023

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# **CONTENTS**

1.	Message from the president	4
	1.1 Four Workstreams	4
	1.2 Dataset development	4
	1.3 Translation	5
	1.4 Implementation	5
	1.5 Education	6
	1.6 Sustainability	6
	1.7 Thank you	6
2.	ICCR's Vision and Mission	7
	2.1 Vision statement	7
	2.2 Mission statement	7
3.	Goals and Objectives	7
	3.1 Development of cancer pathology datasets	7
	3.2 Translation of datasets into multiple languages	7
	3.3 Implementation of ICCR datasets	7
	3.4 Education	7
4.	Organisational overview	8
	4.1 Membership	9
	4.2 Board of Directors	10
	4.3 Council	10
	4.4 Dataset Steering Committee	11
	4.5 Dataset Authoring Committees	11
	4.6 Structured Reporting Implementation Committee	11
5.	Dataset development	11
	5.1 Published datasets	12
	5.2 International Standard Book Numbers (ISBN)	13
	5.3 Datasets in progress	13
	5.3.1 Cytology	13
	5.3.2 Genitourinary	13
	5.3.3 Central nervous system	14
	5.3.4 Head and neck	14
	5.3.5 Endocrine	15
	5.3.6. Female reproductive organs	15
	5.4 Datasets in planning	15
	5.0 INVISIAGING	I D
,	Translation	۱۵ ۲ ۲
о.	ITANSIALION	
	6. I Datasets translated	1
	6.2 Breast Suite	10
	0.3 UKIAIMAN 4 Atalian	10
	0.4 Italian	10
	6.7 Euturo translation	10
7		۲۳ ۵ <b>۵</b>
1.	7.1 Structured Departing Implementation Committee (CDIC)	
	7.1 Structured Reporting Implementation Committee (SRIC)	20
	7.2 EIEUTUTIU TUUK Udlasets	∠U ⊃1
0	Finances	1 \
б.	FINANCES	
	8. I BUOGET	21
	8.2 AUGILEO IINANCIAI STATEMENT	21
	8.3 Sustainability	21

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8.4 Sponsorship	21
9 Appendix	
9.1 Published datasets	
9.2 Peer-reviewed publications	



# **1. Message from the president**

The International Collaboration on Cancer Reporting (ICCR) has experienced another busy and productive year in 2023. Our primary focus has been on the development of new datasets, in addition to updating existing datasets to maintain currency with the World Health Organization World Classification of Tumours 5<sup>th</sup> series. There has also been significant work on the other three strategic workstreams, i.e. Dataset translation, Implementation and Education, and on preparing a Philanthropic Approach strategy aimed at ensuring the ICCR's sustainability as well as securing funding for expanding our translation work. Finally, the organisation changes stemming from the constitutional revisions approved at the last Annual General Meeting (AGM) in November 2022 have been implemented, and in addition, the ICCR Council has approved the establishment of an Honorary Advisory Panel of past ICCR office bearers to ensure that the current Board and Council have access to expert advice when needed.

# 1.1 Four Workstreams



# 1.2 Dataset development

The development of international standards for pathologists reporting cancers remains the ICCR's core business. Each dataset incorporates contemporary morphologic and molecular standards from partner organisations that include the International Agency on Cancer Research (IARC), World Health Organization (WHO), the Union for International Cancer Control (UICC) TNM, and the American Joint Committee on Cancer (AJCC), as well as specialty pathology societies from fields such as gynaecological, urological, breast, paediatric and head and neck pathology, amongst others. The datasets serve as a bridge between the standard developers and the global pathology community.

The ICCR has 61 published datasets to date, including datasets for the top ten solid tumours worldwide. Four ICCR datasets have also been updated in the last 12 months to reflect the latest WHO Classification of Tumours and TNM staging, and a further 27 updates are in progress. More than 55 articles related to the ICCR datasets or work of the ICCR in peer-reviewed journals have been published.

In 2022, ICCR entered into a Memorandum of Understanding with the International Academy of Cytology (IAC) to investigate the development of ICCR Cytopathology datasets. The Lung - Small Diagnostic and Cytopathological Specimens dataset is the pilot project and is due for publication in December 2023.



# 1.3 Translation

Translation of the datasets has been identified as a key priority for the ICCR, especially with the feedback that ICCR datasets are valued globally. The ICCR website has been accessed from 187 countries to date, and in the last three months, an average of approximately 100 users per day has been captured in our website metrics, indicating the traction these datasets are receiving worldwide. The top 5 countries of users include India, Japan and China, and the top 3 dataset suites being accessed are for Breast, Gynaecological and Digestive Tract cancers.

The image below was generated by Google Analytics data of the ICCR website, and illustrates the number of users, by country, who visited the ICCR website in the last 12 months.



Significant progress was made last year with the initial translation of the breast cancer suite into six priority languages of Chinese, German, French, Spanish, Portuguese and Russian, and quality assurance assessments by the relevant national societies have been ongoing this year. A second Translation Summit was convened in May this year to discuss the learnings from this translation initiative and models for dataset translation more generally. However, sourcing funding to support the comprehensive dataset translation continues to be a rate-limiting step in advancing this workstream.

The ICCR continues to pursue collaborations with member pathology organisations, middleware and laboratory information system (LIS) vendors to discuss further opportunities for future translations.

# 1.4 Implementation

Implementation of the ICCR datasets is crucial to pathology reporting dataset progression, integration into reporting practice and utilisation worldwide. The Structured Reporting Implementation Committee (SRIC) was convened in 2021 to guide this process and has been investigating structured reporting tools for low and middle-income countries (LMICs), developing electronic versions of the ICCR datasets for upload into Laboratory Information Systems (LIS), development of terminology to support analysis and comparison of data, quality assurance, overseeing of implementation projects, and improving cancer registry interface standards.

The SRIC committee explored the necessary requirements for transposing the PDF ICCR datasets into electronic formats, which could then be used in future within electronic health records/ databases,

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by means of a Request for Proposal document to be sent to relevant vendors. A review of different technologies incorporated by the College of American Pathologists (CAP) and the Pathological Anatomical National Automated Archive of the Netherlands (PALGA) was incorporated in this evaluation. Good progress has been made with the request for proposal (RFP), with many key specifications outlined for electronic transposing of the ICCR datasets.

Furthermore, a project to assign SNOMED-CT coding to the ICCR datasets is underway, which will assist with the standardization of ICCR terminology. The invaluable work of our collaborators at the University of Nebraska on this project is greatly appreciated. The ICCR is also one of the Participating Organizations in the NCI's Cancer PathCHART (Cancer Pathology Coding Histology and Registration Terminology), which aims to develop a unified resource for deriving public health statistics from pathology reporting for cancer prevention programs and research.

# 1.5 Education

After including Education as the fourth workstream of the ICCR in 2023, there has been progress in developing collaborations such as a joint cervical webinar, in both English and French, delivered in Africa to pathologists, oncologists and other medical staff, with the World Continuing Education Alliance (Memorandum of Understanding under discussion). Additionally, there were excellent presentations of the ICCR's dataset work at three sessions at the European Congress of Pathology Dublin 2023 (Breast, Paediatrics and Head and Neck cancer sessions). Further presentations at the European Congress of Pathology Florence 2024 are under discussion.

The ICCR will continue to seek partnerships with relevant organizations to continue the development of the Education workstream. We aim to facilitate educational events such as webinars for professional development, University and College lectures, outreach sessions, and conference presentations.

# 1.6 Sustainability

The ICCR has continued to have the highly valuable support of 18 international pathology organisation members, and the membership fees have continued to drive the maintenance and growth of the four workstreams of the ICCR. Future funding is crucial to the delivery of key projects within the four workstreams.

Additionally, the ICCR is grateful to Donna Meredith, the Managing Director of Keystone Corporate Positioning, who has offered her services pro bono, to develop the Philanthropic Approach strategy aiming to gain additional funding.

# 1.7 Thank you

On behalf of the ICCR Board and Council, I would like to express our sincere thanks and gratitude to all our members, sponsoring organisations and strategic partners for their invaluable support. Without their contributions and those of the numerous pathologists from our membership, who have voluntarily and enthusiastically have contributed their time and expertise, the ICCR would not have been able to achieve its goals. We are especially thankful to the Chairs of both the Dataset Steering Committee, Sigurd Lax, and of the Structured Reporting Implementation Committee, George Birdsong, for their crucial work and input. Finally, we are grateful to our General Managers, Meagan Judge and Rajuel Nandakumar, as well as all the project managers and assistants for their tireless efforts over the last year.

James Kench, President ICCR

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# 2. ICCR'S VISION AND MISSION

# 2.1 Vision statement

Internationally standardised, multilingual and machine-readable pathology reports documenting cancer subtype, grade, stage and other morphologic and molecular tumour parameters are necessary to improve patient care and outcomes and to advance cancer control in populations.

