

# Catalysing change:



## Participant Perspectives on the EUPATI Learning Lab trainings (2019 - 2024)



### Executive Summary

This report evaluates EUPATI's Learning Lab Fundamentals and Essentials Module 1 training programmes from 2019 – 2024. A survey of 10 professionals from an approximate pool of 200 participants found that 90% have applied their learnings in practice and feel the training has made or will make an impact in their work. Respondents reported increased confidence in their knowledge and skills on patient involvement, greater use of structured patient involvement methods, and practical application of the EUPATI Patient Involvement Roadmap. While the small sample size limits the scope of conclusions, the overall feedback is positive, with 70% agreeing the training was worth the investment. Future evaluations should aim for a higher response rate to provide more representative findings.

## Introduction

**Learning Lab** is EUPATI's training portfolio for those working in academia and industry looking to upskill in patient involvement, and it includes: EUPATI Fundamentals, EUPATI Essentials and EUPATI Customised trainings. EUPATI has been providing this training since 2019. **This evaluation report summarises the participant perspectives from a survey of the Learning Lab Fundamentals & Essentials training Module 1, from 2019 - 2024.**

Currently, the **EUPATI Fundamentals** training exists in both **online and face-to-face** formats (12 and 7 hours respectively). However, the Fundamentals training is being updated and converted to a blended learning format.

**EUPATI Essentials** are composed of 2 **online** modules: Module 1 - Establishing successful relationships with patients and Module 2 - Collaborating with patients across cultures. These modules can be completed independently and it is not required to complete both modules. Each module is completed by attending an online training session. **The scope of this report is 2019 - 2024 however, it includes Essentials Module 1 only.** Module 2 was launched in December 2024, after this evaluation was completed.

Here is a brief summary of both trainings:

- **EUPATI Fundamentals** teaches the basics of patient involvement, and is aimed at those working in academia and industry, the focus is on gaining a basic knowledge of patient involvement, with an overall introduction to standards and best practice.
- **EUPATI Essentials** is for those who already have experience in patient involvement. It enables you to build on your current knowledge or deep dive into more specific topics.

## Overview of Fundamentals & Essentials Trainings

### Training Programme

Training that covers the basics of patient involvement.



### Participants

Addressed to those working in academia and industry but open to all individuals.



### Structure

Programme composed of 4 modules over 12 hours online or 7 hours in person.



### Programme Completion

Participants need to attend the training online or in person.

### Training Programme

Training for those who already have experience in patient involvement.



### Participants

Addressed to those working in academia and industry but open to all individuals.



### Structure

Module 1 and/or 2 can be completed individually online over 4 hours per module.



### Programme Completion

Participants need to attend the online training session for the selected module(s).

# Survey Objectives

1

Understand and demonstrate the value of the training in patient involvement.



2

To enable continuous reporting on the outcomes of the Learning Lab to the Sustaining Partners, and to external parties working with EUPATI.



# Methodology

<b>Research type</b>	Quantitative and qualitative questions - 19 questions in total.
<b>Data collection method</b>	Survey
<b>Demographics</b>	A survey was sent to approximately 200 participants that completed the Fundamentals & Essentials Module 1 training between 2019 and 2024.
<b>Total Survey Responses</b>	10 survey respondents
<b>Start date</b>	Nov 18, 2024
<b>End date</b>	Dec 18, 2024

## Survey results

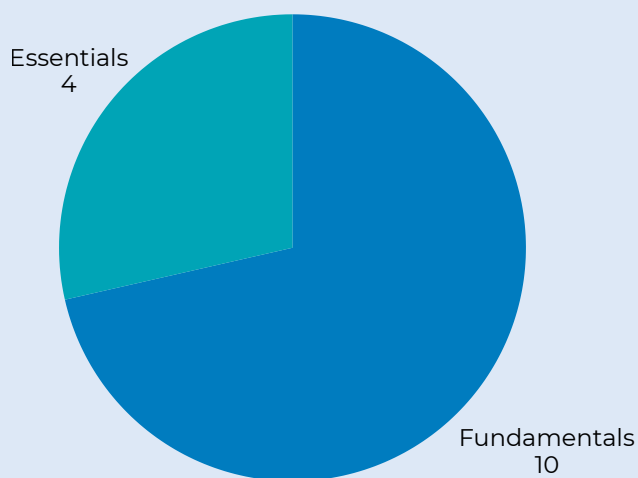
This section outlines the survey results. The survey received a total of 10 responses. Each respondent provided their professional role which are outlined below.

