International Collaboration on Cancer Reporting

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ANNUAL REPORT
2020

Index

1. MESSAGE FROM THE PRESIDENT

As we approach the tenth anniversary of the formation of the International Collaboration on Cancer Reporting (ICCR it is important to recognise the progress that has been made.

From its early start in 2011 with four members - the Colleges of Pathology of the USA, UK and Australia and the Canadian Association of Pathologists-Association Canadienne des Pathologists (CAP-ACP) in association with the Canadian Partnership Against Cancer (CPAC) - the ICCR has expanded and now has thirteen members. The ICCR incorporated in 2014 and launched its website in 2015.

An important aspect of the work of the ICCR is the building of strategic alliances and over the years the ICCR has built strong relationships with the International Agency for Research in Cancer (IARC), International Association of Cancer Registries (IACR), the American Joint Commission on Cancer (AJCC) and the Union for International Cancer Control (UICC) TNM staging groups as well as organisations working to identify solutions for low middle-income countries (LMIC) such as the City Cancer Challenge.

2020 has been a pivotal year for the ICCR as outlined below

a. Constitutional review

In 2019, the ICCR started a process to update its constitution to better reflect the expanded membership and to ensure all members were equivalent. The revised constitution was adopted by the Board in March 2020.

b. Three workstreams

It has been a focus of the executive team this year to clearly identify ICCR's vision, mission and goals. The outcome of this has been to identify the three key workstreams that the ICCR will focus on in the future:

- To develop internationally harmonised cancer pathology datasets and reporting guides incorporating contemporary morphologic and molecular standards from partner organizations including IARC (World Health Organization (WHO)), AJCC and UICC TNM and specialty societies.
- To translate datasets into multiple languages for adoption of reporting standards in both well developed and LMIC.
- To transform the dataset standards into machine readable formats and to facilitate their electronic implementation.

1. Standards Development

The core business of the ICCR is the development of internationally standardised and evidence based datasets for the pathology reporting of cancer and as at the end of November 2020 there are 43 datasets published, including 13 updates. There are 14 new datasets and 7 updates currently in development. In 2017, the ICCR agreed on an ambitious plan to develop datasets in synchrony with the WHO Classification of Tumour updates 5th edition and has been successful in keeping pace. We have published over 31 articles related to the ICCR datasets or work of the ICCR in peer-reviewed journals.

2. **Translations**

In 2018, with the kind support of the American Society for Clinical Pathology (ASCP), 21 datasets were translated into Spanish, French and Portuguese. The translation of ICCR datasets is critical as the IARC/WHO Classification of Tumours "Blue books" are not being translated, so having the ICCR datasets available in other languages will be crucial to advance adoption of standardised reporting around the globe. This effort will also greatly assist pathologists practicing in LMIC to effectively communicate complete cancer pathology results to clinicians, cancer registrars and other secondary users.

Since the translation of the initial 21 datasets, no further translations have occurred due to lack of funding. However, securing funding for the update of the 21 datasets already published, as well as further translation into three additional languages - Russian, German and Chinese - remains a high priority.

3. **Implementation**

In order to make best use of the ICCR datasets and eliminate the inherent 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 developed parts of the world there are commercially available LIS or middleware solutions. Older LIS, that are currently incapable of electronic structured reporting, are gradually being replaced as they are upgraded, as the importance of structured reporting of cancer is recognised. In this case, the availability of electronic representations for each dataset and applicable terminology are all that is needed to ensure accurate and reliable reporting according to the ICCR standard.

However, in LMIC there is little or no access to electronic structured reporting tools. Reporting remains paper based or at best done on a standalone PC using word processing software. Therefore, the ICCR is looking at options to provide a low-cost structured reporting solution for LMIC. Several possible options have been reviewed this year and a decision to utilise an existing tool rather than develop something from scratch has been made. Further work is needed to secure funding for a series of trials in order to find an appropriate and robust solution.

Another significant area of advancement in 2020 has been the interest shown by Laboratory System and middleware vendors and jurisdictions wanting to implement the ICCR datasets. Several memoranda of understanding are being considered, however, the drafting of these initial agreements has required the ICCR to revise its copyright agreement with dataset authors and to consider the wider impact of funding and commercialisation of the ICCR datasets. The revised copyright statements have commenced rolling out but discussion on the commercialisation of the dataset is ongoing.

Implementation of ICCR datasets also requires the development of terminology, and while ICCR works with other dataset producers to develop SNOMED CT codes, interim codes must be considered to support implementation activities around the world.

With the significant increase in work related to implementation, the ICCR has recently started a Structured Reporting Implementation Committee (SRIC). This committee will provide guidance to the Board on matters relating to the implementation of ICCR cancer datasets as well as to advance the detailed technical aspects impacting the efficient implementation of standardised cancer datasets.   The ICCR is very fortunate that Professor George Birdsong has recently accepted the position of Chair of the SRIC. Prof Birdsong has had immense experience in pathology informatics and is a past chair of the Pathology Electronic Reporting Taskforce of the CAP.

c.   Strategy planning

Funding at the present time is just sufficient for the ICCR to continue development of datasets and operational support but is insufficient for the organisation to significantly advance the other two workstreams - translations and implementation activities.

To assist in planning for, and progressing proposals for further funding, the ICCR has been fortunate to work with Donna Meredith the Managing Director of Keystone Corporate Positioning. Over the last few months Ms Meredith has been working with the ICCR executive, pro-bono, on the development of a fundraising strategy and renewed branding. Donna facilitated a recent strategy planning session for the ICCR which discussed and described ICCR's vision for the future. A new logo and branding were reviewed and accepted in late 2020 and will be rolled out in 2021.

d.   Succession planning

As ICCR's momentum increases, more detailed planning on the succession of key organisational roles is required. This has been a focus of discussion this year and several important changes – to increase the term of office for the ICCR's President and Vice-President and to facilitate the inclusion of younger pathologists onto the Board - were discussed and agreed at the recent strategy planning session.

2021 is ICCR's tenth anniversary year and it is timely that it coincides with the roll-out of a new look. We will diligently pursue additional funding including philanthropic sources to expand the core dataset business and advance our translation and implementation goals. The Executive Team would like to express sincere gratitude to our sponsoring organisations and strategic partners for providing us the resources and intellectual support to accomplish our important goals. We are particularly thankful for the great work done by our Dataset Authoring Committee Chairs and members and especially our dedicated Project Managers who keep the whole process alive.

