

**Integrating the Perspectives of
Vulnerable Populations in iGEM
Research:
A Best Practices Report**

Introduction

Scientific discovery is inextricably linked to day-to-day life. Synthetic biology embodies this principle by harnessing biological innovation to address pressing societal challenges. However, synthetic biologists cannot make progress in this field in a vacuum. Communication beyond academic circles during the research process is crucial to ensuring progression addresses real human needs and avoids unintended harm.

In iGEM, student research teams assume this responsibility through Human Practices outreach, which often involves dialogue with members of the public, who the team's work may directly impact. With iGEM projects spanning diverse fields, relevant community members bring a wide range of prior experiences and emotional connections to the issues at hand.

This report highlights the social responsibility assumed by iGEM teams: not only to protect those potentially affected by their projects, but also to uphold ethical standards of public engagement. In particular, when vulnerable populations are involved, engagement must be deliberate and respectful. This report introduces a framework-oriented approach for ensuring responsible stakeholder engagement with vulnerable populations in the context of iGEM.

Definitions

Impact

Harm is defined within this report as any negative impact on individuals or groups resulting from the action or communications of an iGEM team. This negative impact includes, but is not limited to, re-traumatization-triggering emotional or psychological distress linked to past experiences—or an induced fear in individuals for their personal safety due to biosafety threats.

People

A *vulnerable population* is defined in this report as a group of people at increased risk of harm due to past experiences, educational level, native language, age, or socioeconomic status.

Stakeholders are defined in this report as individuals or groups of individuals who are directly or indirectly affected by, have an interest in, or can influence the outcomes of an iGEM team's project.

A *patient*, as defined by the Canadian Institutes of Health Research, is an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends [1]

An *honest broker* is defined in the context of this report as being an impartial mediator capable of facilitating conversation with or speaking on behalf of a vulnerable population.

Teams and Structures

An *iGEM team* is defined as a student-based research group conducting synthetic biology research as a member of the iGEM (International Genetically Engineered Machine) organization.

Human Practices, as defined on the iGEM website, is the systematic study and thoughtful engagement with the world to understand the impact of synthetic biology projects and to address real-world problems responsibly [2]

iGEM villages, as defined by the iGEM website, are specialized, topic-centred hubs where iGEMers, experts, policymakers, strategic partners, and the broader synthetic biology community come together to address today's critical and interconnected global challenges. [3]

A *high-risk* village is defined in this report as an iGEM village with a high concentration of stakeholders who potentially belong to a vulnerable population*

*This definition is intentionally left broad: while villages such as those in the human health plaza may be a more glaring example of having vulnerable stakeholders (i.e. patients), individual iGEM teams may determine their own village to be 'high risk' and should proceed with appropriate caution.

The Vulnerable Population Engagement Framework

McGill iGEM has proposed the following iterative cycle for risk mitigation during Human Practices activity within high-risk villages. This process is intended to be reflective, with checkpoints built in to encourage reflection and needs-based adaptation throughout the cycle.

The Vulnerable Population Engagement framework centers the needs of vulnerable populations and holds iGEM teams accountable for ethical engagement within their Human Practices activities.



i) Identify

Goal: to identify relevant stakeholders belonging to a vulnerable population and any substitute stakeholders

At the identity stage, gather a suitable caucus of iGEM team members to assess project stakeholders. This list should include those who stand to benefit or lose from a project's success, those familiar with the current status quo, those who may have a particular interest in the project, and, more broadly, stakeholders ranging across sectors such as industry, academia, legislature, and the public.

Once a comprehensive list is compiled, consider each stakeholder group and determine whether they fall under the definition of a vulnerable population. To prompt this reflection, consider the following questions for each previously listed stakeholder group and circle the appropriate response:

1. Is it likely that this stakeholder group has had negative prior experiences with our iGEM team's primary area of research?
very unlikely unlikely **somewhat likely** **very likely**
2. Is it likely that this stakeholder group has had traumatic prior experiences with our iGEM team's primary area of research?
very unlikely unlikely **somewhat likely** **very likely**
3. How familiar is this stakeholder group likely to be with synthetic biology or science more broadly?
very unfamiliar somewhat unfamiliar familiar very familiar

4. How likely is this stakeholder group to misunderstand what our team is researching, even with extensive explanation?
very unlikely unlikely **somewhat likely** **very likely**
5. How likely is this stakeholder group to feel intimidated by being interviewed or consulted with by scientists?
very unlikely unlikely **somewhat likely** **very likely**
6. Could iGEM team members be perceived as being in a position of power relative to this stakeholder group?
Yes No **Unsure**
7. Is this stakeholder a former or current patient of a disease this iGEM team is working with?
Yes No
8. Are members of this stakeholder group legal adults?
Yes **No***

Note: If your team selects an option highlighted in orange or red for any of the questions 1 through 7, this indicates that the stakeholder group may belong to a vulnerable population.

