

## CONTENTS

Section		Page
1.0	Purpose	2
2.0	Definitions	2
3.0	Organizations affected	2
4.0	Background of the organization	2
5.0	Mission, vision and values	3
6.0	Structure and governance	4
7.0	ICRP meetings	6
8.0	Financial structure	9
9.0	Visual identity guidelines and publications	12
10.0	Intellectual property rights	13
11.0	Termination/cancellation policy	13
12.0	Membership policy	13
13.0	Web site, database and privacy policy	17
14.0	Data access, analysis and reporting policy	22
15.0	Data quality policy	27
16.0	Committee, operations and work group remits	29

## 1.0 – PURPOSE

This document provides an overview of the International Cancer Research Partnership’s (ICRP) policies and procedures and details of specific policies. This is a working document, and some areas of the policies are still under development [highlighted in yellow]. All Partners will be notified of changes or updates to any area of the policy (and given the opportunity to highlight potential issues) and all Partners will be consulted before implementing any changes that impact on Partners’ responsibilities. Similarly, prospective Partners will be notified of any changes occurring during their application(s).

## 2.0 – DEFINITIONS

Please note that Canadian English conventions are used throughout this document

Common Scientific Outline (CSO)	A system of classifying cancer research into 7 broad categories and a series of sub-categories
Finance Operations Group (FOG)	Committee overseeing the finances of the ICRP
International Cancer Research Partnership (ICRP or “the Partnership”)	A group of organizations actively engaged in joint activities and adhering to the Policies and Procedures of the ICRP
Partner organization	An individual funding organization that is a member of ICRP, or a group of funding organizations that have joined as a single Partner (e.g. national groups of funding organizations)

## 3.0 – ORGANIZATIONS AFFECTED

- All Partners
- New or Potential Partners

## 4.0 – BACKGROUND OF THE ORGANIZATION

The International Cancer Research Partnership (ICRP)<sup>1</sup>, was formed in 2000. Under the leadership of the United States (US) National Cancer Institute (NCI) and the Congressionally Directed Medical Research Program of the US Department of Defense (CDMRP), a group of 7 US and 2 UK

---

<sup>1</sup> Formerly the CSO Partners

organizations<sup>2</sup> was invited to develop and apply a common categorization – the CSO – for discussing, comparing and presenting their cancer research portfolios. The CSO, a classification system organized around seven broad areas of science, along with a standard cancer type coding scheme provided the tools needed to lay the groundwork for collective portfolio analyses and is designed to enable coordinated strategic planning among the Partner organizations.

Recognizing the need for a database to store common award information from multiple organizations and for a public face to showcase ICRP, the Partners commissioned external contractors to develop and launch a web site including a database to display their combined portfolio. Launched in Summer 2003, this allowed both Partners and the public to view grant-level information about current international cancer research funding online for the first time. Funding amount and CSO/cancer type percentage relevance data for each grant were not included. A number of committees were also initiated to develop the activities of the Partnership, particularly in the areas of research evaluation and outcomes and in producing a data analysis.

Since 2003, the Partnership has expanded steadily, gaining organizations in Canada, the US, UK and in Europe and now comprises 21 Partners, representing over 120 funding organizations<sup>3</sup>. The Partners have also created the role of Operations Manager to manage and administer their activities.

In 2010, the Partners migrated oversight of their web site and data to the NCI and began a redesign to allow for improved functionality for the web site and the database. For the first time, in 2011, ICRP organizations are able to conduct their own analyses of the ICRP portfolio to help inform their internal strategic planning.

## 5.0 – MISSION, VISION AND VALUES

### 5.1 MISSION

The Partnership's MISSION is to add value to cancer research efforts internationally by fostering collaboration and strategic co-ordination between cancer research organizations

### 5.2 VISION

The Partnership's VISION is that all funders of cancer research collaborate to enhance the

---

<sup>2</sup> American Cancer Society (US), California Breast Cancer Research Program (US), California Cancer Research Program (US), Cancer Research Campaign (UK), Congressionally Directed Medical Research Program of the US Department of Defense (US), Medical Research Council (UK), National Cancer Institute (US), Oncology Nursing Society (US), Susan G. Komen Breast Cancer Foundation (US).

<sup>3</sup> Correct as of 26 March 2018

impact of research on individuals affected by cancer

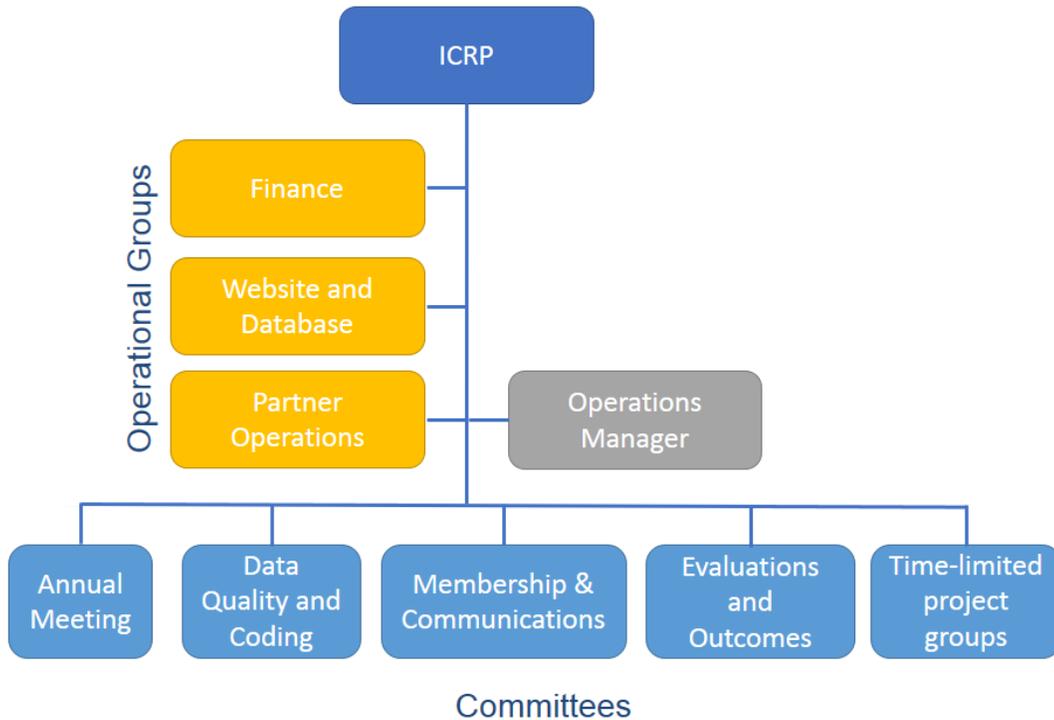
### 5.3 VALUES

The Partnership is founded on principles of commitment to the ICRP mission and equality of representation. The membership fees and structure of the Partnership are designed to ensure as far as possible, that all eligible organizations can participate in, contribute to and benefit from the Partnership.

## 6.0 – STRUCTURE AND GOVERNANCE

### 6.1 - ORGANIZATIONAL STRUCTURE

The ICRP is a partnership of cancer research organizations from around the world, united in a common mission. The ICRP’s administrative structure is made up of the Fiscal Sponsor, Web site & Data Hosting, Internal Communications, Secretariat Services (provided as in-kind contributions by Partners), and the Operations Manager. ICRP’s activities are distributed between Committees, Operational Groups and time-limited projects run by workgroups. Operational Groups are related to the day to day operation of ICRP and a component may be provided as an in-kind contribution from Partners, Committees are charged with developing and over-seeing specific areas of ICRP activity and time-limited Work groups are project-specific:



## **6.2 – ICRP CHAIR AND VICE-CHAIR**

The purpose of the Chair is to establish call agendas, facilitate and preside over monthly teleconference and annual meetings and to act as a representative and spokesperson for ICRP when required. The Chair of ICRP is distinct from the host of the annual meeting to ensure that the ICRP workload is balanced. Election of a Vice-Chair ensures continuity and effective transition of the Chair, and representation in the absence of the Chair. The office of Chair and Vice-Chair rotates among Partner organizations. The Chair serves for 2 calendar years, at which point he/she is succeeded by the Vice-Chair and a new Vice-Chair is appointed.

