

Revision of EU Legislation on Medicines for Children and Rare Diseases

Part II - Public Consultation

Deadline: Friday 30 July midnight CEST

ORGANISATIONAL INPUTS NEEDED FROM AS MANY AS POSSIBLE

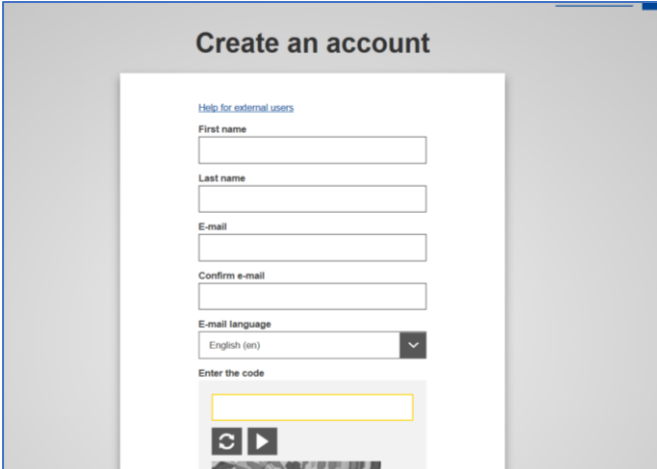
This is a key opportunity to make sure that paediatric haemato-oncology is not overlooked in the EU agenda, We invite being straightforward in requesting that children & adolescents unmet medical needs are addressed within the revision of legislation. Your responses and spreading the information within your networks is key to maximise the number of replies on childhood cancer issues.

GUIDANCE ON HOW TO PROVIDE YOUR INPUTS

STEP 1. Create an account on EU Health Policy Platform (required to be able to submit comment)

1a. Go to: <https://webgate.ec.europa.eu/cas/eim/external/register.cgi>

1b. Fill in form



1c. Create password (activation link will be sent to your email address)

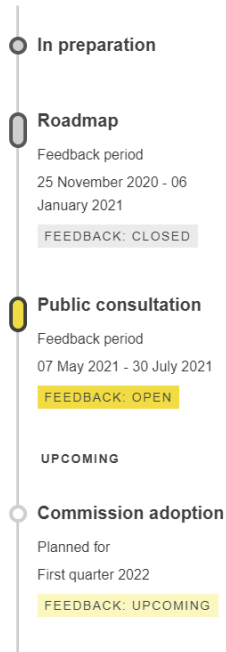
Confirmation email on newly created account may take up to 24 hours to receive!

STEP 2: Access the EU Consultation for the Legislation on Medicines for Children and Rare Diseases

2a. Go to:

https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12767-Medicines-for-children-&-rare-diseases-updated-rules_en

Scroll below through the page where written 'Public Consultation' and press 'Go to consultation'



Public consultation

FEEDBACK: OPEN

Feedback period

07 May 2021 - 30 July 2021 (midnight Brussels time)

The Commission would like to hear your views.

Through public consultations you can express your views on aspects of EU laws and policies before the Commission finalises its proposals.

[Go to consultation >](#)

Commission adoption

FEEDBACK: UPCOMING

Type

Proposal for a regulation

[More about adopted acts](#)

Planned for

First quarter 2022

Subscribe to receive notifications

Be notified by email when new initiatives are added on topics you're interested in or follow developments to individual initiatives.

2b. After clicking 'Go to consultation' you will be directed to this website page:

https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12767-Medicines-for-children-&-rare-diseases-updated-rules/public-consultation_en

PAGE CONTENTS

[About this consultation](#)
[Target audience](#)
[Why we are consulting](#)
[Responding to the questionnaire](#)
[Contact](#)

About this consultation

Feedback period 07 May 2021 - 30 July 2021 (midnight Brussels time)

Topic Public health

Target audience

Stakeholders and members of the general public, including patients and doctors, are welcome to contribute to this consultation. Organisations representing patients and civil society active in public health, healthcare professionals and providers, academia, researchers and the pharmaceutical industry may also have an interest to contribute.

Why we are consulting

This initiative will explore several options to address the shortcomings identified in the evaluation of the Regulations on medicines for children and rare diseases, in view of a revision of the existing legislation.

With this public consultation, citizens and stakeholders are invited to share their views and experiences on the main obstacles they are facing concerning treatments for rare diseases and children, on possible ways to overcome these obstacles and on how to make the current legislation future-proof.

Responding to the questionnaire

You can contribute to this consultation by filling in the online questionnaire. If you are unable to use the online questionnaire, please contact us using the email address below.

Questionnaires are available in some or all official EU languages. You can submit your responses in any official EU language.

For reasons of transparency, organisations and businesses taking part in public consultations are asked to register in the EU's [Transparency Register](#).

[Respond to the questionnaire >](#)

Press 'Respond to the questionnaire' and you will be directed to below page.

Give your feedback on:

EU Legislation on Medicines for Children and Rare Diseases

How to add your feedback

Log in

Register

European Commission website

This site is managed by the Directorate-General for Communication

Strategy

About the European Commission

Business, Economy, Euro

3d. Click 'Log in' or 'Register' to respond to the roadmap consultation (you will be asked to log in your account on EU Health Policy Platform)

STEP 3: Provide your inputs

The consultation is addressed to individual citizens, patients, and carers replying in their personal capacity as well as health professionals and organisations involved in cancer prevention, diagnosis, treatment, follow-up care and research.

Drawing on your input, the Commission will go on to complement this initial public consultation with further targeted interactions with specific stakeholder groups.

REFERENCE DOCUMENTS

- SIOPE draft response on the EU Legislation on Medicines for Children and Rare Diseases: [here](#)
- SIOPE and CCI-E 6 Key Recommendations on Paediatric Cancers: [here](#)

For any questions, please contact: marko.ocokoljic@siope.eu