



International Experience Exchange
with Patient Organisations



LEARN



Part of the [IEEPO](#)
[LEARN Library](#)

A Co-Created Personalised Healthcare Hub and Toolkit for the Patient Community

Equipping you to increase understanding of personalised healthcare and its potential within your community



A Hub and Toolkit to increase knowledge and action towards personalised healthcare in your community



1

How and why was the Personalised Healthcare Hub and Toolkit for the Patient Community made?

Slides 4-8



- ❖ Understand why personalised healthcare education and advocacy is important to transform care
- ❖ Discover the tools you can share to increase personalised healthcare knowledge and action in your community

2

What is the Personalised Healthcare Hub for the Patient Community?

Slides 9-10



- ❖ Find out how the Hub can help individuals impacted by health conditions learn more about the benefits of personalised healthcare
- ❖ Help health advocates identify key priority topics and action areas to improve understanding of, and access to, personalised healthcare options for their communities

3

What is the Personalised Healthcare Toolkit for the Patient Community?

Slides 11-15



- ❖ Ensure individuals with various levels of knowledge and experience of personalised healthcare understand what it can mean for them and their community
- ❖ Help the community learn how they can advocate for personalised healthcare on an individual and community level

A Hub and Toolkit to increase knowledge and action towards personalised healthcare in your community

4

How can I adapt these resources so the content is specific to my community?

Slides 16-17



- ❖ Increase the relevance of, and engagement with the materials by adapting them for the specific condition/community, in accordance with the Creative Commons license guidelines
- ❖ You can also browse existing condition-specific materials on the Personalised Healthcare Hub

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How can I engage my community on personalised healthcare using these tools?

Slides 18-21



- ❖ Use template email communications and social media posts to share the Personalised Healthcare Hub and Toolkit for the Patient Community
- ❖ Ensure the materials benefit as many people in the community as possible and raise awareness of personalised healthcare in general

6

How can I see that my communities' understanding of personalised healthcare has changed?

Slides 22-24



- ❖ Understand the change in awareness of personalised healthcare as a result of sharing the Personalised Healthcare Hub and Toolkit, to ensure the tools continue to be relevant and useful for communities for the long-term



How and why was the Personalised Healthcare Hub and Toolkit for the Patient Community made?





Introduction

Personalised healthcare is more than just a buzzword of the moment. It is **an approach** that **has the potential to radically improve outcomes for people affected by health conditions and their communities**, whilst benefiting healthcare systems and societies around the world. Never has it been more important to **understand, educate and advocate for personalised healthcare**, with the aim of **achieving effective and sustainable healthcare for all**. But what actually is personalised healthcare?

Levels of understanding around personalised healthcare and what it means for you and different communities vary widely. That's why the **Personalised Healthcare Hub** and **Toolkit for the Patient Community** were made with – and for – the patient community. Together they support advocates in their work to make personalised health solutions available for everyone, and help those affected by health conditions to get to know personalised healthcare more generally.

Containing educational materials that increase knowledge and understanding of personalised healthcare, this **toolkit** can be used and adapted by you, in your local efforts to **educate and engage important stakeholders on the topic**.

The Personalised Healthcare Hub can be found within the IEEPO LEARN Library.



The Personalised Healthcare Hub and Toolkit for the Patient Community were co-created with, and informed by needs and aims identified by, patient organisation leaders.

Foreword: From concept to creation



As part of ongoing co-creation with patient communities, including the [International Experience Exchange with Patient Organisations \(IEEPO\)](#), the [IEEPO LEARN Library](#) launched in July 2021. It brings together open-source learning resources and materials to support advocacy organisations of all sizes in their work around the world.

The **Personalised Healthcare Hub and Toolkit made with and for the Patient Community** is one of its first resources: a growing collection of educational materials, guidance, and best practice examples that will support health advocates and the patient community to co-create personalised health solutions and make them available for everyone.

It all started when Roche formed the **Global Personalised Healthcare Patient Council**, a group of advocacy organisation leaders who are interested in, and leading the way for, involving people with health conditions in personalised healthcare solutions from the start. In August 2019, Roche and the Council met and agreed that increasing personalised healthcare literacy among the patient, carer and health advocate community should be a priority. We agreed on a compelling narrative and key elements delivering value for people affected by health conditions.