Although the office is expected to rotate among Partner organizations, Partners are requested to indicate their willingness to serve as Chair/Vice-Chair. In the event that there are multiple organizations volunteering, the Operations Manager will consult with the relevant organizations to establish a rota. If this is not possible, the organizations receiving the largest number of votes at a teleconference or annual meeting for which a quorum exists, will be elected. In the event that a Chair resigns before the end of the term, the Vice-Chair will assume the role and a new Vice-Chair will be elected. No individual from the same organization may serve as Chair for consecutive terms.

## **6.3 – OPERATIONS MANAGER**

The Operations Manager is appointed on contract, and repaid for hours worked and allowable operational expenses incurred. No benefits are paid.

### **6.3.1 - Roles & Responsibilities**

1. Preparing an overall workplan for ICRP following each annual meeting. This will involve recording all the workstreams agreed upon, people responsible, actions and timelines and will provide the basis for in-year monitoring and tracking.
2. Participating in individual workstreams as required or reminding others to fulfill their agreed upon actions; ensuring coordination and avoiding duplication across work streams.
3. Participating in the Partnership's monthly teleconferences, ensuring that all Partners are kept up-to-date with all activities, and that issues requiring collective resolution or decision are brought to the Partners in a timely manner.
4. Participating in Committee and workgroup meetings to maintain oversight of projects and overall work plans
5. Overseeing the record archives (all ICRP documents, including the CSO and disease site documents, meeting minutes, etc.); ensuring that archives are kept up to date and materials are readily retrievable when needed.
6. Assisting in the development of the private area of the ICRP web site as space for Partners to share information and experiences.
7. Preparing and arranging publication of documents (information packets for new Partners, reports, etc.).
8. Working with Partners on the proactive recruitment of new members, briefing new members on ICRP and its benefits.
9. Mentoring new members and arranging training/seminars on use of the CSO.

10. Conducting analyses on the ICRP database.
11. Monitoring finances and legal documents, including periodic invoicing for annual dues/contributions; requesting the issuing of payments as required by the Partnership. Coordinating the annual audit of Partners' finances by an independent agency.
12. Administering/managing contracts, including preparing RFPs and solicitations; coordinating evaluations and submittal to the Partners, life-cycle management, and closeout/termination.

### **6.3.2 - Operations Manager – Hiring Process**

The post of Operations Manager is advertised publicly through the ICRP and other suitable scientific recruitment networks (e.g. LinkedIn). Applications are received by the Partner Operations Committee, which conducts an initial screen of the candidates. After this, two committee members conduct a telephone interview. If, due to a conflict of interest, no two committee members are suitable, members outside the subcommittee are called upon to conduct the interview. The Partner Operations Committee makes its recommendation to the Partners at the next available teleconference and is charged with informing applicants of the outcome of their applications.

### **6.3.3 - Operations Manager – Contracting Issues and Performance Review**

The Operations Manager position is a 6 month to 1-year contract term with additional year(s) available as options. The Partner Operations Committee is responsible for establishing objectives and targets, and overseeing the work of the Operations Manager. Performance review will be conducted at least 1 month before the end of the contract term.

## **7.0 – ICRP MEETINGS**

Regular meetings are critical in driving forward the Partners' activities, maintaining an active network and disseminating information relevant to cancer research co-ordination. An overview of the purpose and mode of operation of the meetings and committees are given below. Terms of reference for the operation of the annual meeting, teleconferences and committee meetings are listed separately.

### **7.1– ANNUAL MEETING**

The purpose of the annual meeting is to review strategy, to agree to new policies and to allow face to face networking between Partners. At least one representative from each Partner organization is expected to attend the Annual Meeting.

The annual meeting is hosted by Partners on a rotational basis. The financial contributions of the Partners ensure that the costs of annual meetings are borne by the Partnership (with the exception of travel and accommodation costs for attendees), allowing each Partner the option

to host.

The annual meeting has three parts:

- 7.1.1. An open session, which is open to prospective members, organizations that are part of multiple-partner organizations like NCRI and CCRA, and others as required given the agenda and/or priorities of the Partnership
- 7.1.2 A business meeting, which is attended by all the partner representatives
- 7.1.3 A group dinner, which is also an open event

Other events may be organized and sponsored by the hosting organization. The order of the sessions noted above is determined by the meeting host and may vary from year to year.

#### **7.1.4 Attendance at annual meetings:**

The designated ICRP contact named on the application form, or their nominated representative should attend the annual meeting and teleconferences on behalf of the Partner organization. However, the Partners recognize that others within Partner organizations bring added value to the Partnership, especially in larger organizations where ICRP-related activities are devolved to different individuals.

Annual meetings provide an important opportunity to learn about each Partner organization, learn about new initiatives and cancer research trends, network and conduct the business of the partnership.

Because one of the core values of the Partnership is equity across Partner organizations regardless of size and because participant numbers drive meeting costs, the number of representatives from each organization attending the annual meeting may be limited. Regardless of the number of attendees, each Partner is allotted only one vote.

Any ICRP representatives may participate in the ICRP Committees or Work Groups and membership of Committees or Work Groups is not limited to those attending the Annual Meeting. The principle of one Partner, one vote must, however, be maintained at Committees, Operational Groups and full ICRP teleconferences and meetings.

Additional representatives (e.g. speakers covering a specific ICRP interest, external contractors) may be required from time to time, but this should be agreed in advance with the Annual Meeting Committee. Supplementary meeting charges may be levied for additional representatives unless it is agreed by the Partners that their costs should be covered.

Where a Partner organization hosting the meeting represents multiple funding organizations, one representative of each of these will be invited to attend the meeting, with the attendance costs to be borne by ICRP. Travel and accommodation costs must be borne by the individual organizations.

## **7.2 PARTNER TELECONFERENCES**

Full Partner teleconferences are scheduled monthly to allow the Partners to maintain the momentum generated by the Annual Meeting and to review actions and projects regularly. The quorum is a majority of Partners and a monthly teleconference may be cancelled if attendance on the call does not make quorum. For more information, see section 8.4.

## **7.3 COMMITTEE AND WORK GROUP MEETINGS**

ICRP maintains a number of long-standing Committees and Operational Groups and time-limited Work Groups to manage and review specific ICRP functions or projects. The current Committees and Operational Groups are listed below and full terms of reference are listed separately under Section 18.

### Committees

- 7.3.1 – Partner Operations
- 7.3.2 – Data, including Data Quality Group
- 7.3.3 – Membership and Communications
- 7.3.4 – Evaluation and Outcomes
- 7.3.6 – Annual Meeting

### Operational Groups

- 7.3.6 – Web site and Database
- 7.3.7 – Finance
- 7.3.8 – Partner Operations

Committee and Operational Group meetings are normally by teleconference, and the schedule is governed by the nature of the business. However, the Committees will meet at minimum twice a year and will report back to the Partners at teleconferences, where appropriate, and at the annual meeting.

Time-limited workgroups are set up to implement a specific project. Initiating a workgroup involves defining the membership, scope, milestones and deliverables of the workgroup at the outset in a common template. During the lifetime of the project, the workgroup will be expected to report on progress at teleconferences and to present a final report at the annual meeting.

## **7.4 MEETING VOTING AND DECISION-MAKING PROCEDURES**

At all meetings of the ICRP, whether annual, monthly teleconference, committee or work group, voting on agenda items may only occur if there is a quorum. A quorum is defined as the majority of the Partners (either attending in person, or through a nominated representative or voting by proxy through the Operations Manager/Chair) for annual and monthly

teleconferences, Committee or Workgroup meetings.

### **Approvals & Decisions**

A distinction is drawn between approval of minutes and decision-making. Minutes of meetings must be approved by the majority of those present on the call or at the meeting.

