Equity, Diversity and Inclusion - Guiding Principles

Génome Québec is committed to integrate the principles of Equity, Diversity and Inclusion (EDI) in its funding opportunities, to promote representation and participation of different groups and individuals. Bringing a variety of expertise, perspectives and ideas to a project will allow for more comprehensive research, results and solutions. The quality of genomic research improves, and the solutions provided by it become more comprehensive, when different expertise, perspectives and ideas are brought together. Project leaders are expected to integrate EDI concepts and principles and showcase concrete activities to promote an inclusive research environment. This includes diversifying team composition, considering and including individuals that will be impacted by the research and making the research accessible to diverse audiences. This integration will allow to ensure that the results of genomic research benefit a larger community in an equitable way.

EDI principles are transversal and should be reflected throughout your application by incorporating them into your project design. We have listed below topic areas and some guiding questions to help you develop EDI considerations and design concrete activities to be integrated into the research proposal.

Please note that this a general list of topic areas conceived for all sectors funded by Génome Québec. This list is not exhaustive and some of the considerations listed below may not apply to your project, the competition, or your sector.

Depending on the competition, different degrees of integration and extent of EDI activities can be required. Please refer to the funding opportunity for further details.

1) **Stakeholder* engagement:** Thoughtful interactions with stakeholders can help build solutions that will be quickly adopted and positively impact the community. A “stakeholder-driven” approach can bring depth and weight to the project and acts as a selling point of the proposal. Here are some key items to consider:
    a. Engagement and consultation of stakeholders
        i. How will you ensure to recruit/select a diverse set of participants for consultations (surveys, meetings, round tables, workshops, etc.)?
        ii. Is the diversity of relevant stakeholders sufficient? Are key parties missing?
        iii. Do you plan to consult marginalized groups or communities?
        iv. How can different groups meaningfully contribute to the research?
    b. Relevance
        i. Are research questions and solutions addressing the needs of stakeholders? Were they defined or refined following consultation of the latter?
        ii. Is the developed technology useful and practical for stakeholders?

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*Stakeholders: Stakeholders are individuals, groups or organizations with a specific interest in the research project or affected by the research project or topic. Concrete examples of stakeholders: patient partners (see section 6), indigenous communities (see section 5), the public, farmer organizations, and Users. Users are a specific group of stakeholders. Users are organizations able to use the information generated through research to make informed decisions on issues such as practice guidelines and standards, policies, development and use of products. Examples of Users include companies (private or public, Canadian or foreign-owned), consortia and industrial associations, government departments and agencies (federal, provincial and municipal), health-care organizations, and not-for-profit organizations.

c. Inclusion
    i. Did stakeholders participate in the development of research questions or objectives? Do you plan to co-create?
    ii. How will stakeholders be involved throughout the project?
    iii. Are the stakeholder contributions valued, recognized and do they influence decision-making?

d. Result sharing
    i. Are the result-dissemination strategies adequate for various stakeholders impacted by the research?
    ii. Will results, data generated, and technologies developed be accessible to various stakeholders? Will stakeholders be automatically informed of the project outputs?

2) **Team Composition and environment:** Building a strong research team is paramount to the completion and success of the project. Skill, expertise, and proficiency are essential, and EDI considerations can contribute to a high-performing, diverse team, including multiple experiences and perspectives, ultimately leading to a more comprehensive project. Consider:

a. Creating a diverse team and an inclusive environment
    i. Thrive for a diversity of experiences, perspectives and different groups represented on your team and ask yourself if they are truly included (ex: is their contribution valued?).
    Important: Avoid adding statistics regarding the diversity within your research team, as providing such information could disclose personal information of these individuals, and it could be interpreted as tokenism.
    ii. Consider international hires despite challenges that may be associated with it.

b. Adopt and describe best practices for recruitment and human resource management
    i. Unconscious bias training (See Unconscious Bias and Recruiting).
    ii. Following the institution's human resources policies and following EDI principles for selection (criteria, language, inclusive language, dissemination of posting in diverse forums, diverse selection committees, diverse candidate shortlists for interviews, etc.).
    iii. Establishing conflict management guidelines.

c. Early-stage researchers, users, students and postdocs
    i. What type of support and mentorship will be provided to each group?
    ii. Does the institution have specific programs for students and postdocs?
    iii. How will you encourage recognition of students and postdocs, and promote inclusive excellence?
        1. Scholarships (for social implication, for parental support, for academic excellence, for diversity, for travel, for publishing, etc.).
        2. Participation at student competitions and conferences.

d. Clarifying the roles and accountability within the research team
    i. Responsibility of the research design.
    ii. Executing and analysis of research activities.
    iii. Dissemination of results.
    iv. Interaction with stakeholders.
e. Training
    i. EDI training for all your team (resources from your institution, Dimensions charter, workshops, consultants, etc.).
    ii. Ensure equity in training opportunities within the team.