### Respondents professional roles:

- Patient Relations Director in Cardio & Metabolic topics in industry
- Senior Scientific Associate
- Global Patient Advocacy Lead
- Director Public Affairs in industry
- Global Patient Advocacy Manager
- Patient Advocacy Lead
- Clinical Trial Partner - pharmaceutical early development
- Scientific assistant/regulatory aspects in clinical studies
- Patient Advocacy Consultant
- Patient Engagement Director

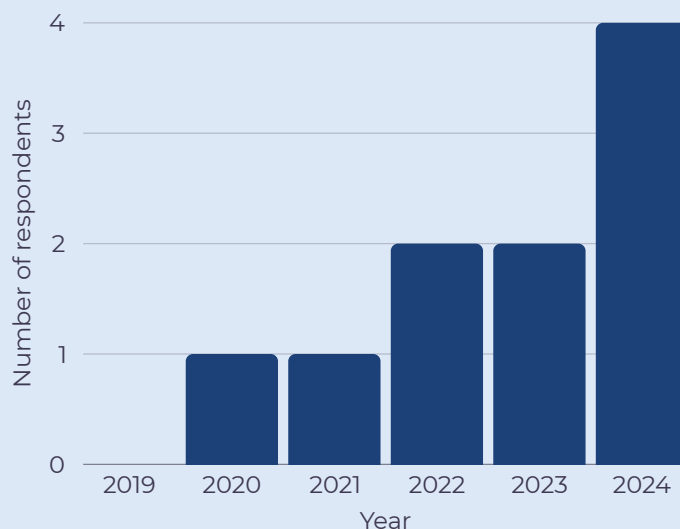
### OVERVIEW OF SURVEY RESPONDENTS

#### TRAINING(S)



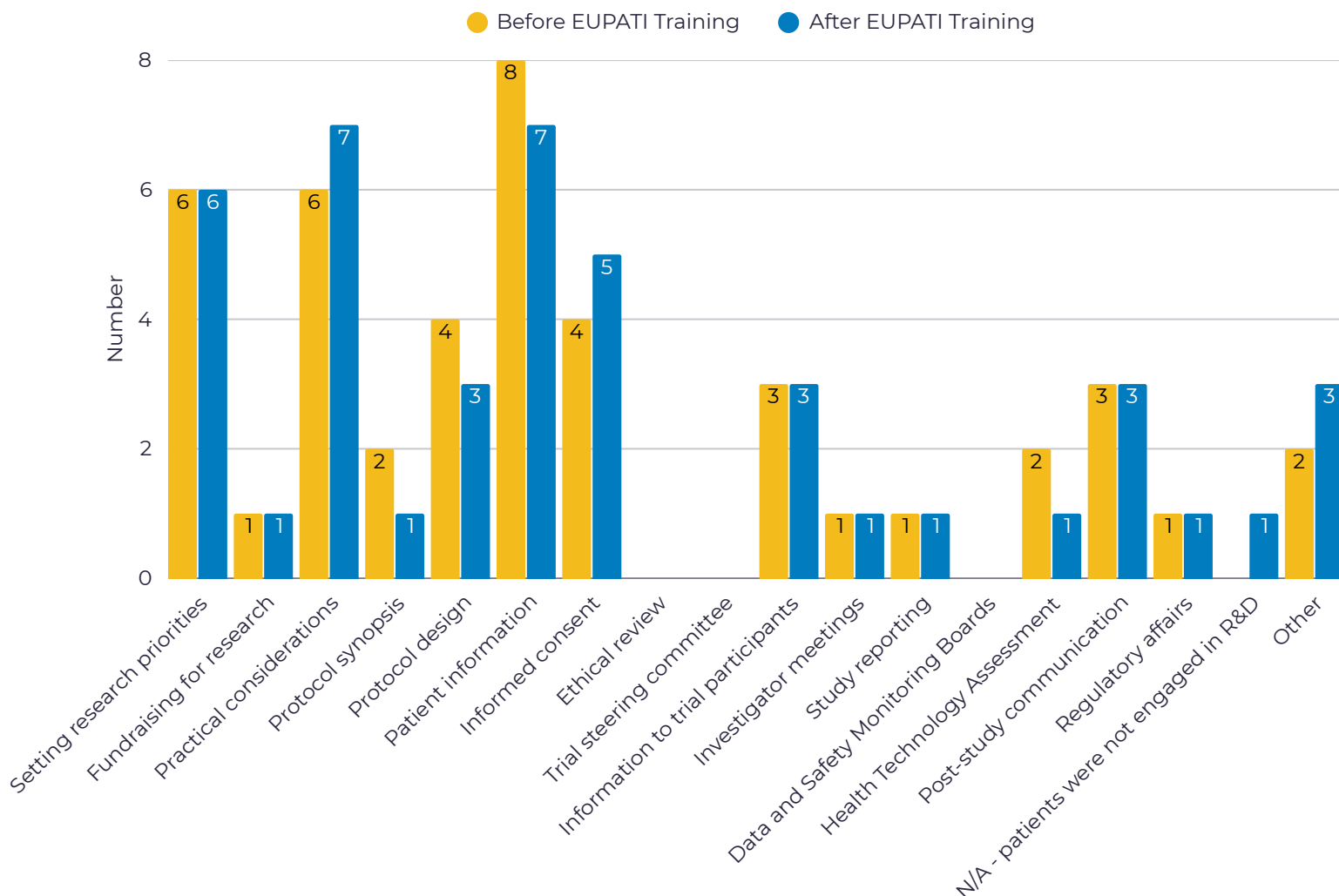
All respondents completed the Fundamentals training. 40% completed both the EUPATI Fundamentals and Essentials training.