John Srigley, President ICCR

2. ICCR's Vision and Mission

2.1 Vision statement

Internationally standardized, 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 ICCR produces internationally standardized 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. ORGANISATIONAL OVERVIEW

The International Collaboration on Cancer Reporting (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:
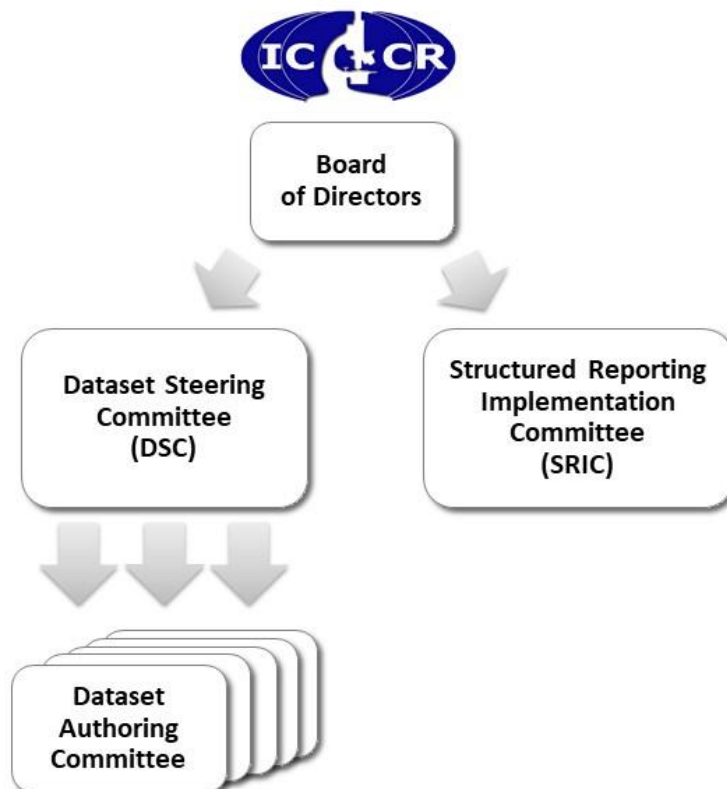
The ICCR is supported by membership and sponsorship.

Following constitutional review in 2019, ICCR has three levels of membership:

- Platinum – which provides the member organisation with both Board of Directors (BoD) and Dataset Steering Committee (DSC) representation. Platinum membership entitles the organisation to four votes on the Board. The annual subscription for a platinum member is US$20,000.

- Gold - which provides the member organisation with both Board and DSC representation. Gold membership entitles the organisation to two votes on the Board. The annual subscription for a Gold member is US$10,000.

- Silver - which provides the member organisation with DSC representation only. The annual subscription for a Silver member is US$5,000.

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

As at November 2020 there are twelve GOLD members, which are:

- The European Society of Pathology (ESP),

- The Royal College of Pathologists UK,

- The College of American Pathologists (CAP),

- The Royal College of Pathologists of Australasia (RCPA),

- The Canadian Association of Pathologists (CAP-ACP) in association with the Canadian Partnership Against Cancer (CPAC),

- The American Society of Clinical Pathology (ASCP),

- The Royal College of Physicians of Ireland, Faculty of Pathology (RCPI FoP),

- The German Society of Pathology (DGP),

- The Brazilian Society of Pathology (SBP),

- The Hong Kong College of Pathologists, and

- The Austrian Society of Pathology/IAP Austrian Division (ASP), and

- The Japanese Society of Pathology (JSP).

Each of the member organisations is represented on the ICCR BoD which has strategic oversight of all ICCR operations and financial and legal responsibility for the running of the ICCR. Each member has nominated directors as follows:

- John Srigley for the Canadian Association of Pathologists - Association Canadienne des Pathologistes (CAP-ACP) in association with the Canadian Partnership Against Cancer (CPAC),

- Tim Helliwell for The Royal College of Pathologists UK (RCPath),

- James Kench for the Royal College of Pathologists of Australasia (RCPA), and Sanchia Aranda, the second Australian director as per constitutional requirements,

- Marta Cohen for the European Society of Pathology (ESP),

- Thomas Wheeler for the College of American Pathologists (CAP),

- James L Wisecarver for the American Society of Clinical Pathology (ASCP),

- Kieran Sheahan for the Royal College of Physicians of Ireland, Faculty of Pathology (RCPI FoP),

- Peter Schirmacher for the German Society of Pathology (DGP),

- Katia Ramos Moreira Leite for the Brazilian Society of Pathology (SBP),

- Nga Yin Annie Cheung, for the Hong Kong College of Pathologists,

- Gerald Hoefler for the Austrian Society of Pathology /IAP Austrian Division (ASP), and

- Atsushi Ochiai for the Japanese Society of Pathology (JSP).

At the BoD in January 2020, John Srigley was re-elected as President and Tim Helliwell, re-elected as Vice-president of the company. David Ellis was re-affirmed as Executive Officer. In that role Dr Ellis provides advice to the BoD and continuing corporate knowledge as Past President.

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 such as the IARC the European Organisation for Research and Treatment of Cancer (EORTC), and the IACR. Tim Helliwell, Vice President of the ICCR, continues as Chair of the DSC.

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.

The ICCR SRIC is a new committee convened late this year. Its purpose is to provide guidance to the BoD 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 LMIC and terminology binding. Dr Birdsong has been appointed Chair.

The BoD, DSC, SRIC and DAC members are all volunteers that provide their expertise and time altruistically.

3.1   Branding/Logo

The ICCR has been investigating various potential fund-raising strategies with the kind assistance of Ms Donna Meredith the Managing Director of Keystone Corporate Positioning. Ms Meredith has recommended that as part of ICCR's strategy that a renewed logo and branding is needed to better promote the ICCR to potential funding organisations.

A new logo and branding materials were reviewed and accepted by the BoD at its Strategic Planning meeting in October 2020. It will be rolled out in 2021.
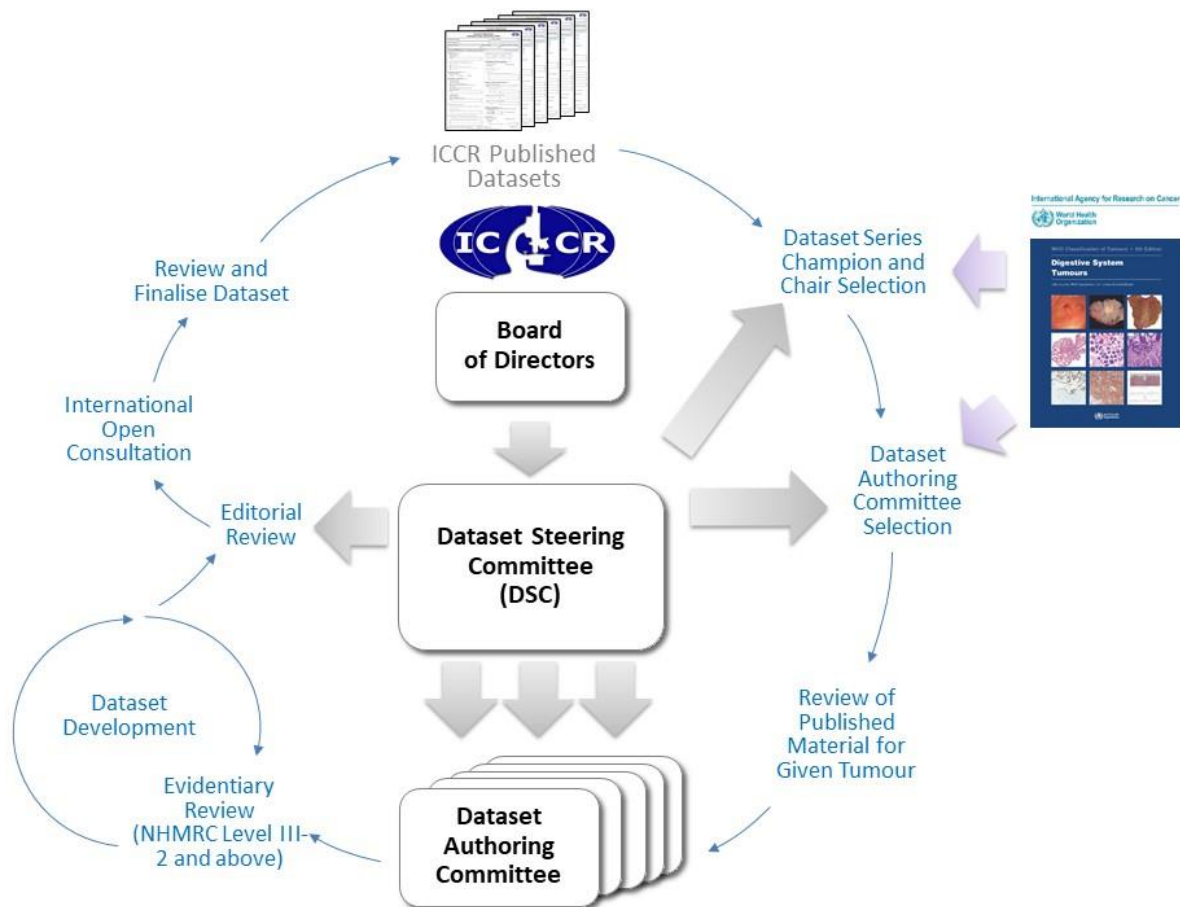
4. DATASET DEVELOPMENT STATUS