Together, we worked on the Personalised Healthcare Value Framework, a set of clear and evidence-based key messages that articulate the **advantages and benefits of personalised healthcare** for patients. We sourced examples of these **benefits** in action, and agreed on a way of **defining personalised healthcare** from the perspective of those affected by health conditions:

“Personalised healthcare involves the tailoring of care to an individual’s unique health needs and preferences”

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This definition covers a wide range of healthcare approaches and personalised solutions, such as **patient-centred care**, individualised care, **value-based care** and the growing fields of **genomic testing**, **biomarkers**, **health data** and **digital health**.

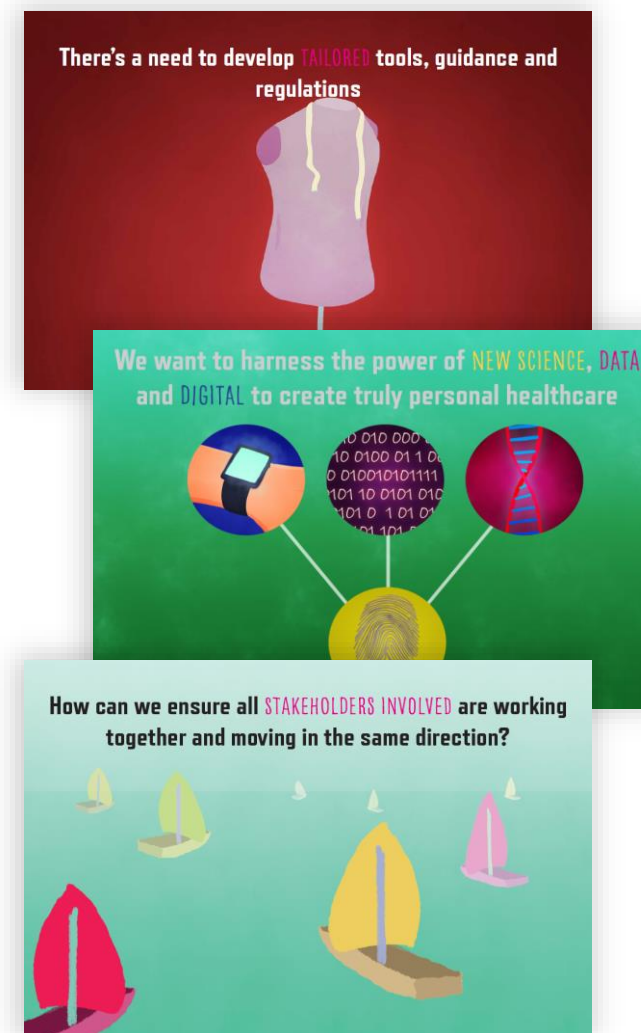
The Council suggested that we develop a toolkit to help bring these messages to the patient community in a practical, useful way. We formed a working group of patient organisation leaders, and in July 2020 we started to develop a collection of educational materials for people affected by health conditions, the wider community and the health advocates that support them. These materials form the [Personalised Healthcare Toolkit](#).

Knowing that there are also so many excellent resources created by patient and health organisations available online, we started collecting existing materials, guidance and best practice examples.

Our [key topics](#) provided the framework for an interactive [Health Advocates Playbook](#) with clear ideas and support for taking action to make personalised solutions available to everyone. It includes resources covering key topics such as **genomic testing**, **biomarkers**, **health data**, **digital health**, **patient-centred** and **value-based care**. The Playbook forms the final part of the Toolkit.

In May 2021, we decided to bring the Toolkit online – building the [Personalised Healthcare Hub](#) as one of the first resources in the [IEEPO LEARN Library](#). The Hub is a living repository – with new materials added and updated by our patient partners and community.

In 2022, we are working with the community to broaden the resources, and ensure **condition-specific materials** are included. These show examples of personalised healthcare in action and the benefits it can bring to people affected by specific health conditions.