3) **Barriers and benefits**: Genomics research projects can have significant positive impact for a variety of stakeholders. Impacts can include better precision in treatment, practice change, cost or time reduction, or even a contribution to lessen global challenges. Considering EDI can increase impacts, lead to more equity, and can help align the research to increase the chances of the project having a positive impact. Consider:
    a. Ensuring that research benefits the targeted group and the participants that contributed to the project. Consider if different groups beyond those initially targeted could benefit from your research and should be included. This is especially important in projects addressing global challenges. (Ex: Nagoya Protocol).
    b. Limiting unintended consequences of the research. For example, research results related to a health problem prevalent in a specific group could lead to stigmatization and to reinforce prejudices.
    c. Addressing systemic barriers (policies, procedures, practices) and proposing concrete activities to mitigate them.
    d. Putting forth EDI elements into the research plan is essential for successful implementation. This could include but is not limited to:
        i. Elaborating a strategy to engage a diversity of users and stakeholders.
        ii. Determining if social or demographic data will be collected and if analyses will be disaggregated according to key identity factors.
        iii. Research that relies on animals or living organisms that are either male or female should include a note on disaggregated sex analysis.
        iv. Carefully selecting research methodologies (participatory methods, sampling strategies, participant profiles, consultation, co-creation of collection tools, etc.).
    e. For projects that include a GE^{3}LS section (ethical, environmental, economic, legal and social aspects, as well as any other aspect that enables responsible implementation of genomics research), the EDI considerations listed above can feed into the GE^{3}LS research and vice versa. GE^{3}LS research can propose strategies lowering the risk to adoption of the research outcomes (the latter could be linked to an EDI challenge or not). In this context consider:
        i. Are there barriers to the change of practice? How will they be handled?
        ii. How will delays impacting the research plan and team be addressed?

4) **Accessibility:** Defined as "the combination of aspects that influence a person's ability to function within an environment", it refers to the openness to put in place specific accommodations (logistical, financial, technical, linguistic, cultural, physical, related to work-family balance, etc.) for the research personnel to thrive in the research environment and participate efficiently to the research. It could also refer to accessibility of research deliverables, outputs, and datasets. Your proposal could elaborate on:

   a. How can you provide a safe, inclusive and barrier-free environment? How will this type of support be managed? Who will be responsible for this?
   b. Management of parental or other types of leave policies and work-family or study-family balance measures.
   c. Accessibility in the context of lab work, but also in other contexts, such as field research, while travelling, with users or stakeholders, in the context of work with patient partners, etc.
   d. Accessibility and sharing of research data within the team, especially in a decentralized context or within a network. Are there barriers to the sharing of data?
   e. Sharing of data and resources with the broader community:
      i. Plan for dissemination and sharing of information and data to study participants, stakeholders, the global scientific community (including researchers outside your field) and the public. Consider open science approaches and FAIR principles.
      ii. Choose appropriate means of communication in terms of vehicle and language (ex: social networks, providing project results in accessible/lay language, providing information in French, English and other languages, if necessary).
      iii. Make publication and patenting decisions to allow for enhanced visibility and equitable benefit sharing (ex: open access publication can benefit researchers from less well-resourced institutions or the general public). Consider this especially when addressing global challenges.