*McGill iGEM does not condone initiating contact with any stakeholders under the legal age of adulthood. If a stakeholder group consisting of minors is identified at this stage, we strongly recommend proceeding directly towards the third-party honest broker stage. Additionally, we will caution that initiating contact with minors in a Human Practices context (i.e. through surveys or interviews) may violate local legislation or institutional policy. Exceptions may exist for high school teams doing research that will impact their peers.

For any identified vulnerable populations, revisit the stakeholder list and identify any overlapping areas of insight. Attempt to answer the question: *Is there an alternative (lower risk) stakeholder that can contribute the same or similar insights into our work?* If so, the team should proceed to the 'Honest Broker' segment of the framework.

If feedback from a vulnerable population is essential for comprehensive Human Practices documentation, the team should proceed to the Prioritize step of the cycle.

ii) Prioritize

Goal: To set team-specific priorities to guide engagement with vulnerable stakeholders.

At this stage, discuss the intentions of your iGEM team in conducting Human Practices outreach and establish clear guidelines to be followed throughout the process.

Example: McGill iGEM 2025 Priorities

Before consulting with patients affected by gastrointestinal diseases, the team committed to the following principles:

- *We will minimize harm while doing outreach with vulnerable populations.*
- *We will prioritize the needs of the vulnerable stakeholder over our team's personal gain.*
- *We will consider alternative options when they deliver us to the same outcome.*

iii) Seek Guidance

Goal: To rely on external supports to build the skills needed for engaging in dialogue with vulnerable populations.

Before consulting with any vulnerable population, your team should first assess whether it has the skills necessary to navigate potentially sensitive or challenging conversations. Because most iGEM teams operate at the high school or undergraduate level, members may lack professional experience in this area.

Fortunately, a range of resources is available to help students strengthen these skills. Hands-on training programs—often free and available online—can build interviewing and communication capacity.

For Canadian iGEM teams, here is a short list of resources that may be applicable:

- **CIHR-IMHA's How-to Guide for Patient Engagement in Research:** practical guidance on involving patients in research ethically and effectively [4]
- **PASSERELLE SPOR National Training Entity:** training modules on patient-oriented research [5]
- **Skills for Success (Government of Canada):** offers various assessment and training tools for building communication and interpersonal skills [6]
- **Institutional Specific Courses:** universities may offer relevant courses through communication studies departments or as non-credit options within student enrichment programs

In addition to formal resources, teams can also build their skill set through mentorship by consulting with professors, healthcare professionals, or community experts who have experience engaging with vulnerable populations.

iv) Review

Goal: To finalize the course of action and identify individuals to initiate contact with.

This stage of the framework serves as a final checkpoint to reassess whether direct outreach with a vulnerable stakeholder group is necessary or whether engagement should occur instead through a third-party honest broker. Before proceeding, review whether this outreach is essential and whether this is the most suitable stage of the project to initiate it in.

When selecting members of a stakeholder group to engage with, aim for those who are at a lower risk of experiencing harm. Without the use of an honest broker, prioritize the following types of stakeholders to minimize risk:

- **Team contacts or family members** - With prior exposure to the team and/or project context, the potential for misunderstanding or distress is reduced. Existing relationships can also provide a safer, more supportive environment for engagement.
- **Those familiar with iGEM or scientific research more broadly** - Those who already understand research processes are less likely to be confused, misinformed, or alarmed, which reduces the risk of unintended harm.
- **Public advocates with prior lived experience** - Individuals who actively champion issues in their community are often more comfortable sharing their perspectives and less likely to be negatively affected by discussions of past experiences.

v) Consult

Goal: to facilitate meaningful dialogue that benefits the iGEM team while centering the needs of the vulnerable population.

At this stage, teams engage directly with stakeholders. The consultation format and process should be designed to respect participant needs, minimize harm, and ensure ethical communication.

Format

Human Practices dialogue can take many forms, including formal consultations or interviews (in-person or remote), roundtable discussions, surveys, ongoing partnerships, or asynchronous written exchanges. Discuss potential formats both internally and in advance with the stakeholder to find what works best for them.

Consent

Before or at the start of any meeting with a vulnerable stakeholder, ensure that informed consent is obtained. Where applicable, consent should cover the inclusion of summaries in the team's wiki or project materials, as well as any audio or visual recordings that may be made.

Transparency

Maintain honest and transparent communication about your project. Avoid overpromising results (e.g., suggesting to a patient that the project could cure their disease) or oversimplifying the

science for less familiar audiences in misleading ways. Such misrepresentation undermines Human Practices goals and risks causing greater long-term distress.

Additional Resources

For guidance on effective communication:

- Plain Language Guide [7]
- iGEM Bielefeld's 'Feedback cycle' framework for facilitating dialogue in stakeholder interaction [8]

vi) Implement

Goal: to close the loop and create opportunities for stakeholder empowerment.

