

BETA



Precision Medicine (PM) Q&A Resource Builder Instructions



Table of contents

Click on each element to jump to the desired section



About this tool

How to use the PM Q&A Resource Builder

Download the tool and share your feedback

Annex 1

FT3 Toolkit for Precision Medicine Champions

Annex 2

How this resource was co-created and co-designed

About this tool



WHY should you use this tool?

This Precision Medicine Q&A Resource Builder has been co-created to **support patient advocates and patient organizations** in helping patients make informed decisions and actions at the right time:

This resource can be used to:

- **Update existing Q&A resources**, ensuring the crucial elements related to precision medicine are covered;
- **Create a new Q&A resource** by adapting this backbone resource to the relevant country and disease.

WHAT will you find in this tool?

This tool includes a series of **questions that patients can ask their health care provider (HCP)** at different moments in time to guide shared decision-making in precision medicine. It provides a starting point that should be adapted to your specific disease and/or local context.

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.

WHO should use this tool?

Patient advocates and Precision Medicine champions who would like to develop/update a Q&A resource on precision medicine for their patient population.



How to use the Q&A Resource Builder

The following steps outline how to use this tool. We recommend following a co-creation approach when using this resource. This involves working collaboratively with different stakeholders (e.g. patient advocates, individual patients, healthcare professionals) to ensure that different perspectives are taken into account.

Before utilizing this PM Q&A builder it might be helpful to review the [Patient Information Needs Map](#) to identify the topics that you would like to cover.

Step 1: Download and open the Q&A builder

Step 2: Review the steps/ information needs important to your patient population

1. Review the questions for each decision-making step that you selected in Step 1; these should be helpful questions to address the information needs in your resource and/or Q&A.
2. Use the dedicated space to select the appropriate questions in their original form or adapt them to your specific diseases, geography etc

Practical example:
I have adapted the questions to make them relevant to breast cancer patients



- What is the difference between genetic and biomarker (mutation, genomic, or molecular testing) testing?
- Do you recommend biomarker (mutation, genomic, or molecular testing) testing?
 - If so, which biomarkers are important for *breast cancer*?
 - If so, which testing method is most appropriate for *breast cancer* in Spain and why?
 - If so, what types of treatments might biomarker testing identify? If my biomarker test results show I am a candidate for precision medicine, what would the next steps be?

Step 3: Adapt the introductory/supporting text

Introductory text example of adaptation: Your doctor may order various diagnostic tests to help understand and diagnose *breast cancer*. These may include a biopsy, scans and/or blood tests. Please review below some important questions that you can ask your doctor in order to acquire a better understanding of diagnostic and testing options.

Step 4: Test & Refine

This involves working collaboratively with different stakeholders to ensure that different perspectives are taken into account. For example you can test out the resource with other advocates.

Step 5: Delete the supporting template content and the unused content. Save your adapted resource as PDF. Save & Download

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 **PM Q&A Builder** and how we can bring it to the next level!

*To maximize your impact and make your resource widely available, consider uploading it to [Precision Medicine Synapse](#), a mapping and networking tool to reduce duplication, and increase opportunities for collaborations. For more information on what Precision Medicine Synapse is, watch this [video](#).

Please [share with us](#) your feedback on how to improve this **PM Q&A Builder** and how we can bring it to the next level!