# 2.2 Mission statement

The International Collaboration on Cancer Reporting (ICCR) produces internationally standardised pathology datasets incorporating contemporary morphologic and molecular parameters which are translated into multiple languages and are available in machine readable formats. The datasets are based on strong scientific evidence and are used primarily to improve patient care. High quality data also facilitate population-level cancer control initiatives including cancer registration, epidemiology, quality research, resource planning and education.

# **3. GOALS AND OBJECTIVES**

# 3.1 Development of cancer pathology datasets

Cancer patient outcomes are positively impacted by the ability of the medical team to build treatment and management options based on accurate and complete information from the patients' pathology reports. Developing complete, evidence-based cancer datasets containing essential and current reporting information for a given cancer provides the foundation for improved cancer staging and optimisation of treatment. The ICCR now has over sixty cancer datasets available for download.

# 3.2 Translation of datasets into multiple languages

Translating the ICCR datasets into numerous languages is essential to facilitate the implementation of standardised cancer reporting worldwide. In particular, the ICCR is focused on bridging equity access to support pathologists practicing in Low and Middle-Income Countries (LMICs) to effectively communicate complete cancer pathology results to associated clinicians, cancer registrars and other secondary users, thus ultimately benefiting cancer patients globally.

# 3.3 Implementation of ICCR datasets

Implementation of the ICCR datasets is crucial to their progression, integration and utilisation worldwide. This will involve investigating structured reporting tools for LMICs, developing electronic versions of the ICCR Datasets for upload into Laboratory Information Systems (LIS), development of terminology to support analysis and comparison of data, guality assurance, oversight of implementation projects, and improving cancer registry interface standards.

# 3.4 Education

In 2019 the International Association of Cancer Registries (IARC) endorsed the ICCR Datasets as the international standard for cancer pathology reporting. ICCR datasets have enormous educational value for pathologists, oncologists, and other related medical professionals for training and professional development, as well as providing pathologists in developing parts of the world with a benchmark and, therefore, a 'ladder' for progression and advancement in cancer reporting as their capability improves. The ICCR aims to facilitate educational events such as webinars for professional development, University and College lectures, outreach sessions, and conference presentations.

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# 4. ORGANISATIONAL OVERVIEW

The ICCR was founded by major pathology organisations from around the world to produce internationally standardised and evidence based datasets for the pathology reporting of cancer. Its goal is to improve cancer patient outcomes worldwide and to advance international benchmarking in cancer management.

The ICCR was incorporated as a not-for-profit organisation in September 2014.

The organisational structure is as follows:





# 4.1 Membership

The ICCR is supported by membership and sponsorship.

The ICCR currently has three levels of membership:

- Platinum which provides the member organisation with both Council and DSC representation. The annual subscription for a Platinum member is \$20,000 USD.
- Gold which provides the member organisation with both Council and DSC representation. The annual subscription for a Gold member is \$10,000 USD.
- Silver which provides the member organisation with DSC representation only. The annual subscription for a Silver member is \$5,000 USD.

Membership provides the principal amount of funding on which the ICCR depends.

As of December 2023, the ICCR has two Platinum members, which are:

- Royal College of Pathologists of Australasia (RCPA), and
- American Society of Clinical Pathology (ASCP).



These members have provided additional contributions above their membership fees and were recognised with elevation to Platinum membership at a 50% discount.

As of December 2023, ICCR has fourteen Gold members, which are:

- European Society of Pathology (ESP),
- Royal College of Pathologists United Kingdom (RCPath),
- College of American Pathologists (CAP),
- Royal College of Physicians of Ireland, Faculty of Pathology (RCPI FoP),
- German Society of Pathology (DGP),
- Brazilian Society of Pathology (SBP),
- Hong Kong College of Pathologists (HKCPath),
- Austrian Society of Pathology/Austrian Division of the International Academy of Pathology (ÖGPath/IAP Austria),
- Japanese Society of Pathology (JSP),
- Italian Society of Pathological Anatomy and Cytology (SIAPEC),
- Swiss Society of Pathology (SSP),
- Russian Society of Oncopathology (RSOP),
- Chinese Society of Pathology (CSP), and
- Professional Association of German Pathologists (BDP).

As of December 2023, there are two Silver members, which are:

- Canadian Association of Pathologists (CAP-ACP), and
- International Academy of Pathology (IAP) Arab Division.

# 4.2 Board of Directors

The ICCR Board of Directors BoD comprises of: Professor James Kench (President), Professor Kieran Sheahan (Vice President), Professor Annie Nga-Yin Cheung (Director), Associate Professor Kerryn Ireland-Jenkin (Director) and Professor Peter Schirmacher (Director).

# 4.3 Council

To role of the ICCR Council is to expand and promote the work of the ICCR by providing strategic guidance and recommendations to the ICCR Board of Directors. Each Platinum and Gold member can appoint one representative to the Council and one observer (for succession planning purposes).



# 4.4 Dataset Steering Committee

The ICCR DSC has responsibility for all activities relating to the development of ICCR datasets. The DSC invites representation from all sustaining members, as well as strategic partners, including IARC, the International Association of Cancer Registries (IACR) and the European Organisation for Research and Treatment of Cancer (EORTC).

Sigurd Lax of the Austrian Society of Pathology/ Austrian Division of the International Academy of Pathology holds the position of Chair of the DSC.

# 4.5 Dataset Authoring Committees

Dataset Authoring Committees (DACs) are convened as needed for the development of specific datasets. DAC members are recognised as honorary contributors to the ICCR for the lifetime of the datasets on which they contributed.

# 4.6 Structured Reporting Implementation Committee

The ICCR SRIC was convened in 2021. Its purpose is to provide guidance to the Council on matters relating to the implementation of ICCR cancer datasets, and to advance the detailed technical aspects impacting the efficient implementation of standardised cancer datasets such as electronic representation. Structured reporting options for LMICs and terminology binding. George Birdsong is the appointed Chair, SRIC.

The Board of Directors, Council, DSC, DAC and SRIC members are all volunteers that provide their expertise and time altruistically.

# **5. DATASET DEVELOPMENT**

The development of reporting standards for pathologists reporting cancers is ICCR's core business.

The ICCR dataset development follows an agreed process that is outlined in Guidelines for the Development of ICCR Datasets (<u>http://www.iccr-cancer.org/datasets/dataset-development</u>), which is reviewed and updated annually by the ICCR DSC. The process is summarised in the figure below.





The ICCR develops datasets in synchrony with the WHO Classification of Tumours updates. Dataset work commences close to the publication of the revised classification. The 5<sup>th</sup> edition of the WHO is nearing completion.

For the development of a series of datasets, the ICCR appoints a Series Champion who acts in an advisory role to the DSC to assist in the nomination of qualified candidates for the Chair and DAC roles. In addition, the Series Champion oversees the development process, supports the work of the dataset Chairs, and ensures harmonisation across the series. The responsibilities for each of the roles in a DAC are described in Roles and Responsibilities for the ICCR dataset development process (<u>http://www.iccr-cancer.org/datasets/dataset-development</u>). This document is reviewed and updated annually by the ICCR DSC.

For the development of each dataset, the DSC appoints appropriately qualified expert pathologist(s) to take on the role of Chair of the DAC. The Chair(s) are supported in the development process by a Project Manager and a representative from the ICCR DSC.

# 5.1 Published datasets

As of November 2023, the ICCR has published 61 datasets. All published datasets are compliant with the latest 8<sup>th</sup> edition TNM staging, where applicable.

See Appendix 9.1 for all published ICCR datasets.

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# 5.2 International Standard Book Numbers (ISBN)

International Standard Book Numbers (ISBN) have been assigned to each ICCR dataset published from July 2017. Datasets published before this date will be assigned an ISBN as they are updated.

# 5.3 Datasets in progress

The IARC/WHO 'blue books' are integral to all cancer datasets and as such the ICCR is committed to developing harmonised international datasets in synchrony with IARC/WHO. ICCR have a developmental schedule synchronising dataset development with IARC/WHO 'blue book' updates. Given IARC/WHO and ICCR utilise similar experts for the authorship of their documents, IARC and ICCR have agreed a process of resource allocation and timing to avoid over burdening the authorship pool.

There are 27 ICCR datasets currently in progress:

#### 5.3.1 Cytology

In May 2020 the International Academy of Cytology (IAC) entered into a Memorandum of Understanding (MoU) with IARC to work on cytopathology books as an additional resource to the WHO 5<sup>th</sup> Edition Classification of Tumours. In October 2021, ICCR entered into discussions with IAC with a view to potential collaboration on a series of cytopathology datasets.

An MoU between ICCR and IAC was signed in March 2022 agreeing to work on a joint project to develop a dataset for the cytopathology reporting of lung cancer. The ICCR Lung cancer DAC had previously recommended that ICCR consider the development of a dataset for small diagnostic samples of lung cancer. Therefore, it was agreed to expand the scope of this dataset to incorporate cytopathology.

The joint project is administered by a Cytopathology Steering Committee (CSC) that includes representation from ICCR and IAC and reports to the ICCR DSC. Chairs representing both parties were appointed - Andrew Nicholson for the ICCR and Andrew Field for IAC. Wendy Cooper, from Australia, is the appointed Series Champion.