Affiliations

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You may share (copy and redistribute) and adapt (remix, transform, and build upon) this. However you must give appropriate credit to Roche and its co-creation partners (its Global Personalised Healthcare Patient Council and the Personalised Healthcare Literacy Squad), a license notice, and a link to the original material as co-created in June 2021.

If you build upon this material, you must distribute your version under the same license as the original ([CC BY-NC-SA 4.0](#)). For further guidance on material adaptation, please see [here](#).



The Toolkit and Hub were co-created in partnership with:



Canadian Organization
for Rare Disorders



EFNA

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS



International Alliance of
Patients' Organizations

A global voice for patients



LYMPHOMA
COALITION

YOUTH
CANCER
EUROPE

Condition-specific materials, adapted from the Toolkit, are being co-created with patient communities

When localising content, please ensure content complies with local legal and regulatory requirements.

Personalised Healthcare Hub and Toolkit for the Patient Community



What is the Personalised Healthcare Hub?

Slides 9-10 

A bank of guidance, tools and best practice examples to support health advocates in their work to make personalised health solutions available for everyone, and help people affected by health conditions to get to know personalised healthcare more generally

What is the Personalised Healthcare Toolkit for the Patient Community?

Slides 11-15 

Tools for educating people affected by conditions about what personalised healthcare can do for them, and for members of your organisation on what personalised healthcare means for the wider community



What is the Personalised Healthcare Hub?



Supporting health advocates, people living with health conditions, their carers and the wider community



Personalised Healthcare Hub

What is it?

The **Personalised Healthcare Hub** is dynamic, interactive and open-source and intended to help individuals impacted by health conditions learn more about the benefits of personalised healthcare, and health advocates identify key priority topics and action areas to improve understanding of, and access to, personalised healthcare options for their communities.

The Personalised Healthcare Hub is one of the first resources of the **International Experience Exchange with Patient Organisations (IEEPO) LEARN Library**, with the goal of supporting patient communities in their areas of greatest need now and in the future.

Please share any condition-specific guidance, tools or best practice examples which you feel would sit well on the Hub or in the IEEPO LEARN Library directly via the [online contact form](#)

How could I use it?

There are different ways to use the Personalised Healthcare Hub, as it is a resource that you can personalise to your needs or interests.

1. Search for specific tools

- These are resources such as the [Personalised Healthcare Toolkit for the Patient Community](#) and [Personalised Healthcare Playbook for Health Advocates](#)

2. Go on a personalised journey

- People who are looking for more information rather than specific resources can 'choose a topic' to get started. Based on their answers, more questions will appear to help narrow down the most useful resources for them

3. Share the Hub with colleagues and wider networks

- This can be done on websites or at events to improve understanding of personalised healthcare and to signpost to action areas



What is the Personalised Healthcare Toolkit for the Patient Community?

