BETA

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Patient Information Needs Map Instructions

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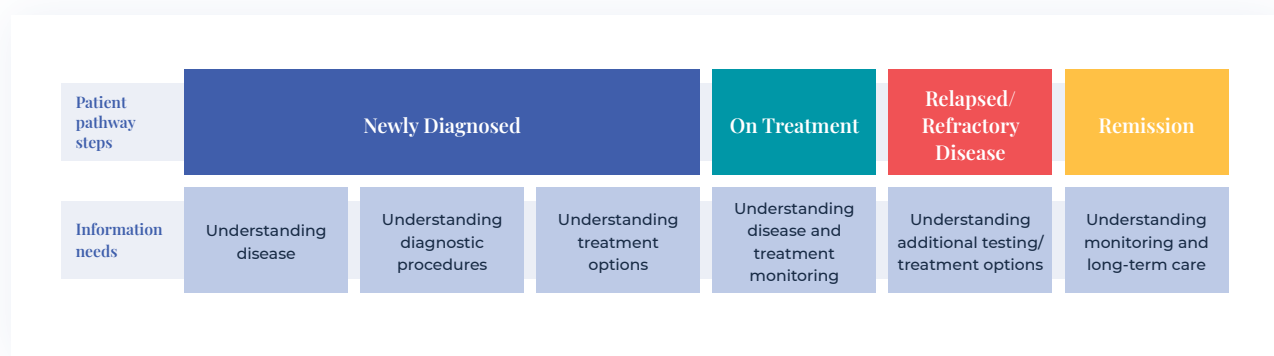
About this tool

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WHY?

Over the past year, the FT3 community has identified the need for information and support that **meets patients where they are, helping them make informed decisions and actions at the right time.**

WHAT?

The **Patient Information Needs Map (beta)** is a tool for Precision Medicine (PM) advocates and champions including HCPs, to identify information needs and gaps in existing resources for individual patients. The map consists of **6 information needs** and **4 patient pathway steps** where patients might need supporting information and resources.

Patient pathway steps	Newly Diagnosed			On Treatment	Relapsed/ Refractory Disease	Remission
Information needs	Understanding disease	Understanding diagnostic procedures	Understanding treatment options	Understanding disease and treatment monitoring	Understanding additional testing/ treatment options	Understanding monitoring and long-term care

It is a **customizable tool to guide and organize information resources and other ongoing efforts to support patient education and awareness.** The current Q&A Resource Builder is the result of a robust co-creation process by a multi-stakeholder group of experts in precision medicine. See annex 1 for more information.

FOR WHO?

Precision Medicine stakeholders (e.g. advocates, champions, and HCPs) who want to **provide education and awareness resources to help patients access the right information at the right time.**

This includes anyone who works in areas related to precision medicine and wishes to develop information resources for patients but doesn't know where to start, or anyone who needs support in identifying the most pressing information needs of their patient community.

Please share your feedback with us on how to improve this **patient information needs** map and how we can bring it to the next level!

How to use the Patient Information Needs Map

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The following steps outline how to use this tool. We recommend following a co-creation approach with the Patient Information Needs Map and any subsequent resources. This involves working collaboratively with different stakeholders (e.g. patient advocates, individual patients, healthcare professionals) to ensure that different perspectives are taken into account.
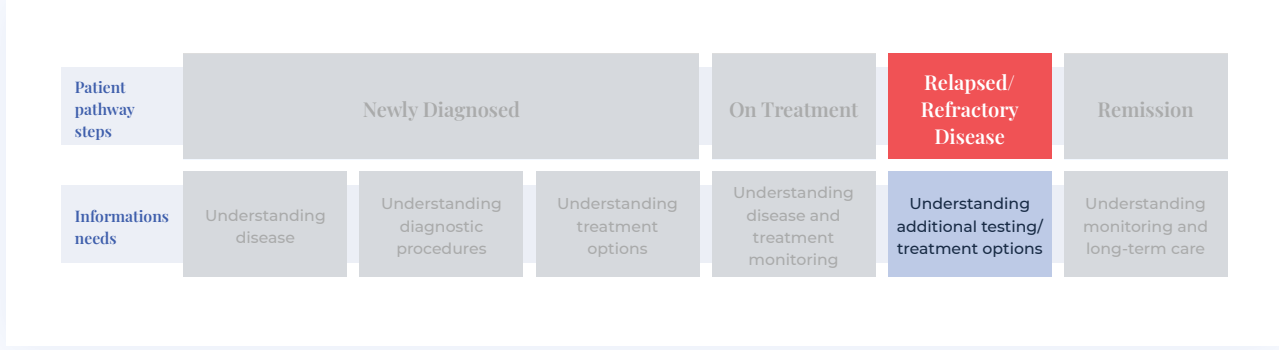
Step 1: Download, draw or Print the Patient Information Needs Map

CLICK HERE TO GET STARTED

Step 2: Review the different patient pathway steps and identify which information needs you want to address

Practical example:
I am a patient advocate working for thyroid cancer patients and I know that understanding the potential benefits of targeted therapies and precision medicine is very important for relapsed or refractory patients.