The core business of the ICCR is to develop internationally validated and evidence-based pathology datasets for cancer reporting for use around the world.

The ICCR Dataset development follows an agreed process that is outlined in *Guidelines for the Development of ICCR Datasets* (http://www.iccr-cancer.org/datasets/dataset-development), which is reviewed and updated periodically by the ICCR DSC. The process is summarised in Figure 1:

Figure 1: ICCR Dataset development process.

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 5th edition of the WHO is currently underway.

For the development of a series of datasets, the ICCR additionally appoints a Series Champion. The Series Champion 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* (http://www.iccr-cancer.org/datasets/dataset-development).

For the development of each dataset, the DSC appoints an appropriately qualified expert pathologist to take on the role of Chair of the DAC who is supported in the development by a Project Manager and ICCR DSC representative.

4.1   Published datasets

As at November 2020, the ICCR has 43 published datasets. All published datasets are compliant with the latest 8th edition TNM staging where applicable.

The following is a list of published datasets:

Urinary/male genital

1. **Prostate carcinoma (radical prostatectomy specimens), 2nd edition,** which has been developed for radical prostatectomy specimens for prostate carcinoma. Published: August 2017

2. **Prostate carcinoma (transurethral resection and enucleation specimens), 1st edition,** which has been 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, 1st edition,** which has been 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, 1st edition,** which has been 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 ie left or right. Published: July 2017, Updated July 2018.

5. **Renal biopsy for tumour, 1st edition,** which has been developed for core or wedge biopsy specimens for tumour of the kidney. Published: July 2017

6. **Carcinoma of the penis, 1st edition,** which has been 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, 1st edition,** which has been developed for the reporting of both partial and radical orchidectomy specimens from patients with 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, 1st edition,** which has been 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 specimens, 1st edition**, which has been 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 transurethral 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 specimens, 1st edition**, which has been 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 specimens, 1st edition,** which has been 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 specimens, 1st edition,** which has been 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.

<u>Female reproductive organs</u>

1. **Endometrial carcinoma 3rd edition,** which covers resection specimens of endometrial cancers. It is not applicable for small endometrial biopsy specimens. Published: July 2017

2. **Carcinoma of the ovary, fallopian tube and primary peritoneal site, 1st edition,** which has been 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: March 2015

3. **Carcinoma of the cervix, 2nd 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. Published: July 2019

Thorax

1. **Lung cancer, 3rd edition**, which has been developed for resection specimens of lung cancer. It is not applicable for bronchoscopic and transthoracic biopsy specimens. Published: August 2017

2. **Mesothelioma in the pleura and peritoneum, 2nd edition**, which covers both biopsy and resection specimens. Published August 2017

3. **Thymic epithelial tumours, 2nd edition**, which covers resection specimens of the thymus ie thymoma, neuroendocrine tumours of the thymus and thymic carcinoma but excludes germ cell tumours and other primary thymic neoplasms. Published September 2017

4. **Neoplasms of the heart, peritoneum and great vessels, 1st edition**, which covers biopsy and resection specimens for primary tumours of the heart, pericardium and great vessels, including both benign and malignant entities, and excluding haematolymphoid neoplasms and mesothelioma. Published May 2016

Digestive Tract

1. **Intrahepatic, and perihilar cholangiocarcinoma and hepatocellular carcinoma, 2nd 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: April 2017, updated November 2020.

2. **Carcinoma of the exocrine pancreas, 1st 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, 1st 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 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), 1st 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 neuroendocrine carcinomas (NECs) and mixed neuroendocrine-non-neuroendocrine neoplasms (MiNENs), are excluded. Published: April 2020

5. **Carcinomas of the stomach, 1st edition**, which covers gastrectomy specimens for gastric carcinomas. Carcinomas involving the oesophagogastric junction (OGJ) with their epicentre >20 millimetres (mm) into the proximal stomach and cardia cancers that do not involve the OGJ are included, as are neuroendocrine carcinomas (NECs) and mixed neuroendocrine-non-neuroendocrine neoplasms (MiNENs) (with the exception of mixed adenoma and well differentiated neuroendocrine tumours (NETs). Endoscopic resections of the stomach, well differentiated NETs, non-epithelial malignancies and secondary tumours are excluded. Published: November 2020.

6. **Endoscopic resection of the stomach, 1st edition**, which covers carcinomas involving the oesophagogastric junction (OGJ) with their epicentre >20 millimetres (mm) into the proximal stomach and cardia cancers that do not involve the OGJ as well as neuroendocrine carcinomas (NECs) and mixed neuroendocrine-non-neuroendocrine neoplasms (MiNENs) (with the exception of mixed adenoma and well differentiated neuroendocrine tumours (NETs)). Well differentiated NETs, non-epithelial malignancies, and secondary tumours are excluded. Published: November 2020.

7. **Carcinomas of the oesophagus, 1st edition**, which covers resection specimens of the oesophagus, including carcinomas involving the oesophagogastric junction (OGJ) with tumour epicentre ≤20 mm into the proximal stomach. Neuroendocrine carcinomas (NECs) and mixed neuroendocrine-non-neuroendocrine neoplasms (MiNENs) of the oesophagus are included. Endoscopic resections of the oesophagus, well differentiated neuroendocrine tumours (NETs), non-epithelial malignancies such as melanoma, and secondary tumours are excluded. Published: November 2020.