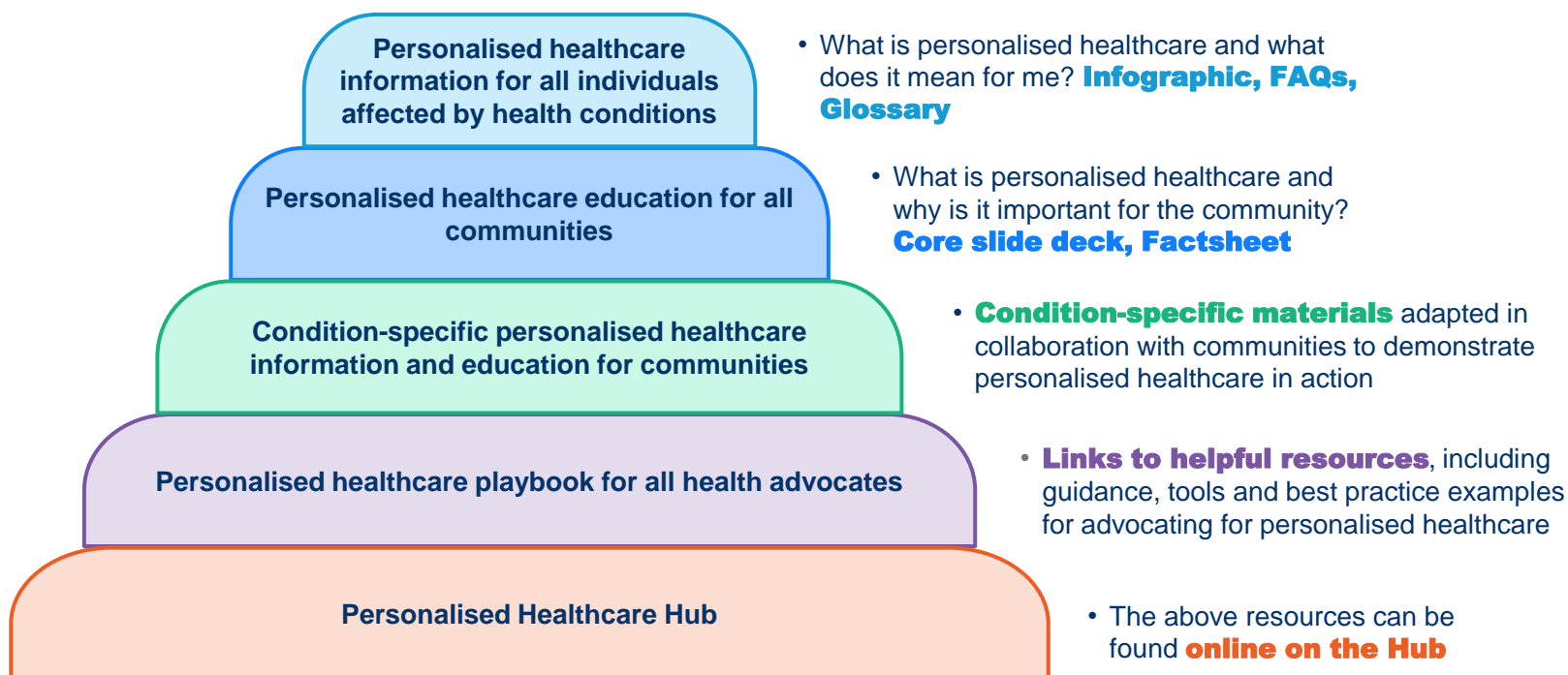




Resources to support you

The toolkit includes a suite of educational resources on the topic of personalised healthcare and its benefits for people and communities affected by health conditions. It is readily available now for adaptation under Creative Commons licensing so that you can pick and choose the appropriate slides, imagery or facts that are most relevant to you and your audience's needs. For example, you may find yourself using the whole core slide deck to brief members of your organisation, or just individual images from the infographic to explain key points to your community. **Condition-specific resources are under development and will be uploaded [here](#) on the Personalised Healthcare Hub.**

The below diagram explains what the different materials can be used for:



Please credit the developers of the toolkit materials by including the following line on any adapted materials, ensuring you also retain an indication of any previous modifications:

“Adapted under the [Creative Commons BY-NC-SA 4.0](#) license from the [Personalised Healthcare Toolkit for the Patient Community](#) co-created by a Global Personalised Healthcare Patient Council and the Personalised Healthcare Literacy Squad, supported by Roche.”

For further guidance on material adaptation, please see [here](#).



Supporting all individuals

Infographic

What is it?

An introduction to personalised healthcare and the value it can bring to people affected by conditions

How could I use it?

Share on websites, at events or select relevant information for use on social media to educate on the benefits of personalised healthcare specific to them

Accessible versions in black and yellow and black and white are available



Frequently Asked Questions

What is it?

Answers questions that people affected by conditions might have about personalised healthcare and what it means for them

How could I use it?

Facilitate a Q&A session to educate on personalised healthcare or house online alongside the infographic



Glossary

What is it?

A bank of definitions for medical jargon and terms often associated with personalised healthcare

How could I use it?

As a quick reference guide to define medical terms used in other materials or by healthcare professionals





Supporting all communities

Core slide deck

What is it?

A presentation introducing what personalised healthcare is, who it's for, its value to people affected by conditions, and potential to improve outcomes and care

How could I use it?