Patient pathway steps	Newly Diagnosed			On Treatment	Relapsed/ Refractory Disease	Remission
Informations needs	Understanding disease	Understanding diagnostic procedures	Understanding treatment options	Understanding disease and treatment monitoring	Understanding additional testing/ treatment options	Understanding monitoring and long-term care

Step 3: Write the information support needs and gaps for your patient community in the first row, below the relevant decision making point

Practical example: *I want to help the relapsed or refractory patients in my community*

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understand what their treatments options and related side effects are before making a decision, but a lay language resource on targeted therapies and related side effects is not available for thyroid cancer patients in my country.

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Patient pathway steps	Newly Diagnosed			On Treatment	Relapsed/ Refractory Disease	Remission
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WHAT ARE THE NEEDS AND GAPS?

Example:
Patients need to understand what their treatments options and related side effects are before making a decision, but a lay language resource on targeted therapies side effects is not available for thyroid cancer patients in my country

Step 4: In the second row, write down the group's ideas on how these information needs could be addressed through information resources and/or support etc.

Practical example:
I will set up a working group to co-create with patients and for patients a lay language booklet that explains the available targeted therapies options and related side-effects for relapsed/ refractory thyroid cancer patients in my country and my language.

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WHAT ARE THE NEEDS AND GAPS?

Example:
Patients need to understand what their treatments options and related side effects are before making a decision, but a lay language resource on targeted therapies side effects is not available for thyroid cancer patients in my country

WHAT RESOURCES AND SUPPORT?

Example:
E.g. Lay language booklet that explains the different treatment options and related side-effects, including tatgeted therapies for relapsed thyroid cancer patients in my country and related language

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Now that you understand how to use this resource, [download it here to get started](#).

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If you have any additional questions, the FT3 team is here to help: get in touch with silvia@thesynergist.org.

Please [share with us](#) your feedback on how to improve this resource and how we can bring it to the next level!
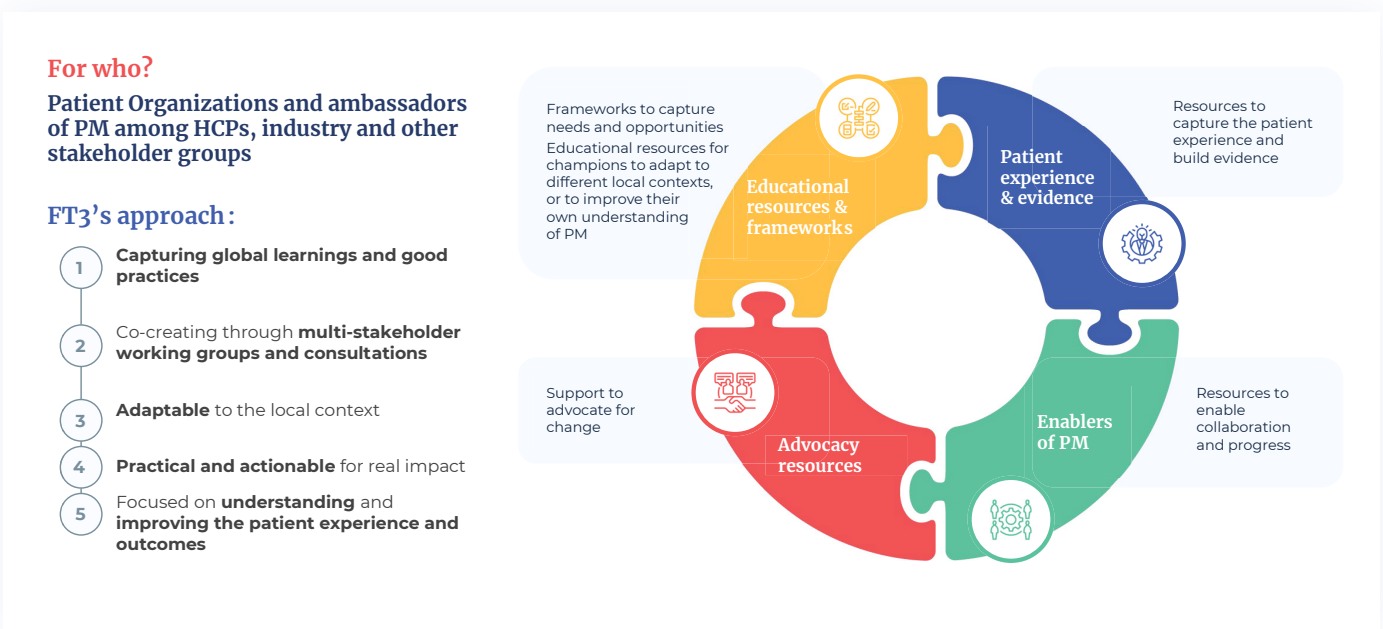
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*Remember: To maximize your impact and make your resource widely available, consider uploading it to [Precision Medicine Synapse](#), a mapping and networking tool to disseminate resources, reduce duplication, and increase opportunities for collaborations.