The Tumours of the Lung – Small Diagnostic and Cytopathological Specimens dataset is expected to be published in December 2023.

# 5.3.2 Genitourinary

In synchrony with the updates to the WHO Classification of Urinary and Male Genital Tumours, the ICCR has commenced updates to 12 existing datasets as follows:

- 1. Invasive carcinoma of renal tubular origin (update of 1<sup>st</sup> edition) (Co-Chairs: Holger Moch and Sean Williamson)
- 2. Renal biopsy for tumour (update of 1<sup>st</sup> edition) (Co-Chairs: Holger Moch and Sean Williamson)
- Carcinoma of the renal pelvis and ureter nephroureterectomy and ureterectomy specimen (update of 1<sup>st</sup> edition) (Co-Chairs: Eva Compérat and Toyonori Tsuzuki)
- Carcinoma of the bladder cystectomy, cystoprostatectomy and diverticulectomy specimen (update of 1<sup>st</sup> edition) (Co-Chairs: Eva Compérat and Toyonori Tsuzuki)

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- 5. Carcinoma of the urethra urethrectomy specimen (update of 1<sup>st</sup> edition) (Chairs: Eva Compérat and Toyonori Tsuzuki)
- 6. Urinary tract carcinoma biopsy and transurethral resection specimen (update of 1<sup>st</sup> edition) (Co-Chairs: Eva Compérat and Toyonori Tsuzuki)
- 7. Prostate cancer radical prostatectomy specimen (update of 2<sup>nd</sup> edition) (Co-Chairs: James Kench and Gladell Paner)
- 8. Prostate cancer transurethral resection and enucleation specimen (update of 1st edition) (Co-Chairs: James Kench and Gladell Paner)
- 9. Prostate core needle biopsy (update of 1<sup>st</sup> edition) (Co-Chairs: James Kench and Gladell Paner)
- 10. Carcinoma of the penis (update of 1<sup>st</sup> edition) (Chair: Isabel Alvarado-Cabrero)
- 11. Neoplasia of the testis orchidectomy specimen (update of 1<sup>st</sup> edition) (Chair: Daniel Berney)
- 12. Neoplasia of the testis retroperitoneal lymphadenectomy specimen (update of 1<sup>st</sup> edition) (Chair: Daniel Berney)

John Srigley, from Canada, is the appointed Series Champion.

# 5.3.3 Central nervous system

In synchrony with the updates to the WHO Classification of Central Nervous System (CNS) Tumours, the ICCR has commenced an update to the Tumours of the CNS dataset (update of 1<sup>st</sup> edition) (Chair: Pieter Wesseling).

# 5.3.4 Head and neck

In synchrony with the updates to the WHO Classification of Head and Neck Tumours, the ICCR has commenced updates to 9 existing datasets as follows:

- 1. Carcinomas of the nasal cavity and paranasal sinuses (update of 1<sup>st</sup> edition) (Chair: Justin Bishop)
- 2. Carcinomas of the hypopharynx, larynx and trachea (update of 1st edition) (Chair: Nina Zidar)
- 3. Carcinomas of the oral cavity (update of 1st edition) (Chair: Susan Müller)
- 4. Carcinomas of the nasopharynx and oropharynx (update of 1<sup>st</sup> edition) (Chair: Rebecca Chernock)
- 5. Carcinomas of the major salivary glands (update of 1<sup>st</sup> edition) (Chair: Lester Thompson)
- 6. Malignant odontogenic tumours (update of 1<sup>st</sup> edition) (Chair; Edward Odell)
- 7. Ear and temporal bone tumours (update of 1st edition) (Chair: Ruta Gupta)

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- 8. Mucosal melanomas of the head and neck (update of 1<sup>st</sup> edition) (Chair: Michelle Williams)
- 9. Nodal excisions and neck dissection specimen (update of 1<sup>st</sup> edition) (Chair: Martin Bullock)

Lester Thompson, from USA, is the appointed Series Champion.

#### 5.3.5 Endocrine

In synchrony with the updates to the WHO Classification of Endocrine Tumours, the ICCR has commenced updates to 4 existing datasets as follows:

- 1. Carcinoma of the adrenal cortex (update of 1<sup>st</sup> edition) (Chair: Thomas Giordano)
- 2. Parathyroid carcinoma and atypical parathyroid neoplasm (update of 1<sup>st</sup> edition) (Chair: Ozgur Mete)
- 3. Phaeochromocytoma and paraganglioma (update of 1<sup>st</sup> edition) (Chair: Ronald de Krijger)
- 4. Carcinoma of the thyroid (update of 1<sup>st</sup> edition) (Chair: Ronald Ghossein)

Anthony Gill, from Australia, is the appointed Series Champion.

#### 5.3.6. Female reproductive organs

In synchrony with the updates to FIGO and TNM staging, the ICCR has commenced an update to the Endometrial cancer dataset (update of 4<sup>th</sup> edition) (Chair: Xavier Matias-Guiu.

The datasets for Carcinoma of the vulva (update of 1st edition) (Chair: W. Glenn McGluggage) and Carcinoma of the cervix (update of 4th edition) (Chair: Kay Park) have been updated and published in 2023.

W. Glenn McGluggage, from United Kingdom, is the appointed Series Champion.

# 5.4 Datasets in planning

The following dataset series are currently being considered for a development start in 2024:

- Gastrointestinal gaps (GI tumours not covered by current ICCR datasets)
- Gastrointestinal neuroendocrine tumours
- Skin.

# 5.6 TNM staging

#### 8th edition

The 8<sup>th</sup> editions of the UICC and AJCC TNM Classification of Malignant Tumours were published in late 2016. Given that the UICC TNM is widely used in Europe, United Kingdom and other parts of the world, while AJCC TNM is used extensively in the North America and Australia, the ICCR was keen to be inclusive in its approach. Ostensibly these versions are harmonised, however on a more detailed review a number of differences were noted.



Having investigated the issues, the ICCR decided to use UICC TNM 8th edition in cases where there is concordance between the versions but use the AJCC TNM 8th edition in cases where the AJCC version more accurately reflects the most contemporary and scientifically validated information.

In 2020, the AJCC adopted a new approach to publication of its TNM staging system, moving from an edition-based model to a versioning approach or 'rolling updates'. In this model, the various anatomic sites will be updated individually and published separately.

At this stage the UICC has agreed to consider publishing errata to align with AJCC updates.

ICCR will continue to work with both organisations choosing the best approach for each of its datasets series.

# 5.7 Peer-reviewed publications

A key step in the ICCR dataset development process is the development of an accompanying article submitted to a peer-reviewed journal. To date, more than 55 ICCR dataset related manuscripts have been published.

See Appendix 9.2 for all ICCR dataset related peer-reviewed publications.

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# **6. TRANSLATION**

The ICCR considers that translation of the ICCR datasets into other languages is an essential step to advance adoption and uptake of the datasets around the world, in particular in LMIC especially as the WHO Classification of Tumours are not being translated.

Several models of translation have been discussed and various trials are underway to gather information to inform future efforts.

Currently, funding is the rate-limiting step for further translations.

# 6.1 Datasets translated

The following datasets translated into Spanish, French and Portuguese are available on the ICCR website:

Group	Dataset
Genitourinary	Carcinoma of the urethra - urethrectomy specimen
	Carcinoma of the renal pelvis and ureter - nephroureterectomy and
	ureterectomy specimen
	Urinary tract carcinoma - biopsy and transurethral resection specimen
	Carcinoma of the bladder - cystectomy, cystoprostatectomy and
	diverticulectomy specimen
	Invasive carcinoma of renal tubular origin
	Renal biopsy for tumour
	Carcinoma of the penis and distal urethra
	Neoplasia of the testis - retroperitoneal lymphadenectomy
	Neoplasia of the testis - orchidectomy specimen
	Prostate cancer - transurethral resection and enucleation specimen
	Prostate cancer - radical prostatectomy specimen
	Prostate - core needle biopsy
Digestive tract	Intrahepatic cholangiocarcinoma, perihilar cholangiocarcinoma and
	hepatocellular carcinoma
Thoracic	Lung cancer
	Thymic epithelial tumours
	Neoplasms of the heart, pericardium and great vessels
	Mesothelioma in the pleura and peritoneum
Gynaecology	Endometrial cancer
	Ovary, fallopian tube and primary peritoneal carcinoma
	Carcinoma of the cervix
Skin	Invasive melanoma

# 6.2 Breast Suite

Four datasets in the Breast Suite are being translated into the six priority languages (French (European), Spanish (European), Portuguese, German, Chinese and Russian) and two variants (French – Quebecois and Spanish – Latin American):

- Ductal carcinoma in situ, variants of lobular carcinoma in situ and low-grade lesions
- Invasive carcinoma of the breast
- Invasive carcinoma of the breast in the setting of neoadjuvant therapy
- Surgically removed lymph nodes for breast tumours.