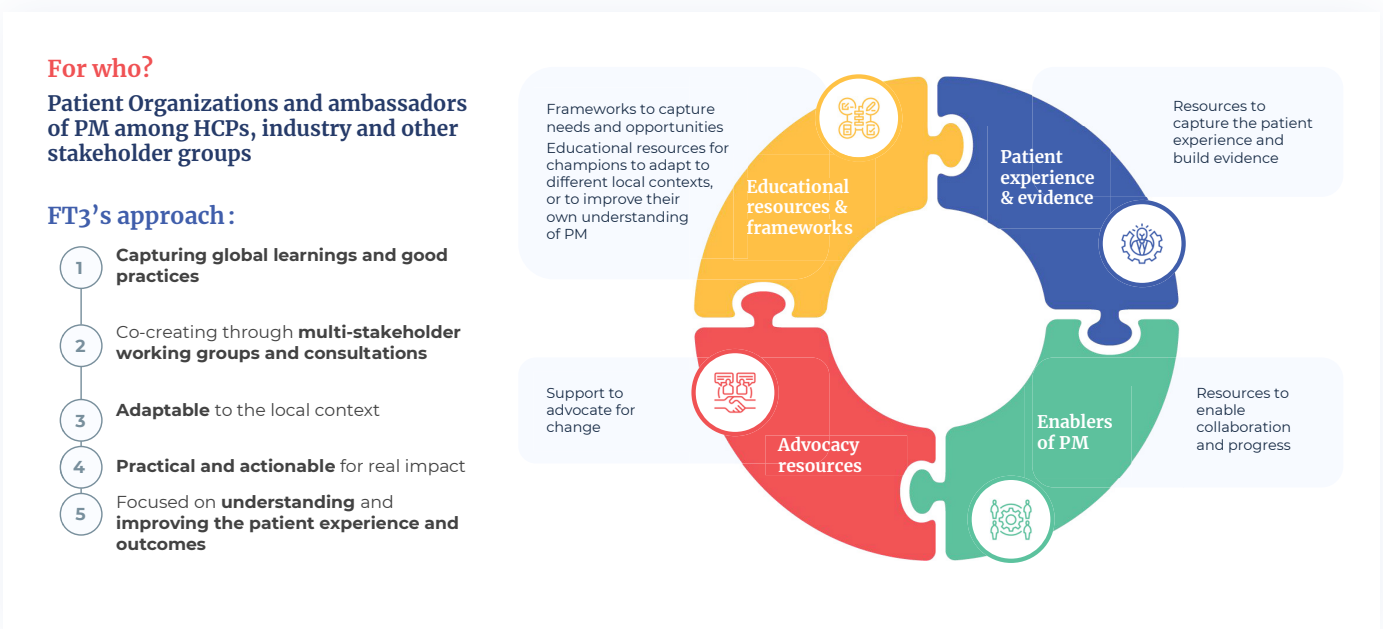
fromtestingtotargetedtreatments.org



Annex 1.

FT3 Toolkit for Precision Medicine Champions

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](#).



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.

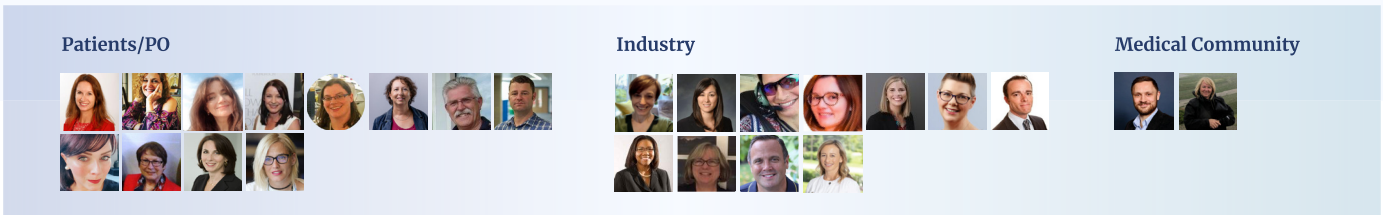
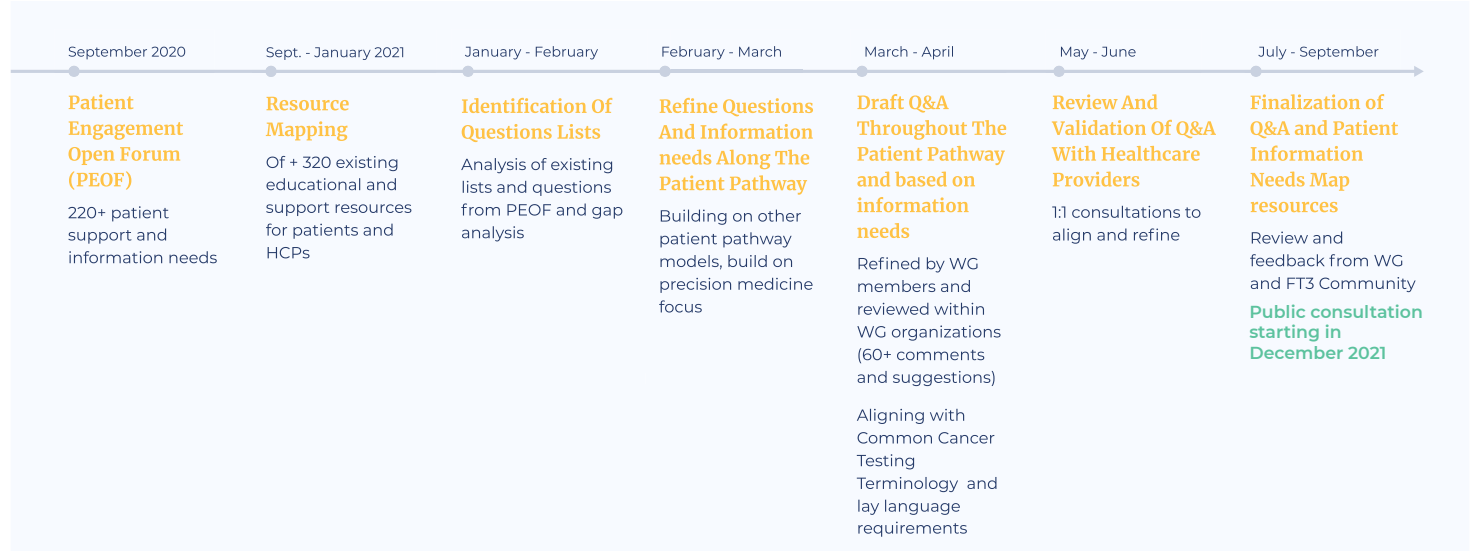