Please [share your feedback](#) with us on how to improve this **patient information needs** map and how we can bring it to the next level!

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Annex 1.

FT3 Toolkit for Precision Medicine Champions

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This Patient Information Needs Map is part of a broader Toolkit for Precision Medicine Champions. The toolkit is one of the methods that the "From Testing to Targeted Treatments Program (FT3)" community aims to utilize to make precision medicine a reality for all who can benefit from it. Through pilots and consultations, these tools and resources will continue to be refined and expanded. If you are interested in learning more, getting involved or piloting the tools, please contact us.

For who?

Patient Organizations and ambassadors of PM among HCPs, industry and other stakeholder groups

FT3's approach :

1. Capturing global learnings and good practices

2. Co-creating through **multi-stakeholder working groups and consultations**

3. **Adaptable** to the local context

4. **Practical and actionable** for real impact

5. Focused on **understanding** and **improving the patient experience and outcomes**

Frameworks to capture needs and opportunities
Educational resources for champions to adapt to different local contexts, or to improve their own understanding of PM

Educational resources & frameworks

Patient experience & evidence

Resources to capture the patient experience and build evidence

Support to advocate for change

Advocacy resources

Enablers of PM

Resources to enable collaboration and progress

The From Testing to Targeted Treatment Program (FT3) is a non-profit multi-stakeholder collaborative program that aims to unify, accelerate and build on existing efforts to make precision medicine a reality for all patients who could benefit from it.

FT3 brings together diverse stakeholders and activities in precision medicine to identify shared needs, build on existing good practices and learnings and make them replicable through practical and actionable tools and resources for precision medicine champions to drive real change and impact, starting with cancer and testing.

Ultimately, the goal is to develop integrated and optimized resources for different stakeholders to improve access to precision medicine, and to develop a positive momentum to be able to improve patient outcomes and experiences.

This was developed thanks to the FT3 Members and Community of Practice.

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Annex 2.

How this resource was co-created and co-designed

This resource was co-created by a global, multi-stakeholder group with the shared goal to make precision medicine an accessible reality for all patients who could benefit from it.

The journey started with a landscape analysis, with the mapping of 320+ existing patient information resources and the identification of +220 patient information needs through the Patient Engagement Open Forum in September 2020.

These needs were co-reviewed and co-refined by the FT3 Education & Awareness Working Group in several meetings and consultations to define the best ways to approach these information needs.

Building on existing good practice resources and through discussion with over 25 multi-stakeholder representatives, the Education & Awareness working group identified an opportunity to create a patient information "map" that could support precision medicine stakeholders in identifying the most important information needs and possible solutions at different patient decision-making points.

The following resources were consulted in developing this map:

- Personalized Medicine Coalition (PMC) More than a Number: Better health begins with you
- Decibio, Precision Medicine Landscape Map
- MacMillan Cancer Support, Ask about your cancer treatment
- IQVIA, Barriers to the Use of Biomarker Tests Throughout the Patient Journey
- FT3, PEOF 2020 - From Testing to Targeted Treatments Program (FT3) session
- FT3, From diagnosis to treatment and beyond: personalized medicine – what's in it for patients and understanding patient needs to make it a reality?

Acknowledgments

This resource was co-developed in a multi-stakeholder working group representing patient organizations, healthcare providers and researchers, pharmaceutical and diagnostics companies, and external experts. Special thanks for drafting, editing, reviewing, and maintaining momentum to deliver the resource.

Please share your feedback with us on how to improve this **patient information needs** map and how we can bring it to the next level!

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