Decisions on partnership business will be reached, where possible, by consensus. Where this is not possible, decisions will require the vote of two-thirds of the members to be approved (except where the decisions involve individual Partners' data, in which case the Data Access Policy rules [Section 14.0] will apply). Individual Partner organizations have one vote. Votes on ICRP decisions can also take place by email, provided that 10 days' notice of the vote is given to all members. As at meetings, decisions will require the vote of two-thirds of the members to gain approval.

The principle of one Partner, one vote must be maintained at all teleconferences.

## **7.5 MEETING MINUTES, ACTION ITEMS AND OTHER DOCUMENTATION**

Documentation for all types of ICRP meetings must be maintained by the meeting chairs and posted to the ICRP member site according to the filing conventions established by the Operations Manager. The documentation archive is an important priority for ICRP and it is the responsibility of all members to ensure that information is posted in a timely and complete way.

## **8.0 – FINANCIAL STRUCTURE**

### **8.1 – OVERVIEW**

Individual Partners contribute to the Partnership in-kind, or according to an annual membership fee structure<sup>4</sup>. In-kind contributions are primarily, but not exclusively, focused on web site/database hosting, internal communications and fiscal sponsorship. The membership fees are used to fund the cost of the Annual Meeting, the Operations Manager and specific initiatives in line with the ICRP Strategic Plan. The ICRP Finance Operations Group monitors all aspects of the Partnership's finances.

### **8.2 – FISCAL SPONSOR**

Fiscal sponsorship for the ICRP is provided by the Canadian Partnership Against Cancer (CPAC). This includes banking, financial reporting and audit. The ICRP fiscal year runs from 1 April to 31 March.

---

<sup>4</sup> See Membership Application Pack for the current membership tier structure

## **8.3 – BUDGETARY PRINCIPLES**

### **8.3.1 – Operational budget**

The Partners' operational budget covers the cost of Annual Meetings for the hosting organization (see 8.3.5 for details of what is covered), an Operations Manager working on contract, and specific initiatives.

### **8.3.2 – Reserve and surplus**

The Partnership agreed to maintain an annual reserve of approximately \$100,000 (US Dollars) for the purpose of winding down operations over a period of 6 months to 1 year. The Finance Operations Group monitors the financial account and presents three-year projections to the Partners at the annual meeting. Income over and above reserve is held for the purpose of supporting website maintenance and enhancements once NCI's in-kind contribution is reduced. Once non-NCI data upload and website maintenance/enhancement costs are migrated to the ICRP, the Partners, through the Finance Operations Group, monitor income/expenditure, and recommend options to reduce any surplus to \$0 either through reduction of Partner contributions or funding strategic initiatives. The operational and website reserve may be affected by fluctuations in exchange rates, acquisition of new Partners, or under-spend on operational activities.

### **8.3.3 – Membership Fee Structure**

(a) Membership fees: The Partners' membership fee structure provides 6 levels of membership fee, from \$500 (US Dollars, for organizations whose annual research expenditure is under \$5 million USD or equivalent) to \$25,000 (US Dollars for organizations whose annual research expenditure is over \$500 million or equivalent). ICRP aims to ensure affordability for all organizations. New organizations are allocated to a Membership fee tier at the time of application, according to their research spend for the preceding fiscal year, as quoted in the membership application pack. The US dollar equivalent is calculated according to exchange rate valid on the date of the application and used to calculate the relevant Membership fee tier. Membership fees are payable in US dollars.

(b) In-kind contributions: In exceptional circumstances, some Partners may be precluded from making annual contributions to the Partnership, e.g. US government Partners. Existing Partners contribute at or above their membership fee structure level by making in-kind contributions to the Partnership. The levels of these contributions are monitored by the Finance Operations Group. It is recognized that Partners contributing in-kind may contribute at or above the tier relevant for their organizations and downward adjustments to the Membership Fee structure may also require Partners contributing in-kind to consider a commensurate reduction in their in-kind contribution, if feasible. Potential partners wishing to contribute in-kind at or above their Membership fee tier must first discuss this with the Operations Manager. The Partners will

decide if the proposed contribution is in the interest of the Partnership.

#### **8.3.4 – Funding for Strategic mission initiatives**

From time to time, the Partners may agree expenditures for strategic mission initiatives. Such initiatives must be approved by a 2/3 (two thirds) majority vote of all Partners.

#### **8.3.5 – Annual Meeting Costs**

ICRP includes the cost of annual meetings in its central budget to enable all member organizations to host the annual meeting. The budget for the annual meeting is set in advance and monitored by the Finance Operations Group. Host Partners should liaise closely with the Group to ensure that their expenditure is within budget. In general, allowable costs for the annual meeting from the central ICRP budget are:

- (a) Venue hire for up to 3 days
- (b) Audio-visual and teleconference equipment rental
- (c) Catering costs (Breakfast and lunches on the days of the annual meeting, Partner dinner excluding alcoholic beverages)
- (d) Meeting materials (Name tags, handouts etc)
- (e) Travel/accommodation expenses and honoraria/small gifts for guest speakers

The host organization is responsible for providing copies of all relevant invoices to Finance Operations Group.

Meeting costs may be deducted from the host organization's annual membership fee. If the agreed maximum meeting costs exceed the host organization's annual membership fee, the Finance Operations Group will discuss reimbursement with the host organization, either through direct reimbursement or credit against future membership dues.

### **8.4 – INVOICING**

New Partners are invoiced at one of two fixed points: July 1<sup>st</sup> if the membership application is approved in calendar year before July 1<sup>st</sup>, or Jan 1<sup>st</sup> if the membership application is approved on or after July 1<sup>st</sup>. Existing Partners will continue to be invoiced at the July or January point as previously requested. The two point invoicing method maintains ease of administration whilst providing some flexibility for organizations to select a suitable application point to fit with their fiscal years.

The Chair of the FOG liaises with the Operations Manager to coordinate the invoice process. Letters are sent by email to partners on the January/July 1<sup>st</sup> date, with the requirement for a net 30 day payment. Payment is requested to be made by bank transfer to the Canadian Partnership Against Cancer:

SWIFT code: BOFMCAM2

CPAC account number: 1532655

Branch number: 0002

Financial institution number: 001

Account Name: Canadian Partnership Against Cancer

Bank: Bank of Montreal

Bank Address: 100 King Street West, Mezzanine level, Toronto, Ontario M5X 1A3, CANADA

The following information must be included with the Wire Transfer to ensure that the money is deposited in the correct account:

- 1) Please indicate: Canadian Partnership Against Cancer – Re: ICRP
- 2) Partnership Contact person and telephone number: Kamran Ali [416-915-9222 x 5816]
- 3) The purpose of the payment: ICRP Annual Contribution Fee

### **8.5 – FINANCIAL REPORTING AND AUDIT**

The Finance Operations Group (FOG) shall supervise the financial activities of the ICRP. Specifically, the Group shall see that (a) full and accurate accounts of receipts and disbursements are kept, (b) a system is in place such that all monies and other valuable effects are deposited in the name and to the credit of the ICRP in such depositories as shall be designated by the FOG, (c) the Partners at the annual meetings of the Board, receive an account of the financial condition of the ICRP, and (d) an annual audit of the ICRP's books and records is performed by an auditor appointed by the Fiscal Sponsor. The FOG shall also perform such other duties as may be prescribed by the Partners. In performing these functions, the FOG may rely on employees of the ICRP or any affiliated organizations who possess special financial training and skills and whose employment responsibilities include management of the ICRP's financial affairs. In the absence or disability of the Chair of the FOG, the Vice-Chair, if any, shall perform all the duties of the Chair and when so acting shall have all of the powers of and be subject to all of the restrictions upon the Chair.

### **8.6 – ASSOCIATED DOCUMENTS**

Invoice template

## **9.0 – VISUAL IDENTITY GUIDELINES AND PUBLICATIONS**

### **9.1 – VISUAL IDENTITY GUIDELINES**

In ICRP documents, publications and web sites visual identity guidelines have been produced (Appendix II) to maintain the look and feel of the Partnership

Name: The International Cancer Research Partnership is the agreed name of the group. This may be shortened to “ICR Partnership”, or “the Partnership” in publications. The acronym is

ICRP.