Annex 2.

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 work on this Q&A builder started at the Patient Engagement Open Forum (PEOF) workshop in September 2020, where 220+ patients' needs in precision were identified. Thanks to the PEOF insights and the learnings from a landscape mapping of 320+ existing good resources for patients in precision medicine, the working group identified the lack of a comprehensive PM resource that could support patients to ask the right questions at the right time. While several good Q&A resources exist, they are often piecemeal, do not incorporate all the PM elements, and are usually disease and country-specific.

Therefore, building on good existing resources and through several working groups calls with more than 25 multi-stakeholder representatives, the Education & Awareness working group agreed to fill this knowledge gap by co-creating a comprehensive Q&A builder designed to be adapted by Patient Organizations and Patient Advocates to the needs of their specific patient population disease and/or local context.



You can find below the primary good resources that were consulted:



- Personalized Medicine Coalition (PMC) [More than a Number: Better health begins with you](#)
- MacMillan Cancer Support, [Ask about your cancer treatment](#)
- Cancer101, [Questions to Ask My Health Care Team](#)
- Cancer Support Community, [Cancer Diagnosis? What You Need to Know](#)
- MacMillan Cancer Support, [Questions to ask your healthcare team](#)
- American Cancer Society, [After diagnosis: a guide for patients and families](#)
- American Cancer Society, [Questions to Ask Your Doctor When You Have Cancer](#)
- Cancer.net, [Mobile application](#)
- FT3, [The true meaning of personalized medicine](#)
- 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.



Violeta Astratinei (MPNE), Shirlene Badger (Illumina), Anne-Marie Baird (Lung Cancer Europe), Sandra Blum (Roche), Ellen Bowe, Laura Divine, Andrea Ferris (Lungevity), Christine Ghione (Alivia Foundation), Jean Jenkins, Tanya Knott (SJK Foundation), Peter Lakwijk (Thyroid Federation International), Leslie Manot (Mon Réseau Cancer du Poumon), Susan McClure, Ralph Riley (Janssen), Debbie Schwartz, Judith Taylor (Thyroid Cancer Alliance), Brian Tomlinson (Foundation Medicine), Sonia Ujupan (Eli Lilly), Karen Wood (Roche), Ben Westphalen (Comprehensive Cancer Center).