8. **Endoscopic resection of the oesophagus and oesophagogastric junction, 1st edition**, which covers endoscopic resection of pre-malignant and malignant lesions of the oesophagus and oesophagogastric junction (OGJ) including neuroendocrine carcinomas (NECs) and mixed neuroendocrine-non-neuroendocrine neoplasms (MiNENs) of the oesophagus. Well differentiated neuroendocrine tumours (NETs), non-epithelial malignancies such as melanoma, and secondary tumours are excluded. Published: November 2020.

Skin

1. **Invasive melanoma, 2nd edition**, which has been developed for reporting of primary cutaneous invasive melanoma. The second edition of this dataset includes changes to align the dataset with the TNM Pathological staging 8th edition and the World Health Organization (WHO) Classification of Tumours, Pathology and Genetics of Skin Tumours (2018), in addition to other revisions as listed in the scope section of the dataset notes. Published: October 2019.

2. **Merkel cell carcinoma, 1st 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), 1st edition,** which is split into three sections:

   a. Histological assessment of CNS specimens. 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 World Health Organisation (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. 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. 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, 1st edition**, which has been 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, 1st edition**, which has been 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 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, 1st edition**, which has been 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, 1st edition**, which has been 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, 1st edition**, which has been 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, 1st edition**, which has been 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, 1st edition**, which has been 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, 1st edition**, which has been 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, 1st edition**, which has been developed for the reporting of lymph node resections from patients with carcinomas and melanomas 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, 1st 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 & atypical parathyroid neoplasm, 1st 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 1st 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, 2nd 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

4.1.1 *International Standard Book Numbers (ISBNs)*

ISBNs 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.

4.2 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 five year forward plan, 2018-2023, 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 21 datasets currently in progress:

4.2.1 Breast

A series of four datasets for the breast are underway in synchrony with the publication of the 5th series of the IARC/WHO "blue books". Invasive breast cancer (Chair: Ian Ellis).

1. Ductal carcinoma in situ (DCIS) (Chair: Stephen Fox).

2. Lymph node dissection/sentinel Lymph node biopsies (Chair: Edi Brogi).

3. Invasive Breast in the post neoadjuvant therapy setting (Chair: Ian Ellis).

Puay Hoon Tan, from Singapore, is the appointed Series Champion.

4.2.2 Bone and Soft Tissue (BST)

A series of six datasets are underway in synchrony with the publication of the 5th series of the IARC/WHO "blue books".

1. Bone tumours – resections (Chair: Judith Bovée),

2. Bone tumours – biopsies (Chair: Judith Bovée),

3. Soft tissue sarcoma – resections (Chair: Angelo Paolo Dei Tos),

4. Soft tissue sarcoma – biopsies (Chair: Angelo Paolo Dei Tos),

5. Gastrointestinal stromal tumours – resections (Chair: Jason L. Hornick)

6. Gastrointestinal stromal tumours – biopsies (Chair: Jason L. Hornick).

Dr Chris Fetcher, from the USA, is the appointed Series Champion.

4.2.3 Gynaecology

The ICCR has commenced development of updates to 3 of its published datasets:

1. Endometrium cancer (3rd edition) (Chair: Xavier Matias-Guiu)

2. Carcinoma of the cervix (2nd edition) (Chair: Kay Park)

3. Ovary, fallopian tube and primary peritoneal site carcinoma (1st edition) (Chair: Blake Gilks)

In addition, 4 new datasets in the gynaecological suite are underway:

4. Carcinoma of the vagina (Chair: Glenn McCluggage)

5. Carcinoma of the vulva (Chair: Glenn McCluggage)

6. Uterine carcinoma (Chair: Marisa Nucci)

7. Trophoblastic tumour (Chair: Pei Hui)

Glenn McCluggage, from the UK is the appointed Series Champion.

4.2.4 *Thoracic*

The ICCR has commenced development of updates to 4 of its published datasets:

1. Lung Cancers (3rd edition) (Chair: Andrew Nicholson)

2. Thymic Epithelial Tumours (2nd edition) (Chair: Anja Roden)

3. Neoplasms of the Heart, Pericardium and Great Vessels (1st edition) (Chair: Joseph Maleszewski)

4. Mesothelioma in the Pleura and Peritoneum (2nd edition) (Chair: Sonja Klebe)

Wendy Cooper, from Australia, is the appointed Series Champion.

4.3   Datasets in planning

The following dataset series are in planning following updates to the 5th series of the IARC/WHO 'blue books' in the relevant anatomical areas:

- Paediatric,

- Central Nervous System.

4.4   TNM staging

8th edition

The 8th editions of the AJCC and UICC TNM Classification of Malignant Tumours were published in late 2016. Given that the UICC TNM is widely used in Europe, UK and other parts of the world, while AJCC TNM is used extensively in the North America and Australia, the ICCR was keen to be bipartisan in its approach. Ostensibly these versions are harmonised, however on a more detailed review a number of differences were noted. Some of these issues are significant, particularly in relation to testicular cancer where the pT stage may actually be recorded differently depending on which version of TNM is used.

Having investigated the issue, 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.

<u>Next edition</u>

The AJCC has recently 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. The AJCC Cervical TNM has been recently released. This update aligns AJCC TNM with the most recent updates to The International Federation of Gynecology and Obstetrics (FIGO) staging. However, the UICC TNM Staging for Cervix is not currently aligned with these changes and it is not clear at this stage how UICC will respond to the AJCC 'rolling update' model.

The ICCR is in the process of updating its cervical cancer dataset as part of the development work on the Gynaecology suite to synchronise with the WHO, 5th edition, Classification of Tumour of the Female Genital Tract.

The ICCR will need to discuss and agree the most appropriate way forward for recording staging information in the dataset on cancers of the uterine cervix as well as for the broader issue as other ICCR datasets are developed/updated in the future. To assist with this the ICCR has convened a TNM staging impact task and finish group with representation from the DSC, AJCC, IARC and Gynaecology.

4.5   Peer-reviewed publications

A key step in the development of ICCR datasets is the production of an accompanying article submitted to a peer-reviewed journal. To date, the following 27 dataset related articles have been published:

- Data set for reporting of carcinoma of the adrenal cortex: Explanations and recommendations of the guidelines from the International Collaboration on Cancer Reporting (ICCR). Giordano TJ, Berney D, de Krijger RR, Erickson L, Fassnacht M, Mete O, Papathomas T, Papotti M, Sasano H, Thompson LDR, Volante M, Gill AJ. Hum Pathol. 2020 Oct 12;S0046-8177(20)30199-4. doi: 10.1016/j.humpath.2020.10.001. [Online ahead of print]

- Data set for reporting carcinoma of the thyroid: Recommendations from the International Collaboration on Cancer Reporting (ICCR). Ghossein R, Barletta JA, Bullock M, Johnson SJ, Kakudo K, Lam AK, Moonim MT, Poller DN, Tallini G, Tuttle RM, Xu B, Gill AJ. Hum Pathol. 2020 Sep 10;S0046-8177(20)30171-4. doi: 10.1016/j.humpath.2020.08.009. [Online ahead of print]