Translation is being done by IDEM, an ISO accredited translation company from Chicago. A quality assurance process is underway with the various Societies and Colleges of Pathology.

The project is funded through a very generously donation from the ASCP supplemented by donations from the International Society of Breast Pathology (ISBP) and the Singapore General Hospital Breast Pathology Course.

The purpose of the project is to enable the ICCR to explore the various issues and challenges involved in a project of this size which will inform future translation efforts.

# 6.3 Ukrainian

ICCR was approached in July 2022 by a group of Ukrainian pathologists wishing to translate several of the ICCR datasets into the Ukrainian language. As this was a single jurisdiction project not affecting a broader population, ICCR has agreed and is monitoring progress.

# 6.4 Italian

ICCR has had discussions with SIAPEC and the Italian Ministry of Health regarding a project to translate ICCR datasets into Italian for national use, which is currently underway. ICCR and SIAPEC are in discussion regarding the progress of this project.

# 6.5 German

The German speaking members of the ICCR – Germany, Austria and Switzerland – have put forward a proposal based on the questionnaire developed to pilot the translation of the ICCR datasets. Further discussion is planned between all parties, but funding is the rate-limiting step.

#### 6.6 Language specific webpages

Language specific pages have been added to the ICCR website to host the translated datasets. New pages will be added as needed in the future. An example is shown below:

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About Datasets Ne	ws Membership Contact us Donate Q
Datasets – En Español	
Los conjuntos de datos ICCR se han desarrollado para proporcionar un enfoque coherente y b para la notificación de cáncer. El objetivo es garantizar que los conjuntos de datos producido de tumores tengan un estilo y contenido consistentes, y que contengan todos los parámetros administración y el pronóstico de cánceres individuales.	asado en la evidencia s para diferentes tipos necesarios para guiar la
Si tiene alguna pregunta sobre los conjuntos de datos de ICCR, envíe un correo electrónico a datasets@iccr-cancer.org. Si desea proporcionar comentarios sobre el contenido de los conjuntos de datos ICCR publica enviar comentarios sobre la precisión y la calidad de las traducciones, envíe un correo electro translations@ICCR-cancer.org.	ados, haga clic <u>aquí</u> . Para inico a Órganos reproductores femeninos
	Urinario / Genital masculino
Piel Tórax Tracto digestivo repi	Órganos roductores
fe Urinario / Genital	meninos

#### 6.7 Future translation

ICCR has 61 published datasets and many more in planning. It represents a large body of work to be translated and there is also the ongoing maintenance of the datasets to be considered. This requires a substantial investment in funding. ICCR will continue to investigate various options for funding as well as different models.



# 7. IMPLEMENTATION

# 7.1 Structured Reporting Implementation Committee (SRIC)

ICCR convened the SRIC in 2021 for the purpose of providing guidance to the ICCR on matters relating to the implementation of ICCR Datasets and on the detailed technical aspects impacting the efficient implementation of standardised cancer datasets.

George Birdsong, Professor in the Department of Pathology and Laboratory Medicine at Emory University School of Medicine, is the current Chair of the SRIC.

Membership of the committee includes those with expertise in electronic dataset development, terminology development, informatics and cancer reporting. The committee meet every 2-3 months.

# 7.2 Electronic ICCR datasets

To make best use of the ICCR datasets and eliminate the variability that is introduced when using a paper reference document, pathologists need access to structured reporting tools. Use of a reporting tool also facilitates electronic reporting to cancer registries, as well as improving workflow and supporting research through the availability of database searches etc.

In many parts of the world there are commercially available LIS or middleware solutions, which have the facility for structured data entry and storage to support the implementation of cancer datasets. Older LIS, which are currently incapable of electronic structured reporting, are gradually being replaced as they are upgraded, and as the importance of structured reporting of cancer is recognised.

However, in many LMICs there is little or no access to electronic structured reporting tools and reporting remains paper based, or at best done, on a standalone PC using word processing software.

ICCR needs a scalable solution that best serves the needs of locations with varying degrees of IT sophistication. A tiered approach is being discussed.

For mid-level sites, that is, those with reasonable IT capability, who have an existing LIS but lack adequate structured reporting tools, a solution providing user-friendly front-end reporting tools is needed. It is proposed that such an application would be electronically updateable and cater for multiple laboratory locations.

As noted above, there are laboratories with LIS or middleware solutions, with the facility for structured data entry. These would be classified as sites with a high level of IT capability. For these sites to implement ICCR datasets, they require uploadable files to ensure this is done quickly and efficiently.

Ideally the solution(s) chosen for the mid-level and high-level sites would be interoperable. The SRIC is working on building a list of requirements to support this tiered approach within a Request for Proposal (RFP) document.

The SRIC committee has been developing the RFP to include the necessary requirements for transposing the PDF ICCR datasets into electronic formats, to be sent to relevant vendors. A review of different technologies incorporated by the CAP and the Pathological Anatomical National Automated Archive of the Netherlands (PALGA) was incorporated in this evaluation. Good progress has been made with the RFP, with many key specifications outlined for electronic transposing of the ICCR datasets.

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# 7.3 Terminology

Coded terminology is very important to any pathology implementation as it reduces the variability of terms to a single unique code. Even common terms have variability e.g., lymphovascular space invasion, lymphovascular invasion, and lymph-vascular invasion. Different languages add another layer of complexity. Coding of elements, for example lymphovascular invasion, and response values such as 'not identified' or 'present' with standard clinician terms like SNOMED CT reduces the variation and allows for advanced computer searches and interoperability.

Early in 2017, work commenced on the development of SNOMED CT content to represent the data elements in cancer datasets. This project is led by Scott Campbell from University of Nebraska Medical Centre, USA, under the auspices of the International Pathology and Laboratory Medicine Special Interest Group (IPaLM SIG) of the International Health Terminology Standards Development Organisation (IHTSDO), an international non-profit organisation that owns SNOMED CT. The encoding of cancer synoptic reports, including biomarkers, became an official project with SNOMED International later in 2017, ensuring both support and resources for content creation and publication.

The project aims to align terminology development and cancer dataset development efforts to truly create computable, interoperable cancer reporting tools for use by all participating nations.

# **8. FINANCES**

# 8.1 Budget

The ICCR's financial year (FY) runs from 1 July to 30 June.

A budget based on expenses incurred in the previous year and what is anticipated to be needed in the current year was proposed and accepted at the May 2023 Council meeting for the financial year ending 30 June 2024.

# 8.2 Audited financial statement

The ICCR financial status is audited yearly by BDO Chartered Accountants. A fully audited financial statement was prepared and tabled at the AGM held on 21 November 2023.

In summary, assets exceed liabilities and with continuing support from the member organisations ICCR can meet its financial commitments now and in the foreseeable future.

BDO, in its report, did not raise any matters of concern.

# 8.3 Sustainability

While the membership and sponsorship provide funding for the continuation of ICCR's core business which is the development of cancer datasets, it does not allow for the necessary resources to push forward with translation, implementation, and education activities to the extent needed. The ICCR, therefore, has been investigating various potential fund-raising strategies with the kind assistance of Donna Meredith, Managing Director of Keystone Corporate Positioning, Australia.

The new ICCR website, logo and corporate profile will help position the ICCR to take advantage of new funding opportunities, especially in the philanthropic domain, in 2024.

# 8.4 Sponsorship

In addition to membership fees, the ICCR looks for sponsorship to help support the cost of development of datasets. The ICCR would like to express its gratitude to the following donors which provided donations within 2023:



- Stop Brain Tumours Foundation
- Paediatric Pathology Society
- North American Society of Head and Neck Pathology
- British Society for Oral & Maxillofacial Pathology
- International Association of Oral and Maxillofacial Pathologists
- International Paediatric Pathology Association
- Royal College of Pathologists of Australasia Quality Assurance Programs
- Society for Paediatric Pathology
- American Academy of Oral & Maxillofacial Pathology

# **9 APPENDIX**

# 9.1 Published datasets

The following is a list of ICCR published datasets as of November 2023:

# Urinary/male genital

- 1. **Prostate cancer radical prostatectomy specimen**, **2**<sup>nd</sup> **edition**, which was developed for radical prostatectomy specimens for prostate carcinoma. Published: August 2017.
- 2. Prostate cancer transurethral resection and enucleation specimen, 1<sup>st</sup> edition, which was developed for the examination of transurethral resection and enucleation (suprapubic/simple/open prostatectomy) specimens of the prostate. The elements and associated commentary apply to invasive carcinomas of the prostate gland. Urothelial carcinomas arising in the bladder or urethra are dealt with in a separate dataset, while urothelial carcinomas arising in the prostate are included in this dataset. Published: August 2017.
- 3. **Prostate core needle biopsy, 1<sup>st</sup> edition,** which was developed for the examination of prostate core needle biopsies. The elements and associated commentary apply to invasive carcinomas of the prostate gland. Urothelial carcinomas arising in the bladder or urethra are dealt with in a separate dataset, while urothelial carcinomas arising in the prostate are included in this dataset. Published: August 2017.
- 4. Invasive carcinoma of renal tubular origin, 1<sup>st</sup> edition, which was developed for excision specimens of the kidney. Urothelial carcinoma arising from the upper renal tract, Wilms tumours and other nephroblastic and mesenchymal tumours are not included. This dataset is designed for the reporting of a single laterality of specimen i.e., left or right. Published: July 2017, Updated July 2018.
- 5. **Renal biopsy for tumour, 1<sup>st</sup> edition**, which was developed for core or wedge biopsy specimens for tumour of the kidney. Published: July 2017.
- 6. Carcinoma of the penis, 1<sup>st</sup> edition, which was developed for the reporting of specimens from patients with carcinoma of the penis, including resection, biopsy and lymphadenectomy. The protocol applies to primary carcinoma of the penis, as well as distal urethral squamous carcinomas. Melanomas and other urethral carcinomas are not included in the scope of the dataset. Published: August 2017.
- 7. Neoplasia of the testis orchidectomy specimen, 1<sup>st</sup> edition, which was developed for the reporting of both partial and radical orchidectomy specimens from patients with

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neoplasia of the testis. The protocol applies to all germ cell and sex cord-stromal tumours of the testis. Paratesticular malignancies are excluded. Published: August 2017.