Integration

After consulting with a vulnerable population, promptly reflect on the insights shared. Integrate them into the current project where feasible, or carry them forward into future iterations. Because vulnerable populations are often asked to share perspectives that may be personal, sensitive, or emotionally taxing, incorporating their feedback demonstrates respect for stakeholders' time and lived experience.

Empowerment

Some stakeholders may wish to remain in contact with the team to receive updates on project progress or learn how their contributions shaped the work the team was able to do. Providing such follow-up presents the opportunity to empower stakeholders by creating spaces in research where their voices are heard and valued.

vii) Reflect

Goal: To self-evaluate and outline next steps forward.

Use this final stage to evaluate your team's progress and prepare for future Human Practices work. Reflection ensures accountability to the priorities set earlier and provides a foundation for continuous improvement.

Self-Evaluation

Revisit the guidelines your team established during the Prioritize stage.

Discuss the following questions:

- Were these guidelines upheld throughout the engagement process?
- What mistakes were made during the engagement process?

Future Planning

Consider whether the vulnerable stakeholder(s) provided meaningful insights into the areas of need. If new areas of need have arisen, discuss the following:

- Can anything be improved in our approach before repeating this cycle?

★ Honest Broker

Goal: to facilitate feedback integration from a vulnerable population by way of a third-party honest broker.

The honest broker approach can be applied at any stage of the cycle when a stakeholder is identified as too high risk to contact directly or when a comparable stakeholder is available.

A third-party mediator should be knowledgeable in the experiences of the vulnerable population and can fulfill one of two roles:

- **Role 1: Mediator** - Facilitate dialogue with the vulnerable population, ensuring conversations are handled sensitively and benefit from the mediator's skills or formal training.
- **Role 2: Representative** - Share perspectives and insights on behalf of the vulnerable population, reducing direct risk to individual stakeholders while still preserving their voices in the project.

Identifying an Honest Broker

Teams may look for honest brokers in the following places:

- **Comparable stakeholders** - Look for overlap between the insights of vulnerable groups and lower-risk stakeholders. If another stakeholder can provide similar perspectives, they may serve as a representative (Role 2).
- **Advocacy groups** - Legal or nonprofit organizations working with vulnerable populations often have deep insight and may act as either mediators or representatives.
- **Professionals in support roles** - Caretakers, counsellors, or other professionals who work closely with vulnerable populations, may serve as trusted brokers.
- **Previous iGEM teams** - Previous team members who worked on similar projects may have already documented feedback to questions your team is now exploring.

Documentation

This framework is designed to encourage documentation throughout every stage of the engagement cycle with vulnerable populations. By maintaining accurate records of priority setting, dialogue, and reflection, iGEM teams strengthen accountability and transparency within Human Practices.

Conclusion

Human Practices exists to help iGEM teams conduct responsible and ethical work. However, without careful planning, Human Practices work itself can unintentionally cause harm, undermining this responsibility.

The Vulnerable Population Engagement framework provides a concrete platform for the ethical engagement of vulnerable populations in iGEM research, guiding teams to document, reflect, and act upon stakeholder input while minimizing risk to the stakeholders involved.

Through this process, iGEM teams can ensure they uphold ethical obligations and that stakeholder engagement contributes positively to both research outcomes and community well-being.

[1] "Strategy For Patient-Oriented Research - Patient Engagement Framework," Canadian Institutes of Health Research, <https://www.cihr-irsc.gc.ca/e/48413.html#a4> (accessed Oct. 1, 2025).

[2] "What is Human Practices?," iGEM, <https://responsibility.igem.org/human-practices/what-is-human-practices> (accessed Oct. 1, 2025).

[3] "iGEM Villages," iGEM , <https://villages.igem.org/> (accessed Oct. 1, 2025).

[4] "Patient Engagement," Canadian Institutes of Health Research, <https://cihr-irsc.gc.ca/e/27297.html> (accessed Oct. 1, 2025).

[5] "Home: National Hub in Capacity Development for Patient-Oriented Research," Passerelle, <https://passerelle-nte.ca/en/> (accessed Oct. 1, 2025).

[6] "Skills for Success," Employment and Social Development Canada, <https://www.canada.ca/en/services/jobs/training/initiatives/skills-success.html> (accessed Oct. 1, 2025).

[7] "A Plain Language Checklist for Health Care Professionals," Health Quality Ontario, <https://www.hqontario.ca/Portals/0/Documents/pe/quick-tools-checklist-communicating-clearly-pc.pdf> (accessed Oct. 1, 2025).

[8] "Human Practices," Bielefeld- iGEM 2024, <https://2024.igem.wiki/bielefeld-cebitec/human-practices?tab=hp-quote> (accessed Oct. 1, 2025).