- Pathology data set for reporting parathyroid carcinoma and atypical parathyroid neoplasm: recommendations from the International Collaboration on Cancer Reporting. Williams MD, DeLellis RA, Erickson LA, Gupta R, Johnson SJ, Kameyama K, Natu S, Ng T, Perren A, Perrier ND, Seethala RR, Gill AJ. Hum Pathol. 2020 Jul 17;S0046-8177(20)30131-3. doi: 10.1016/j.humpath.2020.07.008. [Online ahead of print]

- Data set for the reporting of pheochromocytoma and paraganglioma: explanations and recommendations of the guidelines from the International Collaboration on Cancer Reporting. Thompson LDR, Gill AJ, L Asa SL, Clifton-Bligh RJ, de Krijger RR, Kimura N, Komminoth P, Lack EE, Lenders JWM, Lloyd RV, Papathomas TG, Sadow PM, Tischler AS. Hum Pathol. 2020 May 11;S0046-8177(20)30084-8. doi: 10.1016/j.humpath.2020.04.012. [Online ahead of print]

- Dataset for the reporting of carcinoma of the bladder - cystectomy, cystoprostatectomy and diverticulectomy specimens: recommendations from the International Collaboration on Cancer Reporting (ICCR). Compérat E, Srigley JR, Brimo F, Delahunt B, Koch M, Lopez-Beltran A, Reuter V, Samaratunga H, Shanks JH, Tsuzuki T, van der Kwast T, Varma M, Webster F, Grignon D. Virchows Arch. 2020 Jan 8. doi: 10.1007/s00428-019-02727-1. [Epub ahead of print]

- Dataset for the reporting of urinary tract carcinoma - biopsy and transurethral resection specimen: recommendations from the International Collaboration on Cancer Reporting (ICCR). Varma M, Srigley JR, Brimo F, Comperat E, Delahunt B, Koch M, Lopez-Beltran A, Reuter V, Samaratunga H, Shanks J, Tsuzuki T, van der Kwast T, Grignon D. Modern Pathology. 2019. *In press.*

- Dataset for reporting of carcinoma of the urethra (in urethrectomy specimens): recommendations from the International Collaboration on Cancer Reporting (ICCR). Shanks JH, Srigley JR, Brimo F, Comperat E, Delahunt B, Koch M, Lopez-Beltran A, Reuter V, Samaratunga H, Tsuzuki T, van der Kwast T, Varma M, Grignon D. Histopathology. 2019 Oct;75(4):453-467. doi: 10.1111/his.13877. Epub 2019 Jul 2.

- Data Set for the Reporting of Carcinoma of the Renal Pelvis and Ureter-Nephroureterectomy and Ureterectomy Specimens: Recommendations From the International Collaboration on Cancer Reporting (ICCR). Samaratunga H, Judge M, Delahunt B, Srigley J, Brimo F, Comperat E, Koch M, Lopez-Beltran A, Reuter V, Shanks J, Tsuzuki T, van der Kwast T, Varma M, Grignon D. Am J Surg Pathol. 2019 Oct;43(10):e1-e12. doi: 10.1097/PAS.0000000000001305.

- 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.

- Dataset for the reporting of renal biopsy for tumour: recommendations from the International Collaboration on Cancer Reporting (ICCR). Delahunt B, Srigley JR, Judge M, Amin M, Billis A, Camparo P, Fleming S, Griffiths D, Lopez-Beltran A, Martignoni G, Moch H, Nacey JN, Zhou M, Evans AJ. J Clin Pathol. 2019 Sep;72(9):573-578. doi: 10.1136/jclinpath-2019-205959. Epub 2019 Jul 12.

- Data Sets for the Reporting of Tumors of the Central Nervous System. Louis DN, Wesseling P, Brandner S, Brat DJ, Ellison DW, Giangaspero F, Hattab EM, Hawkins C, Judge MJ, Kleinschmidt-DeMasters B, Komori T, McLean C, Paulus W, Perry A, Reifenberger G, Weller M, Rous B.Arch Pathol Lab Med. 2019 Jun 20. doi: 10.5858/arpa.2018-0565-OA. [Epub ahead of print]

- Data set for the reporting of carcinomas of the major salivary glands: Explanations and recommendations of the guidelines from the international collaboration on cancer reporting (ICCR). Seethala RR, Altemani A, Ferris RL, Fonseca I, Gnepp DR, Ha P, Nagao T, Skalova A, Stenman G, Thompson LDR. Arch Pathol Lab Med. 2019 May;143(5):578-586. doi: 10.5858/arpa.2018-0422-SA. Epub 2018 Nov 30.

- Data set for the reporting of malignant odontogenic tumors: Explanations and recommendations of the guidelines from the International Collaboration on Cancer Reporting. Slootweg PJ, Odell EW, Baumhoer D, Carlos R, Hunter KD, Taylor AM, Richardson MS, Slater L, Speight PM, Wright J, Thompson LDR. Arch Pathol Lab Med. 2019 May;143(5):587-592. doi: 10.5858/arpa.2018-0417-SA. Epub 2018 Nov 30.

- Data set for reporting of mucosal melanomas of the head and neck: Explanations and recommendations of the guidelines from the International Collaboration on Cancer Reporting. Williams MD, Franchi A, Helliwell T, Muller S, Thompson LDR. Arch Pathol Lab Med. 2019 May;143(5):603-609. doi: 10.5858/arpa.2018-0412-SA. Epub 2018 Nov 30.

- Data set for the reporting of ear and temporal bone tumours: Explanations and recommendations of the guidelines from the International Collaboration on Cancer Reporting. Gupta R, Sandison A, Wenig BM, Thompson LDR. Arch Pathol Lab Med. 2019 May;143(5):593-602. doi: 10.5858/arpa.2018-0415-SA. Epub 2018 Nov 30.

- Data set for the reporting of carcinomas of the nasal cavity and paranasal sinuses: Explanations and recommendations of the guidelines from the International Collaboration on Cancer Reporting. Franchi A, Bishop JA, Coleman H, Flucke U, Licitra LF, Pendás JLL, Stelow EB, Toner M, Weinreb I, Wenig BM, Thompson LDR. Arch Pathol Lab Med. 2019 Apr;143(4):424-431. doi: 10.5858/arpa.2018-0404-SA. Epub 2018 Nov 30.

- Data set for the reporting of oral cavity carcinomas: Explanations and recommendations of the guidelines from the International Collaboration of Cancer Reporting. Müller S, Boy SC, Day TA, Magliocca KR, Richardson MS, Sloan P, Tilakaratne WM, Zain RB, Thompson LDR. Arch Pathol Lab Med. 2019 Apr;143(4):439-446. doi: 10.5858/arpa.2018-0411-SA. Epub 2018 Nov 30.

- Data set for the reporting of carcinomas of the nasopharynx and oropharynx: Explanations and recommendations of the guidelines from the International Collaboration on Cancer Reporting (ICCR). Lewis JS Jr, Adelstein DJ, Agaimy A, Carlson D, Faquin WC, Helliwell T, Hille J, Ng T, Nicholls J, O'Sullivan B, Thompson LDR. Arch Pathol Lab Med, 2019 Apr;143(4):447-451. 10.5858/arpa.2018-0405-SA. Epub 2018 Nov 30.