#### TIMELINE



The majority of respondents (40%) completed their training in 2024. No respondent selected more than one year.

## 'Roadmap of patient involvement in medicine research and development (R&D)'



Roadmap of patient involvement in medicine research and development (R&D)

The bar chart above illustrates the Patient Involvement areas selected by respondents before and after completing the Learning Lab training(s); in relation to the EUPATI 'Roadmap of patient involvement in medicine research and development (R&D)'.

Respondents were asked to reflect on the time before and after completing the EUPATI Learning Lab training(s); and they were requested to select the patient involvement areas they used in relation to the EUPATI 'Roadmap of patient involvement in medicine research and development (R&D)'.

For an interactive view of the roadmap, please click on the following link: [EUPATI Patient Involvement Roadmap](#).

The table below outlines the top three areas selected for patient involvement before and after the completion of the Learning Lab training(s).

<p>The top three areas selected for patient involvement:</p> <ol style="list-style-type: none"><li>1. Patient information (8)</li><li>2. Setting research priorities (6)</li><li>3. Practical considerations (6)</li></ol> <p>↑ Before training</p>	<p>The top three areas selected for patient involvement:</p> <ol style="list-style-type: none"><li>1. Practical considerations (7)</li><li>2. Patient information (7)</li><li>3. Setting research priorities (6)</li></ol> <p>After training ↑</p>
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Respondents were also asked to share any additional patient involvement strategies employed outside of the context of the 'Roadmap of patient involvement in medicine research and development (R&D)'. Included below are some of the responses received.

## Additional Patient Involvement activities:

<ul style="list-style-type: none"><li>• Patient and Public Involvement (PPI) consulting for researchers</li><li>• Authors on publications</li></ul> <p>↑ Before training</p>	<ul style="list-style-type: none"><li>• Patients' association involvement in an European research project</li></ul> <p>After training ↑</p>
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The main reasons for selecting these patient involvement areas were patient inputs and business priorities. Additional insights are provided below regarding these areas.

## Patient inputs:

Patient inputs' were the most prominent reason for driving patient involvement in the areas selected by respondents. Organisations selected these areas based on where they felt patient input was required, and could potentially have an impact. Patient inputs were sought for some of the following reasons:

- Facilitating discussions between researchers and patients
- To gain patient insights around access to innovation
- To cover patient unmet needs on each level of medicine research and development
- Understanding of disease burden, patient journey and related challenges
- Areas were recognized as high opportunity areas to integrate patient inclusivity in early development

## Business priorities:

Below are some answers received from respondents reflecting the reasons for inclusion and exclusion of patient involvement areas.