## **9.2 - PUBLICATIONS**

Publications arising from ICRP activities are the property of ICRP. Where reports are in the public domain, ICRP expects that use of the whole or extracts of these reports is acknowledged and, where possible, the Operations Manager is notified. Use of data in reports or analyses that are not in the public domain is limited to the Partners and should not be made public without the express permission of the Partnership, using the Procedures outlined in the Data Access Policy (14.1.12).

## **9.3 – ASSOCIATED DOCUMENTS**

ICRP Graphics Standards

# **10.0 – INTELLECTUAL PROPERTY RIGHTS**

ICRP and/or its Partners shall continue to own all intellectual property (IP) it/they now own and which it/they make available to the ICRP, including but not limited to the ICRP's and/or Partners' know how, inventions, plans, designs, copyrighted material, trade secrets, techniques, processes, trademarks and service marks, and all other intellectual property now owned by the ICRP and/or its Partners. All new intellectual property developed and identified by the ICRP as intellectual property shall be owned by the ICRP and each member shall have the right to use any ICRP intellectual property. IP relating to individual research awards remains the property of the funding organization or principal investigator.

# **11.0 – TERMINATION/CANCELLATION POLICY**

Termination of the ICRP Partnership may only be agreed by mutual consent at the annual meeting. Procedures for terminating individual memberships are contained in the Membership Policy (Section 12.6).

# **12.0 – MEMBERSHIP AND COMMUNICATIONS POLICY**

## **12.1 - CURRENT MEMBERSHIP**

The current membership and contact list is maintained in Appendix III, which is updated annually by the Operations Manager in preparation for the Annual Meeting. A dynamic list of members, applications in progress and potential members is maintained in the Partners' area of the ICRP web site.

## **12.2 - ELIGIBILITY**

Organizations, or groups of organizations, may join the Partnership if they satisfy the eligibility criteria. Organizations joining as a group are considered as a single Partner for the purposes of participation in the Partnership's meetings and activities. ICRP recognizes that a consortium may have its own eligibility criteria for membership and that these may not always be identical to those for ICRP. Consortium applicants will be considered to satisfy the eligibility criteria for ICRP if the majority of their funding organizations satisfy the ICRP requirements

To be eligible to join the Partnership, members must:

- (a) Have a scientific peer review system
- (b) Agree to the Partnership's mission statement
- (c) Agree to establish and maintain a system for coding research portfolios to CSO and disease-site (cancer-type) codes or use the ICRP Coding Service
- (d) Agree to post its research portfolio annually on the ICRP web site, which entails submission of research portfolio datasets to a US database
- (e) Agree to share its portfolio information with the other ICRP organizations via the Partner-only restricted access section of the ICRP web site
- (f) Agree to contribute financial support annually for the ICRP to provide administrative support for the Partnership and for portfolio analysis
- (g) Agree to sustain membership for a minimum of 3 years
- (h) Agree to abide by the Policies and Procedures of the ICRP
- (i) Nominate a contact who will participate actively in the ICRP

## **12.3 – MENTORING**

Each new Partner's application, membership, and data uploads will be managed by the Operations Manager, working with the web site and database providers. Training on the use of the CSO will also be arranged or given by the Operations Manager. From time to time, partner organizations may be well placed to provide mentoring, advice or assistance to a new partner. The Operations Manager will ensure that mentoring arrangements are limited to partners who have the available time/expertise.

## **12.4 – CONFLICT OF INTEREST**

Membership of ICRP does not preclude membership of other bodies combining national or international data. However it is the Partners' responsibility to inform ICRP of any conflict of interest with the aims or activities of the ICRP.

## **12.5 – MEMBERSHIP OF COMMITTEES/OPERATIONAL OR WORK GROUPS**

Partner organizations are expected to be actively involved in ICRP activities. ICRP designated contacts should be involved in at least one committee, operational or work group.

## **12.6 – PARTNER CANCELLATION/TERMINATION/NON-PAYMENT POLICY**

Partners may cancel their membership after the initial 3 year period. An individual Partner’s membership may also be terminated by the ICRP if the eligibility requirements are no longer satisfied, or the Partner organization does not abide by the Policies and Procedures of ICRP. Annual membership fees already paid will not be refunded.

The Chair of Finance and Operations Group should be notified in writing of any delay in or inability to pay membership dues. Non-payment of dues may result in withdrawal of partner privileges, such as suspension of access to the ICRP partner site, participation in partner calls and suspension of voting rights.

## **12.7 – APPEALS POLICY**

Partners may appeal in writing to the Operations Manager against any decision to cancel their membership. The appeal will be reviewed by the Membership Committee and a recommendation made to the full Partners. The decision of the Partners will be final.

## **12.8 – RESPONSIBILITIES**

### ICRP Membership Committee

12.8.1 – To review and update this policy

12.8.2 – To work with the Finance Operations Group to review any changes to Membership Fees

### Partner organizations:

12.8.3 – It is a Partner organization’s responsibility to inform the Operations Manager of any changes to their organization’s structure, status, or of any conflicts of interests affecting their membership

12.8.4 – Partner organizations’ representatives are responsible for informing the Operations Manager which Committee or Operational Group they would like to join, within the first year of membership.

## **12.9 – PROCEDURES**

### **12.9.1 – Reviewing the Policy**

The ICRP Membership committee will review this policy at least annually. Proposed amendments must be agreed by the full Partnership at its annual meeting or monthly teleconferences according to the general terms of reference of those meetings. The Operations Manager may propose amendments to the policy, for discussion by the Membership Committee and is tasked with implementing changes to the policy.

#### **12.9.2– Reviewing Applications for Membership**

The Operations Manager, and/or a designated mentor from the existing Partners will work with potential members prior to submitting a formal application to ensure that all eligibility criteria can be satisfied. The Membership Committee will review all applications for Membership submitted by the Operations Manager and recommend that the Partners accept/decline at the next Annual Meeting or full Partner teleconference.

#### **12.9.3 – Acceptance of applications**

ICRP will issue an acceptance letter to new organizations (see Appendix V), and a New Partner Pack. Once an organization’s application for membership has been accepted, the organization will receive passwords and access to the Partners’ area of the web site, but will not be able to use the analytic tools to interrogate the ICRP dataset until their own organization’s data has been uploaded to the database.

#### **12.9.4 – Training and Mentoring**

CSO Training will be arranged, if required, for new ICRP organizations by the Operations Manager. Mentors for new organizations will be appointed at the Annual Meeting or monthly teleconferences when the application is accepted. The Operations Manager will maintain a list of all mentors.

#### **12.9.5 – Conflict of interest**

Partners will inform the Operations Manager of any conflict of interest, and a list of conflicts of interest will be maintained.

#### **12.9.6 – Cancellation Procedures**

Partners wishing to cancel their membership after the initial 3 year period should notify the Operations Manager of their intention to cancel at least 3 months before the end of their current membership period. At the end of the Membership period their access to the Partners’ site will be removed. Partners cancelling membership should note that their archival data relating to their period of membership will continue to be maintained within the site, but will not be updated and may be omitted from subsequent analyses if it is incompatible with updates made to Member data. Partners may request removal of their data from the database when departing.

Cancellation of a Partners’ membership by ICRP must be agreed at an annual meeting or monthly full Partner teleconference. The Operations Manager will communicate the decision, and reasons for the decision, to the Partner and make arrangements for removal/archiving data.

#### **12.10 – MAILING LISTS**

ICRP will only contact individuals who previously requested to be on the ICRP mailing list, signed up to the partner site and receive mailings from ICRP. Mailings will be sent to generic (e.g., research@, info@ emails where no individuals have been identified). Mailings will include an unsubscribe option to apprise ICRP of changes to consent and the ICRP website includes an 'opt-out' option from May 2018.