- Data set for the reporting of nodal excisions and neck dissection specimens for head and neck tumors: Explanations and recommendations of the guidelines from the International Collaboration on Cancer Reporting. Bullock M, Beitler J, Carlson DL, Fonseca I, Hunt J, Katabi N, Sloan P, Taylor SM, Williams M, Thompson LDR. Arch Pathol Lab Med. 2019 Apr;143(4):452-462. doi: 10.5858/arpa.2018-0421-SA. Epub 2018 Nov 30.

- Data set for reporting of carcinomas of the hypopharynx, larynx and trachea: Explanations and recommendations of the Guidelines from the International Collaboration on Cancer Reporting. Helliwell T, Chernock R, Dahlstrom J, Gale N, McHugh J, Perez-Ordonez B, Roland N, Zidar N, Thompson LDR. Arch Pathol Lab Med. 2019 Apr;143(4):432-438. doi: 10.5858/arpa.2018-0419-SA. Epub 2018 Nov 30.

- Data set for the reporting of carcinoma of renal tubular origin: recommendations from the International Collaboration on Cancer Reporting (ICCR). Delahunt B, Srigley JR, Judge MJ, Amin MB, Billis A, Camparo P, Evans AJ, Fleming S, Griffiths D, Lopez-Beltran A, Martignoni G, Moch H, Nacey JN, Zhou M. Histopathology. 2019 Feb;74(3):377-390. doi: 10.1111/his.13754.

- Datasets for the reporting of neoplasia of the testis: recommendations from the International Collaboration on Cancer Reporting. Berney DM, Comperat E, Feldman DR, Hamilton RJ, Idrees MT, Samaratunga H, Tickoo SK, Yilmaz A, Srigley JR. Histopathology. 2019 Jan;74(1):171-183. doi: 10.1111/his.13736.

- Dataset for the reporting of prostate carcinoma in core needle biopsy and transurethral resection and enucleation specimens: Recommendations from the International Collaboration on Cancer Reporting (ICCR). Egevad L, Judge M, Delahunt B, Humphrey PA, Kristiansen G, Oxley J, Rasiah K, Takahashi H, Trpkov K, Varma M, Wheeler TM, Zhou M, Srigley JR, Kench JG. Pathology. 2019 Jan;51(1):11-20. doi: 10.1016/j.pathol.2018.10.003. Epub 2018 Nov 23.

- Data set for the reporting of intrahepatic cholangiocarcinoma, perihilar cholangiocarcinoma and hepatocellular carcinoma: recommendations from the International Collaboration on Cancer Reporting (ICCR). Burt AD, Alves V, Bedossa P, Clouston A, Guido M, Hübscher S, Kakar S, Ng I, Park YN, Reeves H, Wyatt J, Yeh MM, Ellis DW. Histopathology. 2018 Sep;73(3):369-385. doi: 10.1111/his.13520. Epub 2018 May 30.

- Data set for the Reporting of Carcinomas of the Cervix: Recommendations from the International Collaboration on Cancer Reporting (ICCR). McCluggage WG, Judge MJ, Alvarado-Cabrero I, Duggan MA, Horn LC, Hui P, Ordi J, Otis CN, Park KJ, Plante M, Stewart CJR, Wiredu EK, Rous B, Hirschowitz L. Int J Gynecol Pathol. 2018 May;37(3):205-228. doi: 10.1097/PGP.0000000000000412.

- Dataset for reporting of thymic epithelial tumours: recommendations from the International Collaboration on Cancer Reporting (ICCR). Nicholson AG, Detterbeck F, Marx A, Roden AC, Marchevsky AM, Mukai K, Chen G, Marino M, den Bakker MA, Yang WI, Judge M, Hirschowitz L. Histopathology. 2017 Mar;70(4):522-538. doi: 10.1111/his.13099. Epub 2016 Nov 28.

- Dataset for Reporting of Malignant Mesothelioma of the Pleura or Peritoneum: Recommendations from the International Collaboration on Cancer Reporting (ICCR). Churg A, Attanoos R, Borczuk AC, Chirieac LR, Galateau-Salle F, Gibbs A, Henderson D, Roggli V, Rusch V, Judge MJ and Srigley JR. Arch Pathol Lab Med. 2016 Oct;140(10):1104-10. doi: 10.5858/arpa.2016-0073-OA. Epub 2016 Mar 31.

- Data set for reporting of ovary, fallopian tube and primary peritoneal carcinoma: recommendations from the International Collaboration on Cancer Reporting (ICCR). McCluggage WG, Judge MJ, Clarke BA, Davidson B, Gilks CB, Hollema H, Ledermann J, Matias-Guiu X, Mikami Y, Stewart CJR, Vang R and Hirschowitz L. Mod Pathol. 2015 Aug;28(8):1101-22. doi: 10.1038/modpathol.2015.77. Epub 2015 Jun 19.

- Data set for pathology reporting of cutaneous invasive melanoma: recommendations from the international collaboration on cancer reporting (ICCR). Scolyer RA, Judge MJ, Evans A, Frishberg DP, Prieto VG, Thompson JF, Trotter MJ, Walsh MY, Walsh NMG, Ellis DW. Am J Surg Pathol. 2013 Dec;37(12):1797-814. doi: 10.1097/PAS.0b013e31829d7f35.

- Data set for reporting of lung carcinomas: recommendations from International Collaboration on Cancer Reporting. Jones KD, Churg A, Henderson DW, Hwang DM, Ma Wyatt J, Nicholson AG, Rice AJ, Washington MK, Butnor KJ. Arch Pathol Lab Med. 2013 Aug;137(8):1054-62. doi: 10.5858/arpa.2012-0511-OA.

- Data set for reporting of endometrial carcinomas: recommendations from the International Collaboration on Cancer Reporting (ICCR) between United Kingdom, United States, Canada, and Australasia. McCluggage WG, Colgan T, Duggan M, Hacker NF, Mulvany N, Otis C, Wilkinson N, Zaino RJ and Hirschowitz L. Int J Gynecol Pathol. 2013 Jan;32(1):45-65. doi: 10.1097/PGP.0b013e31825d808b.

- Dataset for reporting of prostate carcinoma in radical prostatectomy specimens: recommendations from the International Collaboration on Cancer Reporting. Kench J, Delahunt B, Griffiths DF, Humphrey PA, McGowan T, Trpkov K, Varma M, Wheeler TM and Srigley JR. Histopathology. 2013 Jan;62(2):203-18. doi: 10.1111/his.12042.

5. TRANSLATION

Translation of 21 ICCR datasets into Spanish, French and Portuguese has been completed through the kind contribution of the American Society of Clinical Pathology (ASCP), a sustaining member of the ICCR.

The translation work is critical as the IARC/WHO Classification of Tumours "blue books" are not being translated, so having the datasets available in other languages will be very important to advance adoption of standardised reporting in the future.

The ASCP, engaged the services of an ISO 9001:2015 certified company to undertake the translations.

Further translations are planned once funding is secured.