To train and educate people on the benefits of personalised healthcare, at the individual level and for society

Content and imagery can be tailored to specific communities as appropriate, and accessible versions in black and yellow and black and white are also available



Factsheet

What is it?

A factsheet explaining how personalised healthcare can impact people affected by conditions, and improve outcomes and care

How could I use it?

House online or distribute, to educate people on the value of personalised healthcare for them and society





Supporting all health advocates

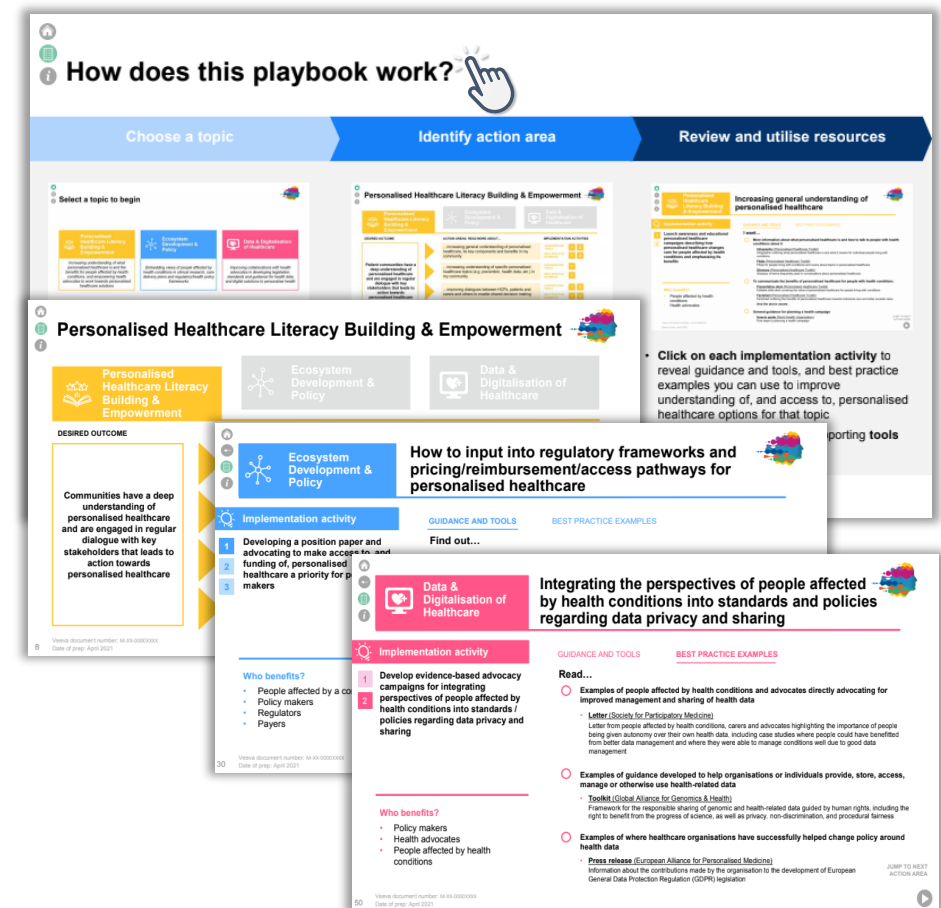
Personalised Healthcare Playbook for Health Advocates

What is it?

A bank of resources intended to help health advocates and people affected by health conditions identify action areas and find resources to support improving understanding of, and access to, personalised healthcare options in their communities

How could I use it?

To access guidance and tools to support your existing advocacy projects and those of other health advocates within your network





How can I adapt these resources so the content is specific to my community?



How to re-use toolkit materials under the Creative Commons License



The **materials** in the co-created Personalised Healthcare Hub and Toolkit for the Patient Community 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

You may wish to adapt materials to add condition- or geography-specific content to ensure they are as relevant as possible for your community.

However when you use the materials 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
- Indicate if you modified the material and retain an indication of previous modifications

Note: 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.