- 8. Neoplasia of the testis retroperitoneal lymphadenectomy specimen, 1st edition, which was developed for the reporting of retroperitoneal and other lymphadenectomy specimens as well as visceral metastasis excision specimens from patients with malignant tumours of the testis. The protocol applies to all malignant germ cell and sex cord-stromal tumours of the testis. Paratesticular malignancies are excluded. Published: August 2017.
- 9. Carcinoma of the urethra urethrectomy specimen, 1st edition, which was developed for the reporting of resection specimens from patients with carcinoma of the urethra. The protocol applies to primary carcinomas (non-invasive and invasive), with or without associated epithelial lesions. Urothelial tumours diagnosed as papilloma or papillary urothelial neoplasm of low malignant potential are not carcinomas and this dataset does not apply to those diagnoses. Biopsy and transure thral resection specimens are dealt with in a separate dataset. Carcinomas arising in the distal penile urethra (glans region) are included in the Carcinoma of the penis and distal urethra dataset and are not to be reported using this dataset. This dataset is to be used for adenocarcinoma arising in the accessory glands of the urethra (Skene, Littre, Cowper). Published: May 2018.
- 10.Carcinoma of the renal pelvis and ureter nephroureterectomy and ureterectomy specimen, 1<sup>st</sup> edition, which was developed for the reporting of resection specimens from patients with primary carcinoma of the ureter and renal pelvis. The protocol applies to carcinomas (non-invasive and invasive), with or without associated epithelial lesions. Urothelial tumours diagnosed as papilloma or papillary urothelial neoplasm of low malignant potential are not carcinomas and this dataset does not apply to those diagnoses. Biopsy and transurethral resection specimens are dealt with in a separate dataset. For bilateral tumours, complete a separate dataset for each. Published: May 2018.
- 11. Carcinoma of the bladder cystectomy, cystoprostatectomy and diverticulectomy specimen, 1<sup>st</sup> edition, which was developed for the reporting of cystectomy, cystoprostatectomy or diverticulectomy specimens from patients with carcinoma of the bladder. The protocol applies to primary carcinomas (non-invasive and invasive), with or without associated epithelial lesions. Urothelial tumours diagnosed as papilloma or papillary urothelial neoplasm of low malignant potential are not carcinomas and this dataset does not apply to those diagnoses. Biopsy and transurethral resection specimens are dealt with in a separate dataset. Published: May 2018.
- 12. Urinary tract carcinoma biopsy and transurethral resection specimen, 1st edition, which was developed for the reporting of biopsy and transurethral resection specimens of the bladder, urethra, ureter and renal pelvis. If biopsies are from different locations, then a separate dataset should be completed for each tumour site. The protocol applies to primary carcinomas (non-invasive and invasive), with or without associated epithelial lesions. Urothelial tumours diagnosed as papilloma or papillary urothelial neoplasm of low malignant potential are not carcinomas and this dataset does not apply to those diagnoses. The most distal portion of the penile urethra in the region of the glans penis is not included in this dataset; it is covered in the Carcinoma of the penis and distal urethra dataset. Published: May 2018.

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#### Female reproductive organs

- 1. Endometrial cancer, 4<sup>th</sup> edition, which covers resection specimens of endometrial cancers. It is not applicable for small endometrial biopsy specimens. Published: August 2021.
- 2. Ovary, fallopian tube and primary peritoneal carcinoma, 2<sup>nd</sup> edition, which was developed for resection specimens of primary borderline and malignant epithelial tumours of the ovary, fallopian tubes and peritoneum. It does not include non-epithelial ovarian neoplasms such as germ cell or sex cord stromal tumours or other primary peritoneal neoplasms such as mesothelioma. Published: September 2021.
- 3. Carcinoma of the cervix, 5<sup>th</sup> edition, which covers pathology reporting of primary cervical carcinomas. Specimens include loop/cone excisions, trachelectomies, simple and radical hysterectomies and exenterations. The dataset applies to epithelial neoplasms only and does not apply to small biopsy specimens. The 5th edition of this dataset incorporates the 2021 UICC Cervix Uteri TNM. Published: October 2023.
- 4. Carcinoma of the vagina, 1<sup>st</sup> edition, which was developed for the pathological reporting of resection specimens of primary carcinomas of the vagina (including carcinosarcomas). Haematopoietic neoplasms, mesenchymal neoplasms, mixed epithelial and mesenchymal neoplasms, malignant melanomas, other non-epithelial malignancies and metastatic tumours are excluded from this dataset. Due to the rarity of primary vaginal carcinomas, there is little published research regarding some of the elements included in this dataset and some of the parameters included are 'extrapolated' from primary cervical and vulval carcinomas and/or represent the opinions and experience of the members of the ICCR Carcinoma of the Vagina DAC. Published: August 2021.
- 5. Carcinoma of the vulva, 2<sup>nd</sup> edition, which was developed for the pathological reporting of resection specimens of primary carcinomas of the vulva. In some patients with a prior diagnosis of vulval carcinoma (especially squamous), it is not clear whether a 'new' lesion is a recurrence, or an independent neoplasm and the dataset can also be used for such tumours, especially when these 'arise' from the surface squamous epithelium. Molecular studies have shown that some of these 'recurrent' neoplasms exhibit similar mutations and are clonally related to the original tumour and are likely to represent true recurrences while others are clonally unrelated with different mutations and are likely to represent new neoplasms. In those rare cases where more than one primary tumour is present, separate datasets should be completed for each neoplasm. These should include all the elements in this dataset, except for lymph node status which does not need to be documented separately for each tumour. Haematopoietic neoplasms, mesenchymal neoplasms, mixed epithelial and mesenchymal neoplasms, malignant melanomas, other non-epithelial malignancies and metastatic tumours are excluded from this dataset. The 2<sup>nd</sup> edition of this dataset incorporates the 2021 International Federation of Gynaecology and Obstetrics (FIGO) staging for carcinoma of the vulva. Published: October 2023.
- 6. Gestational trophoblastic neoplasia, 1<sup>st</sup> edition, which was developed for the pathology reporting of resection specimens for primary uterine gestational trophoblastic neoplasia which includes invasive hydatidiform mole of either complete or partial type, gestational choriocarcinoma, placental site trophoblastic tumour and epithelioid trophoblastic tumour. The dataset should be used primarily for hysterectomy specimens. This dataset may also be used for rare myomectomy specimens but not all elements will be applicable. The dataset is not intended to be used for extrauterine

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primary lesions. Non-gestational trophoblastic tumours (germ cell or somatic origin) and metastatic tumours are excluded from this dataset. Published: August 2021.

7. Uterine malignant and potentially malignant mesenchymal tumours, 1<sup>st</sup> edition, which was developed for the pathology reporting of resection specimens of the uterus for sarcomas and mesenchymal tumours with potentially malignant behaviour. The dataset is applicable to tumours of the uterine corpus and the uterine cervix. Carcinomas, other non-mesenchymal malignancies and metastatic neoplasms are excluded from this dataset. Carcinosarcoma is also excluded as it is considered to represent a malignant epithelial tumour with divergent mesenchymal differentiation based on clinicopathologic, immunohistochemical and molecular analysis; as such, this entity is included in the ICCR Endometrial Cancer dataset. Published: August 2021.

