

## PCHP OPEN SCIENCE GUIDING PLINICIPLES

### I.Context and Scope

The PCHP aims to transform paediatric care into a learning health science ecosystem, where all stakeholders benefit from sharing data and advances in technologies, by sequencing the genome of every child; combining whole genome sequencing data with other 'omics', clinical, treatment outcome and socioeconomic data as a new research resource to support the development of new diagnostic tools and therapies; and advancing new treatments using gene editing, cellular therapy, tissue engineering, immunotherapy approaches, molecular therapies, drug screening and pharmacogenomics.

### II.Open Science Guiding Principles

Open Science is considered a new paradigm for science and knowledge dissemination. It fosters cooperative work and new ways of distributing knowledge by promoting sharing as early and broadly as possible. Through the Precision Child Health Partnership, SickKids and CHU Sainte-Justine are committed to maximizing the public benefit of all its innovations and discoveries. With the goal of increasing the pace and quality of scientific outputs, increasing efficiency, and spurring both discovery and innovation, in accordance with the FAIR principles<sup>1</sup> and the applicable legal and ethical frameworks, the PCHP fosters the implementation of the following five Open Science guiding principles<sup>2</sup>:

**Principle 1: Public Release of Scientific Data and Resources:** PCHP-funded research is expected to be published in open access articles. All positive and negative numerical data, models used, data sources, materials, reagents, algorithms, software and other scientific resources will be made publicly available within six (6) months of the publication date of the first article that relies on this data or resource.

**Principle 2: External Research Partnerships:** Publications, data and scientific resources generated through PCHP-funded research partnerships – whether with commercial, philanthropic, or public sector actors – are encouraged to be released on the same basis as set out in Principle 1.

**Principle 3: Sharing and Use of Patient-Based Research Materials and Tools:** The PCHP supports knowledge creation and innovation by maximizing the long-term value of the physical contributions made by research participants and the physical scientific resources created via PCHP-funded research. The PCHP aims to manage these resources in such a way to enrich and strengthen its informational content and the knowledge it provides. In handling materials originating from patients and participants, the PCHP recognizes the primacy of safeguarding the dignity, autonomy and privacy of patients and research participants.

**Principle 4: Open Science Compatible Intellectual Property:** In order to facilitate the translation of PCHP-generated knowledge and research outputs for the benefit of patients, and subject to patients' confidentiality and participants' informed consent, the PCHP will ensure discoveries are 'as open as possible, and as closed as necessary'. Any commercial licensing activities are encouraged to adhere to Socially Responsible Licensing Principles.

However, private or public external collaborators working with the PCHP may obtain restrictive IP rights in respect of their own contributions to research, provided that this does not impair the freedom-to-use PCHP-generated knowledge and research outputs.

**Principle 5: Researcher and Patient Autonomy**: The PCHP supports the autonomy of its stakeholders, including but not limited to researchers, staff, trainees and patients, through recognizing their right to decline to participate in research and associated activities under an Open Science framework.

### **III. Amendments, Modification or Variation**

Amendments to these **Open Science Guiding Principles** may be made by the **PCHP Board**.