Please credit the developers of the toolkit materials by including the following line on any adapted materials, ensuring you also retain an indication of any previous modifications:

“Adapted under the Creative Commons BY-NC-SA 4.0 license from the Personalised Healthcare Toolkit for the Patient Community co-created by a Global Personalised Healthcare Patient Council and the Personalised Healthcare Literacy Squad, supported by Roche.”



How can I engage my community on personalised healthcare using these tools?





Dissemination guidance

Share the resources with your network

You can **share the Hub with your colleagues and wider network**. The draft **template communication** may be of help. Additionally, you may want to:

1. Be mindful of any key **upcoming opportunities or events** at which the toolkit could be shared
1. Please share any **condition-specific guidance, tools or best practice examples** which you feel would sit well on the Personalised Healthcare Hub and in the IEEPO LEARN Library with Roche via the online contact form
1. Let your Roche contact know if you would like to work on **Disease Area-specific materials** or discuss the **latest available materials** that have been co-created with patient organisation leaders



Template communication

This is a template communication that you may find useful when sharing the Personalised Healthcare Hub and IEEPO LEARN Library and within your network

Dear all,

Explore the IEEPO LEARN Library and Personalised Healthcare Toolkit and Hub for Patient Community now!

I am delighted to share a useful suite of resources with you - the [IEEPO LEARN Library](#)! Co-created by Roche and its patient partners, this growing repository of open-source training tools, resources, and materials will support organisations to build capacity, increase knowledge and strengthen their skills.

One of the first resources is the [Personalised Healthcare Community Hub](#), a collection of 150+ tools including the tailored personalised healthcare [educational materials and playbook](#), which were developed to support health advocates and the patient community in their work to co-create personalised health solutions and make them available for everyone.

This is part of a growing collection of co-created and community-sourced tools made with - and for - the patient community, with many more exciting projects underway as part of the [LEARN](#), [THINK](#), [MAKE](#) and [CHANGE IEEPO](#) domains.

What's next? Our ask of you now

We are now ready to share the IEEPO LEARN Library and Hub, including the tailored personalised healthcare [educational and advocacy materials](#), with the wider community and ask for your support to do so.

Please find ideas and guidance on sharing the Hub and measuring its success in the enclosed guidance document, including:

- **template emails** for sharing the it within your professional network and wider community (page 19)
- **ideas for gathering feedback, such as pre- and post- launch surveys** and tips for adapting these to use on digital channels and during live events (page 23).

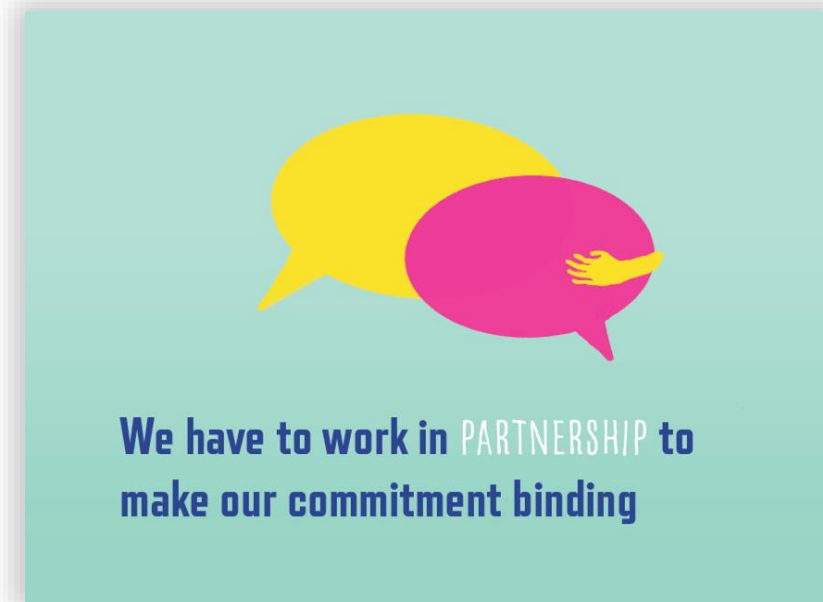
These are vital to measuring the impact of this project and advocating for future co-created resources of this nature, so please do share feedback with us!