#### <u>Thorax</u>

- 1. Lung cancer, 4<sup>th</sup> edition, which covers resection specimens of malignant epithelial cancers of the lung. The dataset applies to small cell carcinoma and carcinoid tumours, as well as non-small cell types of lung car carcinoma. It is not applicable for bronchoscopic and transthoracic biopsy specimens. Published: April 2023.
- 2. **Mesothelioma in the pleura and peritoneum, 3<sup>rd</sup> edition**, which covers both biopsy and resection specimens of mesothelioma in the pleura, pericardium and peritoneum. Published: September 2022.
- 3. Thymic epithelial tumours, 3<sup>rd</sup> edition, which covers resection specimens of the thymus and is applicable for thymoma, neuroendocrine tumours of the thymus and thymic carcinoma. It does not apply to germ cell tumours, soft tissue tumours, haematolymphoid neoplasms, and other primary thymic neoplasms. Published: May 2022.
- 4. Neoplasms of the heart, peritoneum and great vessels, 2<sup>nd</sup> edition, which covers biopsy and resection specimens of neoplasms of the heart, pericardium, and great vessels. It includes both benign and malignant primary tumours of the heart, pericardium and great vessels. It does not apply to mesothelioma and haematolymphoid neoplasms. Published December 2021.

#### Digestive tract

- 1. Intrahepatic cholangiocarcinoma, perihilar cholangiocarcinoma and hepatocellular carcinoma, 2<sup>nd</sup> edition, which covers resection specimens of the liver with intrahepatic, and perihilar cholangiocarcinoma and hepatocellular carcinoma. It does not apply to neuroendocrine carcinomas, hepatoblastoma, carcinomas of the extrahepatic bile ducts, gall bladder and benign lesions such as adenomas. Published: November 2020.
- 2. Carcinoma of the exocrine pancreas, 1<sup>st</sup> edition, which covers resection specimens with carcinomas of the exocrine pancreas, i.e., ductal adenocarcinoma and acinar cell carcinoma. It excludes carcinoma of the ampulla of Vater, common bile duct and duodenum, neuroendocrine neoplasia, lymphoma, sarcoma and secondary tumours. Published: April 2020.
- 3. Colorectal cancer, 1<sup>st</sup> edition, which covers surgical resection specimens from patients with primary carcinoma of the colon and rectum, including neuroendocrine carcinomas (NECs) and mixed neuroendocrine-non-neuroendocrine neoplasms (MiNENs). It is not applicable to carcinomas of the small intestine, appendix or anus, nor

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to neuroendocrine tumours (NETs) or non-epithelial malignancies. Primary colorectal carcinomas treated by local excision are not included. Published: April 2020.

- 4. Colorectal excisional biopsy (polypectomy) specimen, 1<sup>st</sup> edition, which covers local excision specimens from the colon and rectum, including polypectomies, endoscopic mucosal resections (EMR), endoscopic submucosal dissections (ESD), endoscopic full thickness resections (EFTR), transanal submucosal excisions, transanal minimally invasive surgery (TAMIS) and transanal endoscopic microsurgery (TEMS) specimens. Surgical resection specimens from patients with primary carcinoma of the colon and rectum, including NECs and MiNENs, are excluded. Published: April 2020.
- 5. Carcinomas of the stomach, 2<sup>nd</sup> edition, which covers gastrectomy for gastric carcinomas. Carcinomas involving the oesophagogastric junction (OGJ) with their epicentre >20 mm into the proximal stomach and cardia cancers that do not involve the OGJ are included. These criteria are set by the UICC/AJCC 8<sup>th</sup> edition Classifications and have been adopted by the WHO to define the diagnosis 'gastric cancer'. For all other tumours involving the OGJ, refer to the ICCR dataset for carcinomas of the oesophagus. NECs and MiNENs (with the exception of mixed adenoma and NETs) are included in this dataset. NETs, non-epithelial malignancies and secondary tumours are excluded from this dataset. Published: December 2021.
- 6. Endoscopic resection of the stomach, 2<sup>nd</sup> edition, which covers carcinomas involving the oesophagogastric junction (OGJ) with their epicentre >20 mm into the proximal stomach and cardia cancers that do not involve the OGJ are included. These criteria are set by the UICC/AJCC on Cancer 8<sup>th</sup> edition TNM classifications and have been adopted by the WHO and define the diagnosis 'gastric cancer'. An ICCR dataset for carcinoma of the oesophagus is available for tumours not meeting these criteria. NECs and MiNENs (with the exception of mixed adenoma and NETs) are included in this dataset. NETs, non-epithelial malignancies, and secondary tumours are excluded from this dataset Published: December 2021.
- 7. Carcinomas of the oesophagus, 2<sup>nd</sup> edition, which covers resection specimens of the oesophagus. Carcinomas involving the OGJ with tumour epicentre ≤20 mm into the proximal stomach are included. A separate ICCR dataset is available for endoscopic resections of the oesophagus and oesophagogastric junction. NEC and MiNEN of the oesophagus are included. NET, non-epithelial malignancies such as melanoma, and secondary tumours are excluded. Published: December 2021.
- 8. Endoscopic resection of the oesophagus and oesophagogastric junction, 2<sup>nd</sup> edition, which covers endoscopic resection (ER) of pre-malignant and malignant lesions of the oesophagus and OGJ. Surgically resected specimens are covered in a separate ICCR dataset. NEC and MiNEN of the oesophagus are included. NET, non-epithelial malignancies such as melanoma, and secondary tumours are excluded. Published: December 2021.

# <u>Skin</u>

1. **Invasive melanoma, 2<sup>nd</sup> edition**, which was developed for reporting of primary cutaneous invasive melanoma. The 2<sup>nd</sup> edition of this dataset includes changes to align the dataset with the TNM Pathological staging 8<sup>th</sup> edition and the WHO Classification of Tumours, Pathology and Genetics of Skin Tumours (2018). Published: October 2019.



2. Merkel cell carcinoma, 1<sup>st</sup> edition, which covers primary cutaneous Merkel cell carcinoma (MCC) in excision (resection) specimens containing tumour. Published: December 2019.

#### Central nervous system

- 1. Tumours of the central nervous system (CNS), 1<sup>st</sup> edition, which is split into three sections:
  - a. Histological assessment of CNS specimens which was developed for the histological assessment of benign and malignant tumours of the CNS and its coverings, as well as tumours from those aspects of the peripheral nervous system immediately adjacent to the CNS. This dataset applies to both biopsy and resection specimens. Haematological lesions that may originate in the brain are included. Tumours of the anterior pituitary gland are included. It is intended that this section should be used in conjunction with the other sections. A full diagnosis of CNS tumours should ideally conform to the 2016 WHO Classification of Tumours of the CNS which requires integration of elements from histological and ancillary analyses. However, the majority of 2016 CNS WHO entities can be diagnosed solely on the basis of histological features and in this situation only this section needs to be completed.
  - b. Molecular information for CNS specimens which was developed for the molecular assessment of CNS tumour samples (whether that molecular assessment is nucleic acid or protein-based). This section is not needed for those tumours in which molecular information is not captured for diagnostic purposes.
  - c. Final integrated report/diagnosis for CNS specimens which was developed for the histological assessment of benign and malignant tumours of the CNS and its coverings, as well as tumours from those aspects of the peripheral nervous system immediately adjacent to the CNS. This dataset applies to both biopsy and resection specimens. Tumours of the anterior pituitary gland are included. Haematological lesions that may originate in the brain are included. In many situations, 2016 CNS WHO diagnoses integrate histological and molecular information and this section is intended for the capture of that final diagnosis.

Published: August 2018.

#### Head and neck

- 1. Carcinomas of the nasal cavity and paranasal sinuses, 1<sup>st</sup> edition, which was developed for the reporting of resection and biopsy specimens of mucosal malignancies originating in the nasal cavities and paranasal sinuses. Neuroectodermal neoplasms (including melanoma) and sarcomas are not included. Bone, soft tissue and lymphoma protocols are separately listed. Neck dissections and nodal excisions are dealt with in a separate dataset, and this dataset should be used in conjunction, where applicable. Published: September 2018.
- 2. Carcinomas of the hypopharynx, larynx and trachea, 1<sup>st</sup> edition, which was developed for the reporting of resection and biopsy specimens of mucosal malignancies of the larynx, hypopharynx and trachea. The protocol applies to all invasive carcinomas of the larynx, hypopharynx and trachea (including the supraglottis, glottis, and subglottis). Salivary-type malignancies arising from mucosal glands of the hypopharynx and larynx should be recorded in this dataset. Mucosal melanoma is presented in a separate dataset. Lymphomas and sarcomas are not included. Malignancies arising at other sites in the head and neck region, and neck dissections and nodal excisions are dealt

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with in separate datasets which may be used, as appropriate, in conjunction with this dataset. Where more than one anatomically or histologically distinct primary tumours occur, a separate dataset should be completed for each tumour. Published: September 2018.

