



IEEPO LEARN Library 'Submission Guidelines'

A note from the IEEPO Core Team.

We want to thank you for your consideration to contributing to the LEARN Library, we hope that with your help it becomes a useful resource for all patient groups globally and for you!

When you're finished with your submission, please do explore the LEARN Library a bit more, we are excited to be launching a platform such as this.

Thank you for your interest in the IEEPO LEARN Library.

About IEEPO and the LEARN library

The LEARN Library is an initiative launched by the International Experience Exchange with Patient Organisations (IEEPO). IEEPO is a platform of engagement for the international patient community.

IEEPO aims to support the global patient community by providing learning opportunities around global trends in healthcare systems, creating a forum for experience exchange and co-creation, fostering connections with stakeholders from across and outside the healthcare ecosystem, and empowering patient communities to be strong and impactful partners in transforming the future of healthcare ecosystems.

The IEEPO LEARN Library will be hosted on www.IEEPO.com and brings together open-source learning resources and materials to support patient organisations in their work. The library is intended to be a sustainable and trusted repository of materials that will be updated quarterly.

Materials included in the library have been published by third-party organisations or Roche and they encompass a range of subject areas that will be continually added to, for and by the patient community.

This document summarizes the below:

1. [How to submit appropriate materials to the LEARN Library](#)
2. [How to reuse materials in this IEEPO library under the Creative Commons License](#)
3. [Frequently asked questions](#)



1. How to submit appropriate materials to the LEARN Library

LEARN Library submission criteria

The IEEPO LEARN Library will bring together practical learning resources and reference tools that have been made publicly available by reputable third-party organisations.

We value input and contributions from the global patient advocacy community and are inviting leaders of patient organisations and stakeholders to submit resources for consideration, so that the library can become a sustainable repository for the patient community to help strengthen advocacy efforts, regardless of disease area and region.

IEEPO welcomes suggestions from the patient community and other stakeholders for resources that should be included in the library.

Contribute to a global knowledge repository by submitting a resource today!

If you would like to submit a resource, material or tool for consideration please consider the below guidelines.

- Materials should ideally be open-source and preferably have a creative commons license, to allow them to be shared in the public domain. See here for more details: <https://creativecommons.org/licenses/>
- Materials should ideally have relevance to multiple disease areas and geographies
- Materials should be based on valid, reliable, and legitimate information, which includes documented evidence, expert opinion, and personal experience
- Ideally, materials should be no older than three years. However, older materials will be reviewed on a case-by-case basis
- The material should be available in English language; additional language versions are welcomed however not mandatory

Ideas for library submissions

The IEEPO LEARN Library will consider all submissions for materials that fit with the above eligibility criteria. You may wish to consider materials and resources that fit with these subject areas (note: these are suggestions only and not mandatory for submissions):

- Policy
- Health literacy
- Health equity
- Patient-led evidence generation (data generation)
- Evidence-based advocacy (usage of patient data)
- Disease awareness
- Digital health solutions (e.g telemedicine, remote/virtual care, self-care through wearables and personal health apps, medical diagnostic and treatment technologies)
- Patient support services (e.g. lifestyle management, physiotherapy, psychological support)
- Operational (e.g. how to run an effective patient organisation, creating a strategic advocacy plan, effective fundraising, stakeholder management, social media guide).



2. How to reuse materials in this IEEPO library under the Creative Commons License

What am I allowed to do with the IEEPO library materials?

Many of the resources in LEARN library are licensed under a Creative Commons Attribution-Noncommercial-Share Alike 4.0 International (CC BY-NC-SA 4.0) license. By having the resources featured under CC BY-NC-SA 4.0 license it means that you may:

Share — copy and redistribute the material in any medium or format

Adapt — remix, transform, and build upon the material

It does however mean that when you use it you must also:

Give appropriate credit by naming the creator and attribution parties

Provide a copyright notice, license notice and disclaimer notice

Link to the original material

Provide a link to the original CC BY-NC-SA 4.0 license –

<https://creativecommons.org/licenses/by-nc-sa/4.0/>

Indicate if you modified the material and retain an indication of previous modifications

NB: If you remix, transform, or build upon the material, you **must distribute your contributions under the same license** as the original (CC BY-NC-SA 4.0). You may not apply legal terms or technological measures that legally restrict others from doing anything the license permits.

What am I not allowed to do with the IEEPO library materials?



Use the licensed material for commercial purposes.

Commercial use means primarily intended for or directed towards commercial advantage, payment or monetary compensation, which would be a violation of the license.

The license may not give you all of the permissions necessary for your intended use. For example, other rights such as publicity, privacy, or moral rights may limit how you use the material. You do not have to comply with the license for elements of the material in the public domain or where your use is permitted by an applicable exception or limitation.



3. Frequently asked questions

Q: Can also “for-profit” organizations submit their resources to the LEARN library?

A: In principle, other commercial organizations can supply their own resources as long as those are independent, not portraying or advertising any particular brand or molecule or service. Materials need to be co-created with the patient community and fulfill all of the above-mentioned criteria. Ideally, the materials should be stored in multistakeholder platforms such as patient groups websites, alliances websites etc.

Unsure? Still have questions?

Reach out to us at global.ieepo@roche.com and discuss your individual case.

The above is an easy-to-read summary of the license but does not substitute the legal text which is available to read and for download at <https://creativecommons.org/licenses/by-ncsa/4.0/legalcode>.