I hope this is of interest, and that you are able to share this internally at your organisation and with your community where relevant.

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Template social media

These are some example social media posts that you may find useful when sharing the Personalised Healthcare Hub and IEEPO LEARN Library within your network

“ We are thrilled to have collaborated on the [#IEEPO](#) LEARN Library and its [#PersonalisedHealthcare](#) Hub. Both tools were created by and for the advocacy community. Find resources here: <https://www.personalisedhealthcarehub.com/> ”

“ The [#IEEPO](#) Personalised Healthcare Hub is an interactive website to help people affected by health conditions learn more about the benefits of personalised healthcare. Find tools to educate and advocate for [#PersonalisedHealthcare](#) here: <https://www.personalisedhealthcarehub.com/> ”

“ Never has it been more important to understand and advocate for [#PersonalisedHealthcare](#), and here is a tool to help! Explore the [#IEEPO #PersonalisedHealthcare](#) Hub with its wealth of resources - including accessible versions: <https://www.personalisedhealthcarehub.com/> ”

“ The [#IEEPO](#) LEARN Library provides resources for advocates, supporting our work in [#HealthPolicy](#), [#DigitalHealth](#) and [#DiseaseAwareness](#). It includes the resource-rich [#PersonalisedHealthcare](#) Hub – explore the [#IEEPO](#) LEARN library: <https://www.personalisedhealthcarehub.com/> ”





How can I see that my communities' understanding of personalised healthcare has changed?





Impact measurement

Let us know how it goes

Please share the following information with your Roche contact, which will help inform further tools for community use:

1. Answers to the pre-launch survey once you've shared it with your networks (see page 24 for more information)
1. Any **real-time feedback** from your colleagues or wider network
1. Results from the survey if you choose to ask questions on your social channels (see page 24 for more information)

Please share any feedback and survey results with your Roche contact or the online contact form.
Follow-up calls will be scheduled to gauge your feedback and use of the Toolkit materials in your community.



Pre- and post-launch surveys

Please find an anonymous short survey below, which you can share with your network and community to enable you and us to **understand how awareness of personalised healthcare has changed** following use of the Personalised Healthcare Hub and Toolkit for the Patient Community, one of the first resources in the IEEPO LEARN Library.

The survey should take approximately 10 minutes to complete.

[Click here to access the survey](#)

If you wish to, you may **share this survey with your network** *before* you have distributed the link to the Personalised Healthcare Hub and Toolkit for the Patient Community and the IEEPO LEARN Library.

You may then **reshare this survey with your network three to four months** *after* you have distributed the Hub and initial survey.

Ideas to adapt the survey for your social media channels

You may wish to share the survey questions on your social media channels as polls to further engage your network. The survey questions, adapted for use on social media, are copied below for ease of adaptation.

Some tips on how to share these questions on your social media channels:

- **Keep it relevant:** tailor the questions to make sure they are relevant to your audience and disease area
- **Post during peak traffic times:** you will see the highest engagement if you publish the questions when you know your followers are using social media
- **Don't overdo it:** posting once or twice a week should be enough to boost engagement without overwhelming your audience
- **Follow up:** always post a follow up to polls sharing the results and linking to further resources for your followers

You could also use these survey questions during events you hold, as live polls during your presentation. Along with tailoring the questions to your audience, make sure to set them up and test how they work in advance of your event.

Question		Answers
1.	How would you rate your understanding of what personalised healthcare is?	<ul style="list-style-type: none"> • Very good • Good • Not sure • Bad • Very bad
2.	Do you think personalised healthcare is relevant to your health condition?	<ul style="list-style-type: none"> • Yes • No
3.	Have you experienced efforts to personalise your healthcare?	<ul style="list-style-type: none"> • Yes • No • Not sure
4.	Would you be comfortable speaking to your healthcare practitioner about personalised healthcare?	<ul style="list-style-type: none"> • Yes • No
5.	Do you know where to find resources about personalised healthcare?	<ul style="list-style-type: none"> • Yes • No

Please **share any survey results** with your Roche contact.

Please reach out to your Roche contact if you or your colleagues would like to share a more detailed survey about personalised healthcare with your members