- 3. Carcinomas of the oral cavity, 1<sup>st</sup> edition, which was developed for the reporting of resection and biopsy specimens of invasive carcinomas of the oral cavity, including lip and tongue. Mucosal melanoma, lymphomas and sarcomas are not included. Published: September 2018.
- 4. Carcinomas of the nasopharynx and oropharynx, 1<sup>st</sup> edition, which was developed for the reporting of resection and biopsy specimens of the nasopharynx and oropharynx. The protocol applies to all invasive carcinomas of the nasopharynx and oropharynx including the base of tongue, tonsils, soft palate, posterior wall, and uvula. Lymphomas and sarcomas are not included. Published: September 2018.
- 5. Carcinomas of the major salivary glands, 1<sup>st</sup> edition, which was developed for the reporting of resection and biopsy specimens of malignant neoplasms and associated carcinoma in situ arising from the major salivary glands. The protocol applies to all carcinomas of the parotid, submandibular and sublingual glands. Melanomas, lymphomas, and sarcomas are dealt with in separate datasets. Minor salivary gland malignancies arising in the oral cavity, nasal cavity and paranasal sinuses, trachea, nasopharynx, oropharynx and hypopharynx and odontogenic specimens are staged according to their anatomical sub-site and are dealt with in separate datasets. Published: September 2018.
- 6. Malignant odontogenic tumours, 1<sup>st</sup> edition, which was developed for the reporting of biopsy and resection specimens for malignant primary odontogenic tumours. Malignant neoplasms arising in the nasal cavity and paranasal sinuses, oral cavity, salivary glands, trachea, pharynx and larynx are dealt with in separate datasets. Bone, soft tissue and lymphoma protocols will be separately listed. Published: September 2018.
- 7. Ear and temporal bone tumours, 1<sup>st</sup> edition, which was developed for the reporting of resection and biopsy specimens of the ear and temporal bone. It includes ONLY primary tumours of the external auditory canal, middle and inner ear, including both benign and malignant entities (specifically due to anatomic confines and management alternatives which may require significant, destructive or disfiguring surgery). By definition, all malignancies of the external ear (pinna, concha, scaphoid, lobe, etc., such as squamous cell carcinoma, basal cell carcinoma, atypical fibroxanthoma, Merkel cell carcinoma and melanoma) are separately covered by the dermatopathology datasets. Published: September 2018.
- 8. **Mucosal melanomas of the head and neck**, 1<sup>st</sup> edition, which was developed for the reporting of resection and biopsy specimens of mucosal melanoma arising in the nasopharynx, oropharynx, larynx, hypopharynx, oral cavity, nasal cavity and paranasal sinuses. All other malignancies and tumour categories are dealt with in separate datasets, specifically cutaneous melanoma is separately reported. Direct extension of a cutaneous primary into a mucosal site should be excluded and would not be reported in this dataset. Metastasis to a head and neck mucosal site is also excluded. Published: September 2018.
- 9. Nodal excisions and neck dissection specimen, 1<sup>st</sup> edition, which was developed for the reporting of lymph node resections from patients with carcinomas and melanomas

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of the head and neck. This excludes nodal resections for lymphoma and sarcomas. It is not intended for use in reporting lymph node core biopsy or fine needle aspirations. Carcinomas covered by the dataset include squamous cell carcinomas, sinonasal carcinomas, salivary and non-salivary type adenocarcinomas and neuroendocrine tumours. Pathologists may also apply the dataset to metastatic non-Merkel cutaneous squamous cell carcinomas and other cutaneous carcinomas. This dataset is to be used in conjunction with other datasets in the Head and Neck Series. Published: September 2018.

# Endocrine

- 1. Carcinoma of the adrenal cortex, 1<sup>st</sup> edition, which covers malignant adrenal cortical resection specimens, borderline (low-malignant potential lesions), and paediatric adrenal cortical carcinomas. It excludes neuroblastoma, sarcoma, lymphoma, core needle biopsies, benign lesions and tumours and metastasis, and Tumours of the adrenal medulla (e.g., phaeochromocytoma). Published: December 2019.
- 2. Parathyroid carcinoma and atypical parathyroid neoplasm, 1<sup>st</sup> edition, which covers parathyroid resection specimens when the diagnosis is atypical parathyroid neoplasm (atypical parathyroid adenoma or carcinoma. But excludes biopsies, sarcoma, lymphoma and metastasis. Published: December 2019.
- 3. Phaeochromocytoma and paraganglioma 1<sup>st</sup> edition, which covers adrenalectomy/ partial adrenalectomy specimens for phaeochromocytoma, other excisions for paragangliomas and biopsies of related specimens. It excludes sarcoma, lymphoma and metastasis to the adrenal medulla, neuroblastoma, ganglioneuroblastoma and adrenal cortical tumours. Published: December 2019.
- 4. Carcinoma of the thyroid, 2<sup>nd</sup> edition, which covers thyroid resection specimens for carcinoma, but excludes core needle biopsies and metastasis to the thyroid gland, invasive follicular thyroid neoplasm with papillary-like nuclear features (NIFTP), tumours of uncertain malignant potential (UMP), thyroid carcinomas arising from struma ovarii, thyroid carcinomas arising in thyroglossal duct cysts, sarcoma and lymphoma. Published: June 2020.

# Soft tissue and bone

- Primary tumour in bone biopsy specimens, 1<sup>st</sup> edition, which was developed for the pathology reporting of biopsy specimens of primary tumour in bone. Ewing sarcoma and related round cell sarcomas with primary bone presentation are also covered by this dataset. A separate dataset is available for reporting of resection specimens of primary tumour in bone. Some types of soft tissue sarcoma may on rare occasion arise primarily in bone and should be reported using the primary tumour in bone dataset, rather than the soft tissue sarcoma dataset. If biopsies are taken from multiple tumour nodules at different sites, these should be documented separately. Haematologic malignancies and metastatic specimens are excluded from this dataset. Published: April 2021.
- 2. Primary tumour in bone resection specimens, 1<sup>st</sup> edition, which was developed for the pathology reporting of resection specimens of primary tumour in bone. Ewing sarcoma and related round cell sarcomas with primary bone presentation are also covered in this dataset. A separate dataset is available for reporting biopsy specimens of primary tumour in bone. Some types of soft tissue sarcoma may on rare occasions arise primarily in bone and should be reported using the primary tumour in bone dataset, rather than

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the soft tissue sarcoma dataset. Haematologic malignancies and metastatic specimens are excluded from this dataset. Published: April 2021.

- 3. Gastrointestinal stromal tumour (GIST) biopsy specimens, 1<sup>st</sup> edition, which was developed for the pathology reporting of biopsy specimens for GIST. Metastatic GIST specimens are excluded from this dataset. Published: April 2021.
- 4. Gastrointestinal stromal tumour (GIST) resection specimens, 1<sup>st</sup> edition, which was developed for the pathology reporting of resection specimens for GIST. Metastatic GIST specimens are excluded from this dataset. Published: April 2021.
- 5. Soft tissue sarcoma biopsy specimens, 1st edition, which was developed for the pathology reporting of biopsy specimens for soft tissue sarcomas. Adult rhabdomyosarcoma is also included in this dataset. A separate ICCR dataset is available for reporting of resection specimens for soft tissue sarcomas. Some soft tissue tumours which rarely arise primarily in bone should be reported using the ICCR primary Lymphoma, bone datasets. uterine tumour in sarcoma, paediatric rhabdomyosarcoma and metastases are excluded from this dataset. GIST are also not included in this dataset as GIST displays a number of unique features which warrant its separate consideration; separate ICCR datasets for GIST are available. Published: April 2021.
- 6. Soft tissue sarcoma resection specimens, 1<sup>st</sup> edition, which was developed for the pathology reporting of resection specimens for soft tissue sarcomas. Adult rhabdomyosarcoma is also included in this dataset. A separate ICCR dataset is available for reporting of biopsy specimens for soft tissue sarcomas. Some soft tissue tumours which rarely arise primarily in bone and in this case should be reported using the ICCR primary tumour in bone datasets. Lymphoma, uterine sarcoma, paediatric rhabdomyosarcoma and metastases are excluded from this dataset. GIST are also not included in this dataset as GIST displays a number of unique features which warrant its separate consideration; separate ICCR datasets for GIST are available. Published: April 2021.

#### <u>Breast</u>

- 1. Ductal carcinoma in situ, variants of lobular carcinoma in situ and low-grade lesions, 1<sup>st</sup> edition, which was developed for the reporting of resection specimens for ductal carcinoma in situ (DCIS) of the breast. The protocol applies to cases of DCIS and for where microinvasion ( $\leq 1$  mm) is present. It also covers other in situ lesions including pleomorphic and florid variants of lobular carcinoma in situ (LCIS), as well as encapsulated papillary carcinoma and solid papillary carcinoma in situ. This dataset may also be used in those rare cases of DCIS removed at core biopsy but without evidence of residual DCIS in a subsequent excision specimen. This protocol should only be used for re-excisions when they contain the largest extent of DCIS. A separate dataset should be completed for bilateral DCIS and for each excision specimen in unilateral disease. DCIS (with or without microinvasion) diagnosed on needle core biopsies only, and residual DCIS post neoadjuvant therapy are outside the scope. Separate ICCR datasets cover DCIS associated with invasive breast carcinomas and breast resections in the neoadjuvant setting. Surgically removed lymph nodes are covered in a separate ICCR dataset which may be used, as appropriate, in conjunction with this dataset. Published: June 2021.
- 2. Invasive carcinoma of the breast, 2<sup>nd</sup> edition, which was developed for the reporting of resection specimens from patients with invasive carcinoma of the breast, with or



without DCIS. DCIS without invasive carcinoma and microinvasive carcinoma (≤1 mm) are dealt with in a separate ICCR dataset. Ipsilateral multifocal disease should be dealt with in a single report. For bilateral invasive breast tumours, a separate dataset should be completed for each side. Surgically removed lymph nodes are dealt with in a separate ICCR dataset which may be used, as appropriate, in conjunction with this dataset. Invasive breast cancer for the post neoadjuvant setting is also dealt with in a separate ICCR dataset. Published: June 2022.