5) **Research with Indigenous communities**: Work with indigenous communities can have many benefits. If a study includes or touches indigenous peoples' matter, the community should be included in the project. Such inclusion can empower and contribute to autonomy and capacity building in the community, and collaboration or co-creation will allow for more meaningful projects that benefit the communities and society. If your project plan includes research with indigenous communities, it is essential to read and be aware of the different protocols and guidelines related to collaboration with indigenous groups (see links below). Teams should carefully consider if and how the following aspects must be addressed:

   a. Co-creation principles, including engaging with the communities and identifying their needs, interests, expectations, to elaborate research objectives or to formulate research questions.
   b. The First Nations principles of ownership, control, access, and possession (OCAP).
   c. Aligning with reconciliation principles from the Canadian Government or other recommended action towards reconciliation.
   d. Referencing the Tri-Council Policy Statement, Chapter 9, on Research involving the First Nations, Inuit and Métis peoples of Canada.
   e. Adopting the Assembly of First Nations Québec-Labrador research protocols.

   f. Preferred methods for dissemination of results inside and outside the community.
   g. Intellectual property principles within indigenous communities could differ, requiring discussions and mutual agreement on the methods to be used.
   h. Decolonization principles.
   i. How to ensure the project benefits the community?

Indigenous communities are a group of stakeholders, please also consult section 1 for considerations on this topic.

6) **Inclusion of patient partners:** The term “Patients” includes individuals with personal experience of health issues and their informal caregivers such as family and friends. Include patients’ perspectives, lived experiences and context to improve your health research project and, ultimately, care and quality of life, and to empower patients to take on an active role in their health care.
   a. Include patients’ perspectives and lived experiences at different stages of your project for:
      i. Project design: provide novel ideas (issues not discussed in literature) and prioritize research outcomes that are meaningful and relevant to the patients.
      ii. Data collection: input on feasibility of data collection, on informed consent or co-facilitation of qualitative interviews.
      iii. Measured impact of innovation: providing information on patient-reported outcomes.
      iv. Recruitment: Link to other patients (or patient groups), improving transparency, trust and buy-in.
      v. Implementation:
         1. Knowledge transfer: dissemination and training of community and care providers.
         2. Decision-making: Patient organizations hold or can obtain key information on patient-reported outcomes, socioeconomic impacts and quality of life which are a component of the public health decision-making process and policy development.
      vi. Give individuals with lived experience a voice on which health topics are researched.
      vii. Transform patients from passive recipients of health services into proactive, informed partners who help shape health research and healthcare.
   b. Engagement of patient partners can take different levels (information < consultation < involvement < co-creation/collaboration). Ideally, strive for co-creation, when feasible.
   c. Inform yourself about best practices for including patient partners in a meaningful way, respecting their limits, needs, preferences, while valuing and recognizing their contribution. You can consult these references for this aspect CIHR, Strategy for patient-oriented research (SPOR), SPOR’S support unit in Québec and NMND4C. Your institution may also have policies and protocols on this topic.

Patient partners are a group of stakeholders, please also consult section 1 for considerations on this topic.

7) **Diverse data in genomics:** Including data from different groups or from different stakeholders can increase equity in terms of who benefits from genomics research.

   a. If your research topic affects specific groups, it may be imperative to include their data.
   b. Contribute to the production of more diverse datasets. Include existing diverse data in your analysis, where feasible. Consider data from different ethnic, gender, socioeconomic, cultural, geographic, and other groups.
   c. Analyze your data by different groups to gather useful additional information. Consider if sharing disaggregated data could harm such groups and how to mitigate this.
   d. Include traditional knowledge (see section 5 "Research with indigenous communities").
   e. Carefully plan for inclusion of diverse participants, stewardship of data, return of information and how this will benefit (or may unintentionally harm) and how you can enable such benefits (see section 3 "Barriers and benefits").
   f. Consider specific protocols and best practices that govern certain types of data, their collection and governance (Ex: protection of personal data, OCAP, FAIR, etc.).

Other references

BAKER Jocelyn et VASSEUR Liette « Inclusion, diversité et accessibilité (IDEA) – Pratiques exemplaires à l'intention des chercheurs », Commission canadienne pour l'UNESCO, Ottawa, Canada, août 2021

Chaire pour les femmes en sciences et en génie au Québec – Outils pour l'ÉDI en recherche

Commission de la santé et des services sociaux des Premières Nations du Québec et du Labrador, UQAT, UQO, Réseau de recherche et de connaissances relatives aux peuples autochtones — Boîte à outils des principes de la recherche en contexte autochtone

Réseau québécois pour l'équité, la diversité et l'inclusion (RQÉDI) — Ressources

The Natural Sciences and Engineering Research Council of Canada —"NSERC guide on integrating equity, diversity and inclusion considerations in research"