“Business priorities drove the areas chosen, identification of where patient insights are most valuable and/or expected. The objective is always to gain patient insights to advise on business decisions and planning. The EUPATI training strengthened my understanding, and confidence, in pushing for further patient engagement.”

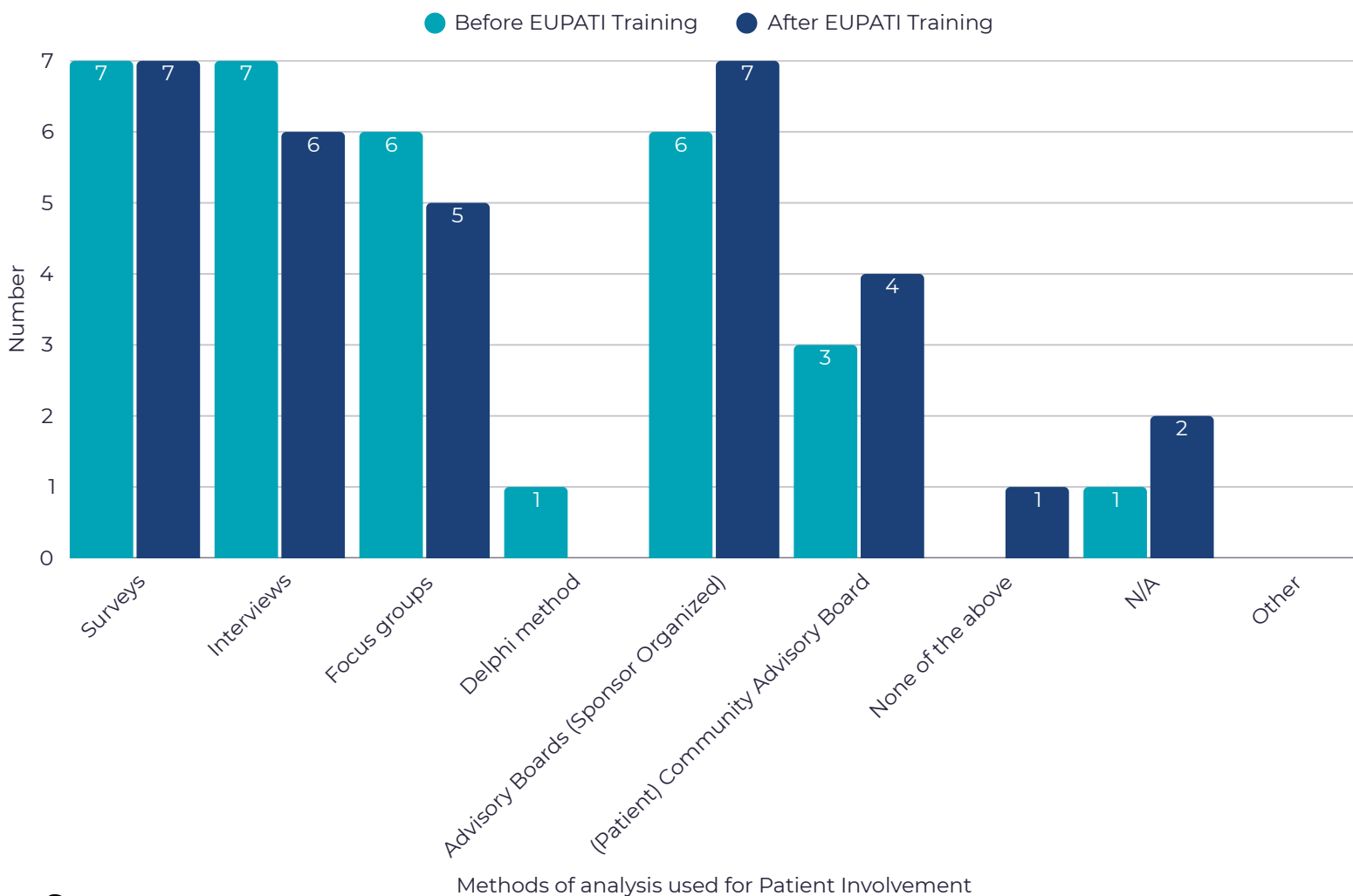
“Areas excluded were not a priority. There were some challenges engaging patients - often we get quite short notice, which makes it difficult to find the right advocates with time available. Sometimes processes aren't clear.”