#### **12.11 - ASSOCIATED DOCUMENTS**

Membership database  
Membership Guide & Application Form  
Acceptance Letter  
New Partner Pack

## **13.0 – WEB SITE, DATABASE AND PRIVACY POLICY**

### **13.1 – DATABASE OPERATION, CONFIDENTIALITY AND SECURITY**

The US National Cancer Institute (NCI) hosts the ICRP database and web site as an in-kind contribution to the ICRP through its contractor. This includes:

#### **13.1.1 – ICRP web site**

Public section of the web site, including a database with defined search interface for use by the wider cancer community

#### **13.1.2 – ICRP Partners web site**

Partners' section of the web site, including analytical tools for Partners to conduct analyses of their own and others' data under the terms of the Data Access, Analysis and Reporting Policy, and defined functionality to manage the workflow, documents and resources of the Partners

#### **13.1.3 – Host's responsibilities**

The host will ensure that all reasonable measures are in place to prevent unauthorized access to or download of the data on the Partners' area of the web site, particularly financial and site-relevance data and to ensure that such data is only accessible to representatives of the Partner organizations who have agreed to share data. ICRP's policies on web page privacy, information quality and security controls are governed by those of the host. Details of these policies can be obtained from the contractor via the ICRP operations manager. General US federal policies for websites can be found at:

- <https://www.whitehouse.gov/sites/whitehouse.gov/files/omb/memoranda/2005/m05-04.pdf>

- [https://iapp.org/media/pdf/resource\\_center/a130revised.pdf](https://iapp.org/media/pdf/resource_center/a130revised.pdf)

#### **13.1.4 – Privacy policy**

ICRP's policies have been reviewed in the light of the EU General Data Protection Regulations (GDPR, active May 2018). Language has been amended accordingly on the ICRP website. ICRP will only contact individuals who have requested to be on the ICRP mailing list and receive mailings from ICRP. Mailings include an unsubscribe option to apprise ICRP of changes to consent. Users who wish to be removed from mailing lists can also contact the Operations Manager ([operations@icrpartnership.org](mailto:operations@icrpartnership.org)) or change preferences via the ICRP website's 'opt-out' option (from May 2018). We collect personal information provided (name, email) for the purpose of mailings. These are not shared with any third parties and are retained for as long as necessary to provide requested services such as mailings. Research funding organizations' business addresses are retained for display on the ICRP map.

### **13.2 – DATA UPLOADS**

#### **13.2.1 – Annual Data Uploads**

Each Partner agrees, as a condition of membership, to upload portfolio data annually to the ICRP database, to be held on US National Cancer Institute's contractor's servers. It is the responsibility of each Partner to ensure that data are submitted in the format specified in the data template and that the data are suitable for inclusion in the ICRP, and that permission has been obtained for any public domain data. It is the responsibility of the Partner organization to ensure that any necessary permission for publication of the data to a public web site has been obtained, in accordance with regional regulations on data processing and publication.

#### **13.2.2 – New Partners' Uploads**

New Partners will be mentored through the first data uploads by the Operations Manager, and/or their ICRP mentor organization. Access to the analytic tools on the Partners' site is contingent on uploading data to the site.

#### **Coding:**

Each Partner is responsible for informing the Operations Manager of their data coding policy and maintaining minimum coding standards as outlined in the Data Quality Policy (Section 15) or agreeing to use of the ICRP Coding Service (automated coding with manual checks)".

### **13.3 – DATA INTEGRITY**

The ICRP system generates error reports during data uploads to identify issues that need to be rectified to ensure successful inclusion of award information in the database. The Operations Manager will identify residual issues and propose resolutions or notify the Partners of unresolved issues.

Any changes to the data template will be discussed and proposed by the Data Committee for consideration by the Partners. Changes can only be made with the full agreement of all Partners. Changes affecting analysis will only be applied prospectively to a specific annual portfolio and will not be applied retrospectively to existing data

#### **13.4 – DATA OWNERSHIP**

Each Partner retains ownership rights to the data submitted to the ICRP database. Joint analyses using aggregate Partners' data are the property of the ICRP. Further details on the use of Partners' data are covered in the Data Access, Analysis and Reporting Policy. Partners or individual researchers covered by regional data protection regulations (e.g., GDPR) have the right to request to have data removed from the site. Please note that aggregated data previously used in analyses and reports will not be updated to take account of individual data elements removed.

#### **13.5 – MAINTAINING PARTNER INFORMATION ON THE WEB SITE**

Each Partner is responsible for informing the Operations Manager of any changes to the information held about their organization on the ICRP web site (e.g. Logo, web address, short description). The Operations Manager will arrange to make any amendments to the web site.

#### **13.6 – ACCESS TO THE PARTNERS' SECTION OF THE WEB SITE**

Use of the partner's site is restricted to Partner Organizations and access is provided to individuals utilizing secure log-in information. Partner organizations may designate multiple individuals to access the Partner site, provided that those individuals are made aware of the terms and conditions of use of the site (see 14.7).

#### **13.7 – USE OF THE PARTNERS' SITE – ANALYTICAL TOOLS**

Until a new Partner's data is uploaded to the ICRP database, the Partner will be able to access only the networking tools and other resources on the Partner-only section of the ICRP web site. Once their organization's data is uploaded to the database, new Partners will gain access to the analytic tools provided on the web site.

Partners must ensure that individuals within each organization who are provided access to the Partners' area are aware of and abide by the Data Access, Analysis and Reporting Policy. Failure to adhere to these policies will result in restriction of web site access. The ICRP will monitor usage of the analytical tools on the Partner-only section of the ICRP web site. Excel data downloads by users will be monitored to allow follow-up for data disposal and to ensure that the excel download tools are not used inappropriately. Data extract requests will be logged, and a scheduled task will be run each night detailing the user account, the

date and time of the extract and the number of projects extracted. The data extract request log includes a link to the row where the data selection criteria are saved. This information will be emailed to technical staff, allowing them to review and identify any suspicious data extract activity. When the staff feels a particular client is misusing the site they can disable the user account. Any data breaches or potential misuses will be reported to the partnership, via the Operations Manager, within 1 business day of the breach occurring.

### **13.8 – USE OF THE PARTNERS’ SITE – FORUM TOOLS**

Partners must use the forum tools appropriately, and only for ICRP business. The Operations Manager monitors use of the forum. A new forum category may only be initiated on request to the Operations Manager.

### **13.9 – CHANGES TO THE WEB SITE**

Amendments to content on the web site may be made where necessary, but must be agreed by all Partners if relating to common content. Changes necessitating functional changes to the web site must be agreed by the Web site and Database and by the Finance Operations Groups if a budget is required.

Changes to information relating to a single Partner may be made on request to the Operations Manager.

### **13.10 – WEB SITE AVAILABILITY AND SCHEDULED MAINTENANCE**

The ICRP aims to make the database and Partners section of the web site available at all times and across all time zones in which the Partners operate, except where downtime is scheduled for maintenance. The Operations Manager will be notified of unexpected downtime and will inform the Partners in turn.

### **13.11 - RESPONSIBILITIES**

#### **13.11.1 - ICRP Web site & Database Operational Group**

Primary responsibility for monitoring and recommending revisions to the policy

#### **13.11.2 - ICRP Data Committee**

Responsibility for informing the Web site and Database Operational Group of any changes likely to impact on this policy

#### **13.11.3 – Partners**

Provision of accurate data suitable for upload to the web site

## **13.12 - PROCEDURES**

### **13.12.1 – Policy Review**

The ICRP Data Committee will review this policy at least annually. Proposed amendments must be agreed by the full Partnership at its annual meeting or monthly teleconferences according to the general terms of reference of those meetings. The Operations Manager may propose amendments to the policy, for discussion by the Web site & Database Operational Group and is tasked with implementing changes to the policy.

### **13.12.2 – Submission of Data**

Partner organizations will ensure that data is provided on the established template, that this is completed appropriately and that the data contained therein are suitable for publication. Data templates are submitted by email and any problems will be communicated to the Partner for resolution via an error report. In the future the Partners will investigate automated uploads of data, if appropriate quality assurance mechanisms can be put in place. For new Partners submitting data for the first time, additional assistance will be provided by the Operations Manager, working with NCI and its contractors, to resolve problems.

### **13.12.3 - Changes to the web site**

Each Partner is responsible for informing the Operations Manager of any changes to the information held about their organization on the ICRP web site (e.g. logo, web address, short description). The Operations Manager will arrange to make any amendments to the web site. Similarly, general errors or amendments to the web site that are not Partner-specific should be addressed to the Operations Manager.

