

Orphan Drug Development Guidebook

Building Block E127

This document defines the content of the Building Block created for each identified tool, incentives, initiative or practice introduced by public bodies or used by developers to expedite drug development in Rare Diseases (RDs).

ITEM	DESCRIPTION
Building Block (BB) Title	European Patients' Academy (EUPATI) toolbox
References	https://www.eupati.eu/
Description	<p>EUPATI was an IMI project. It was completed in 2018 and it is picked up and continued by EPF (European Patients Forum).</p> <p>EUPATI had two major deliverables, the Patient Academy and the Toolbox.</p> <p>The Academy:</p> <p>The EUPATI Academy is the only in-depth training program for patient experts so far in EU that lasts 14months.</p> <p>It includes an <u>online training program</u> supported with <u>two weeks of F2F training</u>.</p> <p>The Academy is still operated by EPF, providing high quality training in drug development to patient from EMEA.</p> <p>It has produced so far more than 150 patient experts that function as advocates all over EU and in various initiatives and fora.</p> <p>The EUPATI has also created the National EUPATI platform that include the patient experts that interact with the local authorities and develop national trainings.</p> <p>The Toolbox concept:</p> <p>Just like a real toolbox that any carpenter or electrician uses, the EUPATI Toolbox contains all the 'tools' you might need around medicines research and development.</p>

	<p>Quite possibly you won't need all of it, and you can certainly specialise in any part of it, but any question you have regarding medicines research and development should be able to be answered here.</p> <p>In this case, the Toolbox is not medicine- or disease-specific, but having said that, the information included in it should be applicable to the majority of diseases and/or medicines you may be concerned with. Besides the 12 categories of development, there are also more interactive areas of how you can group and use the information you need in the Discover!, Adapt!, and Share! areas.</p> <p>Finally, there is a Toolbox for Beginners area where there have been highlighted some key introductory topics to help you begin to explore medicines research and development. Feel free to roam through there as well.</p> <p>The Toolkit so far has more than 1.000.000 unique views!</p>
Category	Developmental Resources Building Block
Geographical scope	European Union
Availability	The EUPATI Academy and Toolbox is not specific to Rare Diseases but provide a broad range of useful information. The information though is very relevant to rare disease medicines development and highly useful and appreciated by the rare disease patients that finished the academy and use the toolbox.
Scope of use	<p>Patient Training and Use the EUPATI toolbox for advocacy</p> <p>Research but also experience in patient advocacy and activism show that experts and patients, and their organisations are an important part of medicines development. They can only achieve effective and sustainable results in advocacy if their knowledge about their disease areas and political environment is sound and scientifically founded.</p> <p>It is essential that experts and patients can clearly see the processes and methods by which medicines are developed and brought to the market to understand where and how they can make a meaningful impact, and how they can influence the process to make sure that patients' interests and viewpoints are duly represented.</p> <p>Eupati.eu provides a useful toolbox of resources to complement the tools already available to patient advocates and organizations.</p> <p>Know what you want and let EUPATI inform/advise you how to achieve it.</p>

Stakeholders	EUPATI was a public private partnership IMI Consortium. The Initiative remains with the PPP spirit but management of it has now been taken over by EPF – European Patient Forum.
Enablers / Requirements	none
Output	Training through Eupati Accademy and Toolbox
Best time to apply and time window	No time window – essential when you want to start exploring medicines research and development
Expert tips	<p>PROs:</p> <ul style="list-style-type: none"> – Focus on Research & Development – online training and resources – translation in several language. <p>CONs:</p> <ul style="list-style-type: none"> – High commitment is required by the participants – Possible sustainability issues after the end of IMI