5.1   Datasets translated

The following translated datasets are posted to the ICCR website:

Group	Dataset
Genitourinary	Urethrectomy
	Ureterectomy and nephroureterectomy
	Urinary bladder – transurethral resection and biopsy
	Urinary bladder
	Kidney
	Kidney biopsy
	Penis
	Testicular cancer - RPLND
	Testicular cancer
	Prostate - transurethral resection
	Prostate - radical prostatectomy
	Prostate - core/needle biopsy
Digestive tract	Liver - intrahepatic & perihilar cholangiocarcinoma and hepatocellular carcinoma
Thoracic	Lung
	Thymic epithelial tumours
	Heart, pericardium and great vessels
	Mesothelioma in the pleura and peritoneum
Gynaecology	Endometrium
	Ovary, fallopian tube & primary peritoneal site
	Cervix
Skin	Invasive melanoma

5.2   Website

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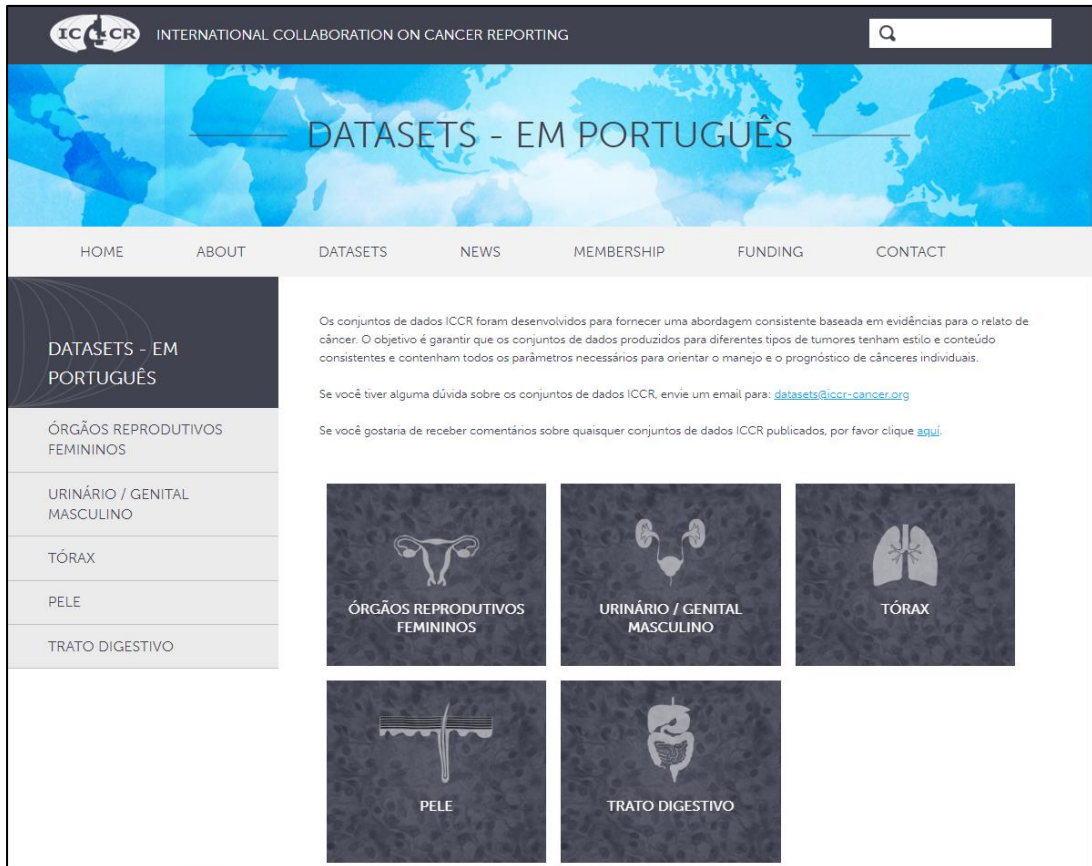
New pages will be added as needed in the future.

6. IMPLEMENTATION

6.1 Implementation – Memoranda of understanding

There has been a significant increase in requests from Laboratory System and middleware vendors and jurisdictions wanting to implement the ICCR datasets. This has prompted detailed discussions on copyright of the ICCR datasets and the level of commercial development ICCR feels is appropriate. Draft memoranda of understanding (MoU) have been developed and are undergoing legal review through the kind assistance of the RCPA.

6.2 Copyright

The draft MoU with Laboratory Information System (LIS) vendors was sent for legal review, which highlighted an issue with the copyright that ICCR currently obtains from its DAC's. Copyright in the datasets resides with the DAC members. The copyright permission letter which each member is asked to sign gave the ICCR a broad range of authority to adapt, edit, modify and published the datasets which was sufficient for activities up to date however, it dd not allow for the ICCR to sublicense the materials which is what will be required for implementation of ICCR datasets by LIS or other organisations. Therefore, a revised letter was drafted and submitted for BoD approval in October 2020. It is now being used for current and future DACs and for some of the recently published datasets which align to the 5th edition of the WHO Classification of Tumours.

6.3 ICCR Standardised Electronic Datasets (ISED)

In order to promote consistent presentation and conformance with the ICCR datasets as well as to facilitate interoperability, electronic representations for each reporting dataset are required.

These representations can be electronically installed within a LIS reducing the manual interpretation and programming that would otherwise be required to implement from a paper dataset. This effectively standardises the implementation across different LIS and makes updating of the datasets a much simpler and more efficient process.

The CAP has successfully created electronic Cancer Checklists (eCC) from their published paper datasets, for distribution to LIS, for many years.

The ICCR is investigating the various avenues available to develop electronic representations of ICCR datasets termed "ICCR Standardised Electronic Datasets (ISED)".

ISED would need to be made accessible to LIS vendors and both the format of this delivery ie file format, and the legal requirements for LIS vendor access need to be considered.

6.4 Structured Reporting for Anatomical Pathology (SRAP)

In order 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, that are currently incapable of electronic structured reporting, are gradually being replaced as they are upgraded, as the importance of structured reporting of cancer is recognised. In this case, the availability of an electronic representation of ICCR datasets 'ISED' is all that is needed to ensure accurate and reliable reporting according to the ICCR standard.

However, in many parts of the world 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. Therefore, ICCR is looking at options to provide a low-cost structured reporting solution for LMIC.

There is enormous interest in rolling out this type of tool for particular problem areas such as cervical cancer in South America and Africa, where the capture of essential data is vital to providing the information necessary for cancer monitoring and management and planning of services. Such a tool would also provide a foundation for educational opportunities through organisations such as American Society of Clinical Pathology (ASCP) and International Gynecolgical Cancer Society (IGCS).

The goal would be to maximise the functionality for our low middle income countries with the minimum of resource requirement and cost.

In late 2019 and early 2020, ICCR worked with IBM, ASCP and INCAN (Paraguay) on the development of a prototype for the Structured Reporting for Anatomical Pathology (SRAP). The web-based application was developed and piloted in Paraguay in February 2020. While it has some very useful functionality (such as being able to work offline) the prototype would require additional functionality before it could be rolled out further. The significant amount of work involved would require programming as well as pathology expertise and quality assurance resources. It would also require ongoing resources for maintenance and support once rolled out, as well as some means of easy update, such as ISED to ensure currency.