“Because the organizational/project objectives did not require engagement in those other areas at the time.”

## Patient Involvement Roadmap - Summary of results:

There were no significant differences observed between patient involvement areas selected before and after the completion of Learning Lab training(s). The main reasons for selecting these areas for patient involvement were patient inputs and business priorities.

## Methods of analysis used to involve patients



### Summary:

Respondents were asked to select the methods of analysis used to involve patients before and after completing the Learning Lab training(s). There were no significant differences observed before and after completion of the Learning Lab training(s). The top three methods selected are outlined in the table below.

<p>The top three most prevalent methods of analysis were:</p> <ol style="list-style-type: none"> <li>1. Surveys (7)</li> <li>2. Interviews (7)</li> <li>3. Focus groups (6) &amp; Advisory Boards (Sponsor Organized) (6)</li> </ol>	<p>The top three most prevalent methods of analysis were:</p> <ol style="list-style-type: none"> <li>1. Surveys (7)</li> <li>2. Advisory Boards (Sponsor Organized) (7)</li> <li>3. Interviews (6)</li> </ol>
<p>↑ Before training</p>	<p>After training ↑</p>

## Participant feedback

"It helped me gain confidence in the value of these methods, and explaining the value to colleagues."

## Impact of Training



- The training provided **valuable insights** and suggestions on best practices
- It provided **methods and examples** that are very useful for daily tasks
- The training has supported **career opportunities**



- **90%** of participants have had the opportunity to **apply the learnings** from the Learning Lab training(s)
- **90%** of respondents feel the training has made or will make an **impact** in their work
- **70%** of respondents agree that the trainings were **worth the investment**

## Participant feedback

"EUPATI trainings have empowered me in my daily work and now we have close contact and relations with some patient organisations/patient representatives who guide us, help us with insights, co-create a lot of different items, e.g awareness campaigns, surveys, publications, advisory boards, educational materials and give talks at conferences and congress regarding their experiences living with a specific disease etc."

"Excellent training."

"I have shared the roadmap to highlight where there are gaps, or where the company is doing well. We've used it in patient engagement planning sessions, and I believe this will help lead to even more patient engagement in future"

"It has given me confidence, and I use the roadmap as a reference and tool in planning meetings."

# Conclusion

The EUPATI Learning Lab training — encompassing Fundamentals and Essentials Module 1 — has demonstrated clear and meaningful value for professionals working in patient involvement. While this evaluation is based on a small sample of 10 respondents from an approximate pool of 200 trained participants, the findings offer encouraging insights into the training's real-world impact.

The results indicate that 90% of respondents have had the opportunity to apply their learnings in practice, and an equal proportion feel the training has made or will make a tangible difference in their work. Participants reported increased confidence in advocating for patient involvement, greater familiarity with structured methods of patient involvement such as using methods of analysis outlined in the training, and a stronger ability to communicate the value of patient-centred approaches to colleagues and organisations.

Qualitative feedback further highlights how the training has supported professionals in building meaningful relationships with patient organisations, using the EUPATI Patient Involvement Roadmap as a planning and communication tool, and integrating patient perspectives more systematically across the medicines research and development process.

Although no dramatic shifts were observed in the patient involvement areas or methods of analysis used before and after training, this may reflect the already-experienced professional profiles of respondents rather than a limitation of the training itself. The training appears to consolidate and deepen existing practice rather than introduce entirely new behaviours.

To strengthen future evaluations, efforts should be made to increase survey response rates and broaden the respondent base, ensuring findings are more representative of the full cohort. As the Fundamentals training continues to evolve into a blended learning format and Essentials Module 2 becomes more established, ongoing evaluation will be essential to track impact over time and demonstrate continued value to Sustaining Partners and the wider patient involvement community.