### **13.12.4 - Notification of web/database downtime**

The host/contractors will notify the Operations Manager of scheduled downtime to the web site for essential maintenance or upgrades. The Operations Manager will inform the Partnership. In the event of unscheduled downtime, the host/contractors will notify the Operations Manager and the nominated representative of each Partner organization by email, noting the actions which are being taken to remedy the situation.

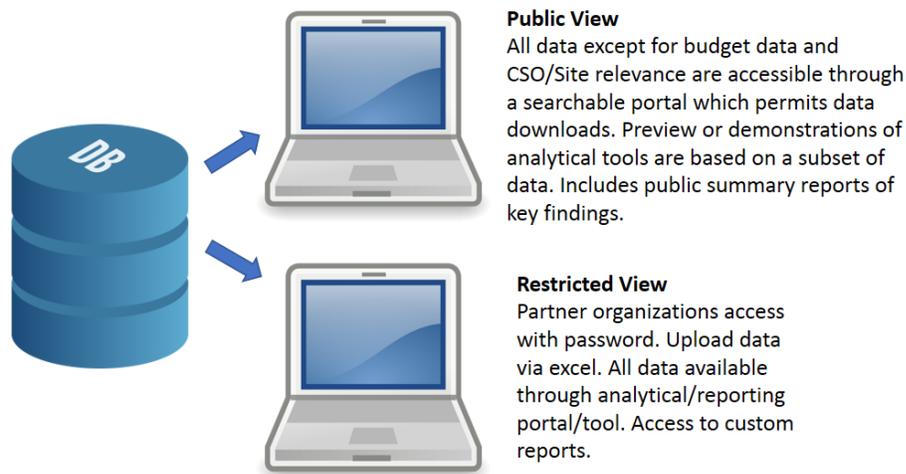
## **13.13 – ASSOCIATED DOCUMENTS**

Data Submission Workbook

## 14.0 – DATA ACCESS, ANALYSIS AND REPORTING POLICY

### 14.1 ACCESS AND INDIVIDUAL REPORTING

Figure 1 shows the channels by which ICRP data are made available.



#### **Non-Partners:**

**Definition:** Organizations that are not members of ICRP, either through individual or group membership. Within Partner organizations, only employees of the Partners (or in the absence of an employee, another individual designated to act on behalf of the Partner) are defined as Partners. Advisory groups, boards and any individuals who are not employees of the Partner organizations are defined as non-Partners.

If data is required for publication, a Data Publication Request must be considered by the partnership at the next available meeting or teleconference, or affected organizations contacted for permission by email. Grant-level data will not be released to any non-Partner organization. Requests for complex analysis that are not part of the ICRP's standard suite of reports may incur a charge, based on the Operations Manager's time. Non-profit organizations will be charged on a cost-recovery basis, an additional administrative charge may be made for commercial organizations. ICRP reserves the right to refuse data requests. Please note that:

- 14.1.1 Non-Partners may view/download data/reports made available through the public view.
- 14.1.2 Non-Partners may request aggregated analyses from the restricted site by completing/submitted a Data Access Request (see Appendix VIII). The reports generated will include a note stating that the analysis is

CONFIDENTIAL and FOR INTERNAL USE ONLY. Grant-level data will not be released to any non-Partner organization. Requests for complex analysis that are not part of the ICRP's standard suite of reports may incur a charge, based on the Operations Manager's time.

- 14.1.3 Where a Data Access Request is approved by the Partnership, must use the data for the purpose(s) identified in the request and for the time period specified
- 14.1.4 Non-Partners must submit a copy of the resulting publication(s) to ICRP for its archives within a month of publication.
- 14.1.5 Data released through the data access request process must be approved by each Partner. If a Partner does not approve release of his/her organization's data to a non-Partner, these data will be excluded from the data requested. A request for approval from Partners to release reports will be considered accepted if no response is received within 10 business days. Partners whose ICRP data is already publicly available may give blanket approval to publish their data in ICRP reports to reduce the burden of administration.
- 14.1.6 ICRP will make every effort to respond to requests for information promptly. However, where the Operations Manager's time is constrained, requests from Partner organizations will take priority.

**Partners:**

Definition: Organizations that are members of ICRP, either through individual or group membership. Within Partner organizations, only employees of the Partners (or in the absence of an employee, another individual designated to act on behalf of the Partner) are defined as Partners.

- 14.1.7 Partners must upload/update their individual organizational data before gaining access to the analytical tools
- 14.1.8 Partners may view/download data/reports made available through the public view and use these data for internal purposes or within their own publications
- 14.1.9 Partners may view/run/download data/reports made available through the restricted view
- 14.1.10 Partners may utilize the analytical tools provided on the restricted site Partners must use data/reports available through the restricted view for internal purposes only. Usage of the analytical tools on the Partner-only section of the ICRP web site will be monitored, allowing follow-up for data disposal and to ensure appropriate use of the excel download tools.
- 14.1.11 Partners may publish data/reports made available through the restricted view only upon the approval of each of the Partners (a Data Publication Request must be completed for this purpose). A request for approval from Partners to release reports will be considered accepted if no response is received within 10 business days. Partners whose ICRP data is already publicly available may give blanket approval to publish their data in ICRP reports to reduce the burden of administration.

14.1.12 Individual Partners who wish to publish findings independently of the ICRP using all or some of the other Partners' data accessed through the restricted site must complete a Data Publication Request. Data released through this data publication request process must be approved by all affected Partners.

## **14.2 PUBLIC REPORTING AND QUALITY ASSURANCE**

All public reports generated by the ICRP will be made available on its public web site. Reports are of two types: annual reports, which summarize the data across the Partnership and present key analyses; and topic-specific/special reports, which analyze the ICRP data to address specific questions/hypotheses. The latter may also contain additional information (e.g. surveys) gathered from the Partner organizations. Both types of reports must be reviewed and approved by all members prior to their public release.

### **Annual Reports:**

- 14.2.1 Will be prepared by the ICRP subcommittee, Data Report & Data Quality
- 14.2.2 Will incorporate Partner feedback in the final version
- 14.2.3 Will be generated on an annual basis, where possible
- 14.2.4 Will contain summary-level and organization-specific analyses for all organizations that have data in the database for the annual period covered in the report. Data from Partners who have left ICRP may be included in the report if their archival data is compatible with the current Partners' data. The Partnership reserves the right to omit ex-Partner data if it is incompatible with current analyses, e.g. if modifications have been made to the current Partner dataset which are not reflected in archival data. Ex-Partners may also request that their data is removed from the database.
- 14.2.5 Will be based on data that have been subjected to a data quality/assurance process
- 14.2.6 Will acknowledge all ICRP representatives, past and present, that contributed to the report
- 14.2.7 Will be copyrighted by the ICRP and will not identify a single author
- 14.2.8 Will incorporate trend analyses where appropriate given data availability
- 14.2.9 Will include caveats from Partner organizations (e.g. variance with existing information published, activities not part of the ICRP 'research' dataset) and a note that "Readers should refer to individual organizations' web sites to get a full understanding of each Partners' research and non-research portfolios"
- 14.2.10 Will include a caveat noting the inherent limitations of CSO coding.