- 3. Invasive carcinoma of the breast in the setting of neoadjuvant therapy, 2<sup>nd</sup> edition, which was developed for the reporting of resection specimens after neoadjuvant therapy from patients with invasive carcinoma of the breast with or without DCIS. This dataset is for post-treatment surgical specimens. Core needle biopsies are not included. Published: May 2023.
- 4. Surgically removed lymph nodes for breast tumours, 1<sup>st</sup> edition, which was developed for the reporting of surgically removed ipsilateral lymph nodes (including lymph node dissection, targeted axillary surgery, nodal sampling and sentinel node biopsy specimens) for breast tumours. It is not intended for use in reporting core biopsy or fine needle aspiration of lymph nodes. The assessment of ipsilateral lymph nodes is part of nodal staging of breast cancer, whereas the rare contralateral lymph node involvement is currently interpreted as distant metastasis and is not part of the dataset. The reporting of invasive breast cancer and in situ disease (DCIS, pleomorphic and florid LCIS, encapsulated papillary carcinoma and solid papillary carcinoma in situ) are dealt with in separate ICCR datasets which may be used, as appropriate, in conjunction with this dataset. Published: May 2021.

# Paediatrics

- 1. **Paediatric renal tumours, 1st edition**, was developed for the examination of resection specimens from paediatric patients with nephroblastoma also known as Wilms tumour, and all other renal tumours of childhood except renal cell carcinomas. It does not apply to procedures involving only biopsy. Published: November 2023.
- 2. **Paediatric rhabdomyosarcoma**, **1**<sup>st</sup> **edition**, was developed for the pathological reporting of biopsy and resection specimens of paediatric rhabdomyosarcoma. The dataset covers both pre- and post-treatment specimens. Published: November 2023.
- 3. **Neuroblastoma**, 1<sup>st</sup> edition, was developed for the pathological reporting of biopsy and resection specimens of paediatric peripheral neuroblastic tumours. Published: November 2023.
- 4. Hepatoblastoma, 1<sup>st</sup> edition, was developed for the pathological reporting of resection specimens of paediatric hepatoblastoma, including tumours in the hepatocellular neoplasm not otherwise specified category. It is not applicable to hepatocellular carcinomas nor to other primary or metastatic paediatric neoplasms of the liver. Published: November 2023.

# 9.2 Peer-reviewed publications

• Dataset for reporting of thymic epithelial tumours: recommendations from the International Collaboration on Cancer Reporting (ICCR). Roden AC, Judge M, den Bakker MA, Fang W, Jain D, Marx A, Moreira AL, Rajan A, Stroebel P, Szolkowska M, Cooper WA. Histopathology. 2023 Sep 18. doi: 10.1111/his.15047. Epub ahead of print.

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- An international unified approach to reporting and grading invasive breast cancer. An overview of the International Collaboration on Cancer Reporting (ICCR) initiative. Ellis IO, Rakha EA, Tse GM, Tan PH. Histopathology. 2023 Jan;82(1):189-197. doi: 10.1111/his.14802.
- Datasets for reporting of soft-tissue sarcoma: recommendations from the International Collaboration on Cancer Reporting (ICCR). Dei Tos AP, Webster F, Agaimy A, Bovée J, Dickson B, Doyle L, Dry S, Gronchi A, Hameed M, Hemmings C, Liegl-Atzwanger B, Thway K, Wagner AJ, Wang J, Yoshida A, Fletcher C. Histopathology. 2023 Apr;82(5):745-754. Doi: 10.1111/his.14862. Epub 2023 Jan 20.
- Datasets for the reporting of primary tumour in bone: recommendations from the International Collaboration on Cancer Reporting (ICCR). Bovée JVMG, Amary F, Baumhoer D, Bloem JL, Bridge JA, Cates JMM, de Alava E, Dei Tos AP, Jones KB, Mahar A, Nielsen GP, Righi A, Wagner AJ, Yoshida A, Fletcher CDM. Histopathology. 2023 Mar;82(4):531-540. doi: 10.1111/his.14849. Epub 2022 Dec 20.
- Dataset for the reporting of neoplasms of the heart, pericardium, and great vessels: recommendations from the International Collaboration on Cancer Reporting (ICCR). Maleszewski JJ, Basso C, Burke A, Castonguay M, Leduc C, Tavora F, Sheppard M, Suri R, Judge M, Cooper WA. Virchows Arch. 2023 Feb;482(2):303-309. doi: 10.1007/s00428-022-03473-7. Epub 2022 Dec 13.
- Reporting of Surgically Removed Lymph Nodes for Breast Tumors: Recommendations From the International Collaboration on Cancer Reporting. Cserni G, Brogi E, Cody HS, Deb R, Farshid G, O'Toole S, Provenzano E, Quinn CM, Sahin AA, Schmitt F, Weaver DL, Yamaguchi R, Webster F, Tan PH. Arch Pathol Lab Med. 2022 Nov 1;146(11):1308-1318. doi: 10.5858/arpa.2022-0060-RA.
- International Collaboration on Cancer Reporting (ICCR) Gynecological Cancer Datasets: A Move Towards International Standardization. McCluggage WG. Int J Gynecol Pathol. 2022 Nov 1;41(Suppl 1):S1-S2. doi: 10.1097/PGP.000000000000872. Epub 2022 Oct 24.
- The International Collaboration on Cancer Reporting (ICCR): 10 Years Progress in the Development of Cancer Pathology Datasets. Helliwell TR, Judge MJ, Birdsong GG, Ellis DW, Srigley JR. Int J Gynecol Pathol. 2022 Nov 1;41(Suppl 1):S3-S7. doi: 10.1097/PGP.00000000000899. Epub 2022 Aug 11.
- Data Set for the Reporting of Carcinomas of the Vulva: Recommendations From the International Collaboration on Cancer Reporting (ICCR). Hoang L, Webster F, Bosse T, Focchi G, Gilks CB, Howitt BE, McAlpine JN, Ordi J, Singh N, Wong RW, Lax SF, McCluggage WG. Int J Gynecol Pathol. 2022 Nov 1;41(Suppl 1):S8-S22. doi: 10.1097/PGP.0000000000000000. Epub 2022 Oct 10.
- Data Set for the Reporting of Carcinomas of the Vagina: Recommendations From the International Collaboration on Cancer Reporting (ICCR). Wong RW, Webster F, Bosse T, Focchi G, Gilks CB, Hoang L, Howitt BE, McAlpine J, Ordi J, Singh N, Lax SF, McCluggage WG. Int J Gynecol Pathol. 2022 Nov 1;41(Suppl 1):S23-S33. doi: 10.1097/PGP.000000000000883. Epub 2022 May 20.
- Data Set for Reporting of Uterine Malignant and Potentially Malignant Mesenchymal Tumors: Recommendations From the International Collaboration on Cancer Reporting (ICCR). Nucci MR, Webster F, Croce S, George S, Howitt BE, Ip PPC, Lee CH, Rabban JT,

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Soslow RA, van der Griend R, Lax SF, McCluggage WG. Int J Gynecol Pathol. 2022 Nov 1;41(Suppl 1):S44-S63. doi: 10.1097/PGP.0000000000000911. Epub 2022 Sep 22.

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- Dataset for pathology reporting of ductal carcinoma insitu, variants of lobular carcinoma insitu and low-grade lesions: recommendations from the International Collaboration on Cancer Reporting (ICCR). Fox SB, Webster F, Chen CJ, Chua B, Collins L, Foschini MP, Bruce Mann G, Millar E, Pinder SE, Rakha E, Shaaban A, Tan BY, Tse G, Watson P, Tan PH. Histopathology. 2022 Oct;81(4):467-476. doi: 10.1111/his.14725. Epub 2022 Aug 8.
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- Dataset for the reporting of prostate carcinoma in radical prostatectomy specimens: updated recommendations from the International Collaboration on Cancer Reporting. Kench JG, Judge M, Delahunt B, Humphrey PA, Kristiansen G, Oxley J6, Rasiah K, Takahashi H, Trpkov K, Varma M, Wheeler TM, Zhou M, Srigley JR, Egevad L, Virchows Arch. 2019 Sep;475(3):263–277. doi: 10.1007/s00428–019–02574–0. Epub 2019 May 16.
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