An alternate option is for ICCR to enter into an agreement with a third party vendor who have a well-developed and commercially robust, web-based structured reporting application. This type of application would be a purpose-built tool and therefore may be expected to cater for all of the required functionality ICCR would expect.
The benefit is the availability of a well developed tool with technical expertise and support available. The unknown issues relate to cost and long term reliance on a third party.

Further investigation of the various options will continue into 2021.

6.5   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, LVI, Lymphovascular invasion, Lymph-vascular invasion. Different languages add another layer of complexity. Coding of elements such as Lymphovascular invasion and response values such as 'not identified' or 'present' with standard clinician terms such as SNOMED CT reduces the variation and allows for advanced computer searches and interoperability.

6.5.1   SNOMED CT

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 Dr Scott Campbell from University of Nebraska Medical Center (UNMC), USA, under the auspice 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 ICCR was very keen to participate and a collaborative relationship with the UNMC team commenced. The ICCR and the Cancer Synoptic Working Group (a working group stemming from the IPaLM SIG), agreed to collaborate in an ongoing manner to ensure terminology is developed for cancer reporting such that it meets the needs of the clinical care teams, national registrars and cancer researchers. 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.

In 2020, the project to assign SNOMED CT terminology to the ICCR's Radical Prostatectomy dataset was published and further projects are planned.

6.5.2   I-codes

As the development of SNOMED CT terminology for cancer checklists will take many years, the ICCR is considering the development of a set of interim codes to assist those implementing ICCR datasets in the meantime.

6.6   Structured Reporting Implementation Committee (SRIC)

With the increasing global interest in implementing ICCR datasets the various technical aspects noted above need to be worked through in detail. This has prompted the convening of a new committee the SRIC whose purpose is to provide guidance to the BoD on matters relating to the implementation of ICCR cancer datasets and advance 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 has accepted the position of chair SRIC. Professor Birdsong has previously chaired the CAP Pathology Electronic Reporting Taskforce (PERT) for many years and brings a lot of experience to the ICCR. Membership of the SRIC is currently being considered.

7. FINANCIAL REPORT

A revised budget based on the Australian Financial Year – July 1st to June 30th was proposed and accepted at the 29th January 2020 Board of Directors meeting.

7.1   Income

Income received to the end of the 2019-20 FY was $148, 683 AUD.

Income is derived from:

1.   Foundation member fees, and

2.   Sponsorship.

7.2   Expenditure

Planned expenditure for the 2019-20 FY was $226,275 AUD. Actual expenditure was $210,484 AUD

Items of expenditure are:

Category	Item
Business costs	Insurances
	Auditor
	Bank fees
Meetings	Teleconference/web meetings
	ICCR DSC face to face meetings*
	Project Manager meetings/update
	Travel to international meetings
Promotion & communication	Web services
	Promotional flier
	Domain specific email
	Domain name registration
	Business cards
Staffing	Project Managers
	Project Management Officer
	Equipment/expenses
Dataset development	Software
	Medical Illustrator
	Copyright fees
	Open access for publications
Miscellaneous	Stakeholder database rework

* Note, this item includes no travel related fees, it relates to costs for room and equipment hire etc for the meetings.

7.3 Sponsorship

In addition to membership fees, the ICCR looks for sponsorship to help support the cost of development of datasets. Singapore General Hospital has very kindly provided $5,000USD sponsorship as well as the International Society of Breast Pathology (ISBP) $2,000 USD for the Breast datasets; and the International Society of Gynaecological Pathology (ISGyP) $6,000USD for the Gynaecological datasets.

7.4 Audited financial statement

The ICCR financial status is audited yearly. A fully audited financial statement has been prepared and was discussed at the Annual General Meeting held 24th and 25th November.

8. STAFFING

The ICCR has adopted a dataset development model based on the involvement of a Project Manager.

Although it is possible for pathologists to produce datasets without the input of a Project Manager, the involvement of an ICCR Project Manager streamlines and standardizes the dataset development process, reduces individual pathologists' time and effort, expedites the development timeline and ensures implementation of, and adherence to, ICCR standards.

The process of dataset development involves a number of activities which can be divided broadly into two categories:

a. Administrative activities, including meeting organization, agendas and meeting notes, collation of feedback, stakeholder database management, referencing, formatting of documents, email notifications etc., and

b. Stakeholder/content management including the development and review of draft dataset documents, timeframe management, harmonization of terms and content, guide development, identification and tracking of issues, reporting to DSC, stakeholder correspondence/support of expert panels etc.

8.1   Project Manager

Project Managers undertake stakeholder/content management. The ICCR employs two Project Managers on a contract basis:

1. Ms Fleur Webster started work in February 2015 and is employed on contract via the RCPA for 26.25 hours (~3.5 days) per week, to support dataset development. Ms Webster works from her home office in Albury, Australia. Ms Webster's current contract concludes in December 2020. It is anticipated that her contract will be extended.

2. Ms Meagan Judge, whilst working for the RCPA, provided services to the ICCR on a volunteer basis from 2010 - 18. From January 2019, Ms Judge has been employed 15 hours (~2 days) per week, on contract via the RCPA, providing operational support for the BoD and DSC. Ms Judge works from her home office in Sussex Inlet, Australia. Ms Judge's current contract concludes in December 2020. It is anticipated that her contract will be extended.

Additional Project Manager services continue to be provided by member organisations to supplement these contributions.

8.2   Project Management Officer (PMO)

A Project Management Officer undertakes administrative activities.

The ICCR employs 1 PMO on a casual basis, 15 hours (across 3 days) per week under the supervision of Ms Webster. Ms Gina Green started work in September 2017 and is employed under a casual contract basis via the RCPA for 15 hours (~2 days) per week. Ms Green works from her home office in Sydney, Australia.

8.3   Human Resources Support

The RCPA provides the human resources infrastructure under which Ms Webster, Ms Judge and Ms Green are employed and invoice the ICCR quarterly for their salaries. The RCPA does not charge the ICCR for this administrative service.

9. WEBSITE

The ICCR launched its website, www.iccr-cancer.org, in July 2015.

A summary of progress is included below.

Year	Users	Sessions*	Pageviews**	Countries	Top 10 users by country
2016	4,965	6,951	23,442	116	Russia, Australia, US, Brazil, UK, India, Canada, Japan, Spain, Germany
2017	7,346	10,898	37,127	134	US, Russia, Australia, UK, India, Canada, Germany, Spain, Italy, Brazil
2018	9,814	15,135	53,425	155	US, India, Australia, UK, Canada, France, Brazil, Italy, Germany, Spain
2019	17,584	23,554	80,530	177	US, India, Brazil, Australia, UK, France, Spain, Canada, Germany, Italy
2020	23,270	31,895	109,131	187	US, India, Brazil, UK, Australia, France, Spain, Germany, Canada, Japan

*A session is the period time a user is actively engaged with the website.
**Pageviews is the total number of pages viewed. Repeated views of a single page are counted.

Top pages utilised in the last 12 months:

- female-reproductive-organs,
- urinary-male-genital, and
- datasets-under-consultation.

The ICCR continues to monitor these statistics to enable it to ensure its continued usefulness to the global audience.

Consideration will be given to registering users (gratis) to enable better engagement with users worldwide, and to provide better metrics regarding dataset utilisation.