### **Topic-specific/Special Reports:**

- 14.2.11 Will be prepared by the ICRP subcommittee, Evaluation Outcomes
- 14.2.12 Will incorporate Partner feedback in the final version

- 14.2.13 Will be generated on an as-needed basis
- 14.2.14 Will be based on data that have been subjected to a data quality/assurance process
- 14.2.15 Will acknowledge all ICRP representatives, past and present, that contributed to the report
- 14.2.16 Will be copyrighted by the ICRP and will not identify a single author
- 14.2.17 Will identify a contact person for the report (or a designate if the lead person is no longer affiliated with the ICRP)
- 14.2.18 Will incorporate trend analyses where appropriate given data availability

### 14.3 - RESPONSIBILITIES

All Partners must:

- 14.3.1 Ensure that their organizations' data are kept current and accurate
- 14.3.2 Maintain the confidentiality of data products or reports downloaded or accessed from the ICRP web site and ensure that restricted data and data products are physically secured from unauthorized access and unauthorized disclosure or exposure of the data. This includes secure disposal of electronic data downloads and related print-outs.
- 14.3.3 Actively participate in the review and approval process for all documents for public release and all data access requests. Partners will be given 10 business days to respond to requests for approval of data. No response after 10 days will be deemed to constitute approval.
- 14.3.4 Communicate any restrictions regarding their organizations' data with regards to data access requests to the systems administrator
- 14.3.5 Provide information on any caveats that need to be applied their organizations' data (e.g. notes stating what is not included, variance with existing public reports) and maintain those caveats
- 14.3.6 Obtain permission from all other Partners through the Data Access Request when publishing findings which include data provided by other Partners that is accessed through the non-public site and acknowledge the data source within the publication as follows: "The data (*or portions of the data*) used in this report were made available by the International Cancer Research Partners (<https://www.icrpartnership.org>)."

In addition,

- 14.3.7 The Operations Manager is responsible for coordinating the Data Access Request process. The Operations Manager will:
  - (a) receive the Data Access requests and manage the decision-making process
  - (b) raise for discussion requests that require full Partner permission at the ICRP teleconferences
  - (c) communicate decisions to requestors
  - (d) maintain/archive requests
  - (e) maintain/archive resulting publications (internally and externally generated)
  - (f) advise the Partners of any data breaches, for example loss/theft of data or computers on which data was held

- (g) schedule data disposal requirements for approved requests
  - (h) notify the Partners that data disposal has occurred
  - (i) work with the web site contractors to monitor data downloads and usage and highlight any inappropriate use to the Partnership
- 14.3.8 The Chair or Vice-Chair of the Data Committee will authorize approved Data Access Requests on behalf of the Partnership.

#### **14.4 - PROCEDURES**

14.4.1 - A Data Access Request must be completed by non-Partners that want to access ICRP data that is not available publicly and also by Partner organizations that wish to publish findings using data from other Partners.

14.4.2 - Non-Partners whose requests are approved are expected to pay a cost-recovery fee determined by the Partnership for the data extract/preparation involved for their request. A fixed fee, plus additional time for complex/non-standard requests will be levied.

14.4.3 - The Operations Manager will bring data access requests to the Partnership for review and approval. Requests will be discussed at the next available ICRP teleconference and distributed in advance to Partners. Where a request involves only selected Partners' data and not the data from all Partners, only the Partners affected will be involved in the permission process.

14.4.4 - Requestors are expected to abide by all the terms of access as well as any additional conditions stipulated by the Partnership. If the terms of access are breached, further requests for analyses will be refused.

14.4.5 - In the event that a Partner organization does not abide by the Data Access Policy rules, the ICRP reserves the right to restrict their access to the Partners' only area of the web site.

14.4.6 - It is recognized that Partners may wish to share analyses with Scientific advisory groups, Committees etc., where some or all of the membership of those groups are not employees of the Partner organization. Aggregate analyses may be shared with these bodies, but grant level data should not be disseminated. It is the responsibility of the Partner organizations to ensure that their advisory groups are aware of and respect the confidentiality of the analyses shared with them.

#### **14.5 – ASSOCIATED DOCUMENTS**

Data Access Request form  
Data Publication Request form

## **15.0 – DATA QUALITY POLICY**

This policy deals with two distinct areas: ensuring the quality of information underpinning specific analyses and reports and maintenance of coding quality

### **15.1 – DATA QUALITY IN ICRP ANALYSES AND REPORTS**

Data quality is essential to ensure that the analyses are robust. During data import, basic data quality routines are run to ensure that the dataset is suitable and formatted for inclusion in the database.

Under the direction of the Data Committee, the Partners develop and implement additional routines to assess data quality within reports (e.g. coding cross-checks on random subsets). A system of ‘sense-checks’ or ‘data challenge sessions’ help to ensure that the conclusions of the report are borne out when relating to underlying data. Any system implemented will be sufficiently robust for purpose, but also manageable given the time available to the Committee members and to the Operations Manager for implementation.

### **15.2 – CODING QUALITY**

The Partners recognize that there are a range of acceptable methods for implementing coding within a Partner organization, that coding is not an exact science and that it is important to ensure that coding procedures are not too prescriptive or expensive for Partner organizations to maintain. However, maintaining quality of coding across the whole portfolio is equally important in providing meaningful data for analysis. To date, Partners have used ‘dipstick testing’ to assess the level of agreement between coders as an assessment of coding quality. Providing a forum for discussing issues relating to coding is also important in maintaining and developing the CSO in a controlled way.

### **15.3 – RESPONSIBILITIES ASSOCIATED WITH DATA QUALITY**

15.3.1 - The Data Committee will be responsible for ensuring data quality within ICRP analyses and reports

15.3.2 - The CSO Coding Group (reporting to the ICRP Data Committee) would cover quality issues relating to CSO coding and updating the CSO.

15.3.3 – Partner organizations are responsible for implementing adequate quality control and communicating issues to the Operations Manager or CSO Coding Group

## **15.4 – PROCEDURES ASSOCIATED WITH DATA QUALITY**

### **15.4.1 – Reviewing the Policy**

The ICRP Data Committee will review this policy at least annually. Proposed amendments must be agreed by the full Partnership at its annual meeting or monthly teleconferences according to the general terms of reference of those meetings. The Operations Manager may propose amendments to the policy, for discussion by the Membership Committee and is tasked with implementing changes to the policy.

### **15.4.2 – Quality control for ICRP analyses and reports**

Data quality control is ensured through manual and automated checks at the point of data upload. Automated checks ensure that key fields essential for analysis are present, including funding amount >100, Title and abstract present, start and end dates valid etc. A system to update awards is also in place, to correct any errors found.

### **15.4.3 – Coding Quality control**

Data quality control is ensured through (1) Manual checks of a proportion of awards (10%) at the point of data submission. Additional automated checks at the point of upload prevent awards being submitted without valid CSO or site codes, or without CSO or Site relevances that total 100%. Periodic coding quality analysis will be conducted using awards coded to a single CSO/Site code, using statistical methods to assess inter-coder reliability. The results of these analyses will be shared with the Data Committee, along with recommendations any changes to CSO/Site to reduce coding ambiguity.

### **15.4.4 – Communicating Quality issues**

The outcomes of quality control will be communicated to the full Partnership, and the CSO Coding Group will be responsible for recommending changes to coding to ensure improvements in quality, if required.

### **15.4.5 – Partner obligations**

Partners are expected to maintain a consistent coding policy and to communicate the method used or use the ICRP Coding Service (involving automated coding as well as manual checks on a percentage of awards). Any changes should also be communicated to the Operations Manager. Further guidance for new coders is given in the Coding Guidelines. A random sample check of 10% of the submitted projects for the first data submission will be conducted. Projects will be CSO and site coded by another partner member and/or Operations Manager. If the check shows that there are problems, an action plan will be developed in tandem with the new partner.

### **15.4.6 – CSO Coding**

A maximum of 2 CSO codes should be applied per award or grant, reflecting the main aim or 'centre of gravity' of the grant and reflecting goals that are achievable within the lifetime of the grant. Coding should not include potential or future applications of the

research findings. It is, however, possible that certain large or multi-faceted awards may require more codes. There is a technical limit of 8 CSO codes per award for inclusion in the ICRP database. Percent relevance to these codes will be split equally across codes unless specified otherwise.

Awards may not be submitted to the database unless they are coded to one or more specific CSO codes ('0' values are not permitted).

#### **15.4.7 – Cancer Site Coding**

Although there is no limit to the number of disease codes, or types of cancer, that may be applicable for a given research project, there is a technical limit of 12 site codes per award for the ICRP database. In the data submission excel file, the research should be given the ICRP numeric code for submission to the database. Percent relevance to these codes will be split equally across codes unless specified otherwise.

Awards may not be submitted to the database unless they are coded to one or more specific Cancer Site codes ('0' values are not permitted)

#### **15.4.8 – Award Type Coding**

Up to three award types may be applied: R (research), C (clinical), and/or T (training).

### **15.5 – ASSOCIATED DOCUMENTS**

Coding Guidelines

([https://www.icrpartnership.org/sites/default/files/cso/ICRP\\_Coding\\_Guidelines.pdf](https://www.icrpartnership.org/sites/default/files/cso/ICRP_Coding_Guidelines.pdf))

## **16.0 – COMMITTEE, OPERATIONAL GROUP AND WORK GROUP REMITS**

### **16.1 – REMIT OF COMMITTEES, OPERATIONAL AND WORK GROUPS**

- 16.1.1 To be responsible for a scope of work as defined in the supplementary Terms of Reference for each individual Committee
- 16.1.2 To fulfil their remits, all Committees or Groups will work (with the Operations Manager) to recommend options to The Partnership at monthly teleconferences and the annual meeting
- 16.1.3 In addition, individual groups or Committees may develop other working relationships with external groups
- 16.1.4 Each committee or group will operate in accordance with these generic Terms of Reference and its specific Supplementary Terms of Reference

## **16.2 – MEMBERSHIP OF COMMITTEES, OPERATIONAL AND WORK GROUPS**

### **Committees and Operational Groups**

- 16.2.1 Chair of Committees: to be appointed by the Partners at the Annual Meeting or Monthly Teleconferences. The Chair will serve in this role for a maximum of three years. The Chair of any group must serve as a member of the parent committee
- 16.2.2 Chair of Operational Groups: In the case of Operational Groups, the Chair should be a representative of the organization providing the in-kind service and the appointment is not time-limited
- 16.2.3 Vice Chair/Deputy: For Committees, the Vice-Chair will act in the absence of the Chair, and will succeed to the Chair at the end of the 3 year term, or before in the case of the Chair's resignation. In the case of Operational Groups, the Deputy Chair should be a representative of the organization providing the in-kind service and need not automatically succeed to the Chair
- 16.2.4 Members: Membership will be periodically revisited and refreshed as needed
- 16.2.5 No more than 25% of the membership should be from the same Partner
- 16.2.6 Members may serve on multiple committees simultaneously
- 16.2.7 Operational groups may include external members, for example contractors working on the web site/database, or individuals from organizations providing fiscal sponsorship. However external members should not comprise more than 25% of the membership
- 16.2.8 The Operations Manager will attend as many Committee or Operational group meetings as is possible

### **Work Groups**

- 16.2.9 The Project leader will be appointed by the Partners at the Annual Meeting, Teleconferences, or by the members of a Committee or Operational Group
- 16.2.10 Membership should be determined by the expertise of the individuals and may include representatives of Partner organizations who do not normally attend Partner or annual meetings and/or external members. However external members should not comprise more than 25% of the membership
- 16.2.11 The Operations Manager will attend as many work group meetings as is possible

## **16.3 – GOVERNANCE**

- 16.3.1 Committees will meet at least twice a year, and more often if required. Work groups will meet on an ad hoc basis according to the requirements of the project
- 16.3.2 The committees will operate mechanisms for recording members' interests and for dealing with potential conflicts of interest during the conduct of its business
- 16.3.3 The minutes or report of each meeting will be presented as soon as is practicable to the full Partners, at an annual meeting or monthly teleconference

- 16.3.4 Meetings will be considered quorate if the majority of members are present. The Chair and Operations Manager are responsible for ensuring that there is adequate representation at a meeting
- 16.3.5 The principle of one Partner, one vote applies in Committees and Work groups. Issues may be approved with a majority vote
- 16.3.6 Committees may only be created or disbanded by the Partners at an annual meeting
- 16.3.7 Work-groups may be initiated by Partners at an annual meeting or full Partner monthly teleconference. The lifetime of the group will be determined in the initial project scope, but may be extended by the Partners at an annual meeting or monthly teleconference if required

#### **16.4 – BUDGET**

- 16.4.1 Committees and work-groups will not normally be responsible for a budget
- 16.4.2 If a budget is required for a specific project, e.g. for external consultancy, the committee or work-group will be responsible for making a funding proposal, with the approval of the Financial Operations Group, to the full Partners at an annual meeting or teleconference

## 16.5 – SPECIFIC COMMITTEE, OPERATIONAL AND WORK GROUP TERMS OF REFERENCE (TOR)

### 16.5.1 – Partner Operations Group: Terms of Reference

- a) To monitor the ICRP Strategic plan and annual workplans, operational structure, , Policies and Procedures, and other related documents as required.
- b) To monitor and oversee the work of the Operations Manager
- c) To monitor internal communications, including services provided in-kind by CDMRP:
  - a. Organizing monthly teleconferences
  - b. Providing minutes for monthly teleconferences and annual meetings
  - c. Working with the Operations manager to maintain the document archive

### 16.5.2 – Website & Database Operational Group: Terms of Reference

This work is being done under the purview of NCI as its in-kind contribution to ICRP

- a) Provide ongoing maintenance of the web site (external and member), member database (including data uploading, member quality control), and design of the member interactive reporting tool.
- b) Ensure security of the Partner records deposited in the ICRP database
- c) Review and recommend enhancements to the ICRP database or website

### 16.5.3 – Finance Operations Group: Terms of Reference

To oversee and provide advice to the Partners on the financial operations of the ICRP, including, without limitation:

- a) Monitoring the financial performance of the ICRP and engaging in financial and capital planning for the Partnership
- b) Reviewing and recommending to the Partnership for approval policies to protect and enhance the assets of the ICRP
- c) Reviewing the audited Financial Statement and recommending it to the Partners for approval at the Annual Meeting (in-kind contribution by McGill University)
- d) Reviewing and making recommendations to the Partners regarding compliance matters
- e) Overseeing mechanisms for invoicing and recommending changes to policy
- f) Recommending mechanisms to the Partners to maintain an appropriate reserve for the ICRP
- g) To make projections of expenditure over a three year period and make recommendations to the Partners for adjustments to the Membership fee structure on the basis of these projections
- h) To monitor expenditure against staff, meeting costs or strategic mission initiatives
- i) Performing other duties as may be assigned by the Partners from time to time
- j) This group shall consist of three persons, including the Chair or Vice-Chair. Additional external members with expertise in financial matters or providing fiscal/in-kind support to the Partners will be included from time to time.

#### **16.5.4 - Membership & Communications Committee: Terms of Reference**

- a) To develop a strategic plan for recruiting new members and execute said plan in conjunction with member organizations and the Operations Manager
- b) To review and applications for new members submitted by the Operations Manager and make recommendations to the Partners to accept/decline such applications
- c) Review changes to the Membership application and New Partners' materials
- d) To review visual identity guidelines for the Partnership and prepare an annual communications plan in tandem with the Web site & Database Operational Group, Membership Committee and Annual Meeting Group
- e) To oversee revisions to communications resources made available to the Partners
- f) To develop and/or approve communications materials (conference abstracts, posters)

#### **16.5.5 – Data, Coding and Analysis Committee: Terms of Reference**

##### ***Including the CSO Coding Group***

- a) To develop annual data reports for member and public audiences
- b) To assess and document data quality issues and develop action plans to address data quality problems
- c) To monitor analyses of specific areas of the ICRP portfolio
- d) To discuss issues with CSO or Cancer Site codes and propose amendments to the CSO for consideration by all Partners
- e) To assess and document data quality issues relating to CSO coding, including regular checks of coding quality across the portfolio
- f) To work with new partners to ensure that the quality of CSO and site coding is good.

#### **16.5.7 – Evaluation & Outcomes Committee: Terms of Reference**

- a) Conduct special reports of interest to the membership based on research evaluation, outcomes or impacts. Special reports may involve using data within the database and/or collecting new information from member organizations. Some of these responsibilities will be devolved to the Operations Manager.
- b) To oversee the Evaluations library on the member site

#### **16.5.8 – Annual Meeting – Operational Group: Terms of Reference**

- a) Plan and organize the annual face-to-face meeting of the membership
- b) Chair rotates on an annual basis, with the Chair being the representative from the host organization