

# PARADIGM: Advancing meaningful patient engagement in the life cycle of medicines for better health outcomes.

Chi Pakarinen, Daphnee Pushparajah, Paula Decola, Magda Chlebus, Mathieu Boudes and Suzanne Ii

## Facts & Figures

Start date: **March 1st 2018**

End date: **Aug 31st 2020**

### CONTRIBUTIONS

IMI funding: **4.5M€**

EFPIA contribution: **4.6M€**

Total Cost: **9.1M€**

Project website

[www.imi-paradigm.eu](http://www.imi-paradigm.eu)

### SOCIAL MEDIA

Twitter:

[https://twitter.com/imi\\_paradigm](https://twitter.com/imi_paradigm)

Youtube:

[https://www.youtube.com/channel/UCzuN9\\_NJ5eIWXEYQYhN6C3w](https://www.youtube.com/channel/UCzuN9_NJ5eIWXEYQYhN6C3w)  
(shorter: <https://goo.gl/qUgUi4>)

LinkedIn:

<https://www.linkedin.com/company/imi-paradigm-patient-engagement/>

## Approach and Methodology

To set a baseline for its work, PARADIGM conducted a survey in July-August 2018 to identify the expectations, needs and aspirations of stakeholders towards patient engagement.

- The survey was co-designed by consortium members building upon their expertise and experience from other similar initiatives (such as PFMD, DIA, and CTTI). It consisted of 15 questions applicable to all stakeholders, as well as a set of unique questions directed at specific stakeholders i.e., regulators, industry, HCP and patients. The English survey was administered using SurveyGizmo and was in the field for approximately 9 weeks.
- It was disseminated to a wide range of stakeholders who are part of PARADIGM members' networks across Europe and globally. This is reflected in the diversity of respondents and responses.

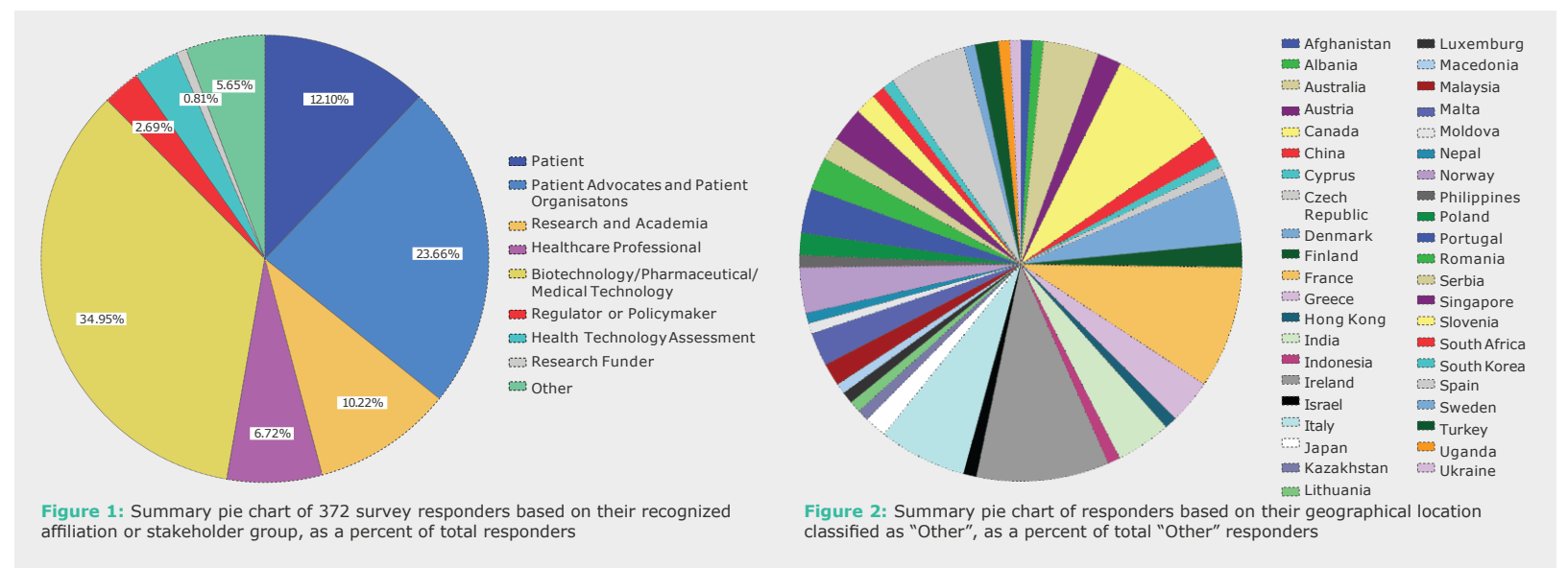
Responses were converted and analysed using SPSS and MS excel. The English survey was also translated into 22 other European languages and these responses are being analysed separately.

## Results

The interim analysis of English responses is presented here, while non-English responses are currently under analysis.

**English Language Survey Responses:** The analysis of the 372 responses revealed that the two biggest groups self-identified as members of Biotechnology/ Pharmaceutical/ Medical Technology industry (**34.95%**) and from Patient advocates and organisation (**23.66%**) (**Figure 1**).

**Respondents' location:** Those answering the English language survey were located in 43 countries and 5 continents. Almost half of the responses were from people in the United Kingdom (**28.2%**) and United States (**16.9%**). Germany, Belgium and Switzerland each had about the same percentage of responses, approximately **5.6%**. The other responses (**32.8%**) came from people residing in the remaining 38 countries (**Figure 2**).

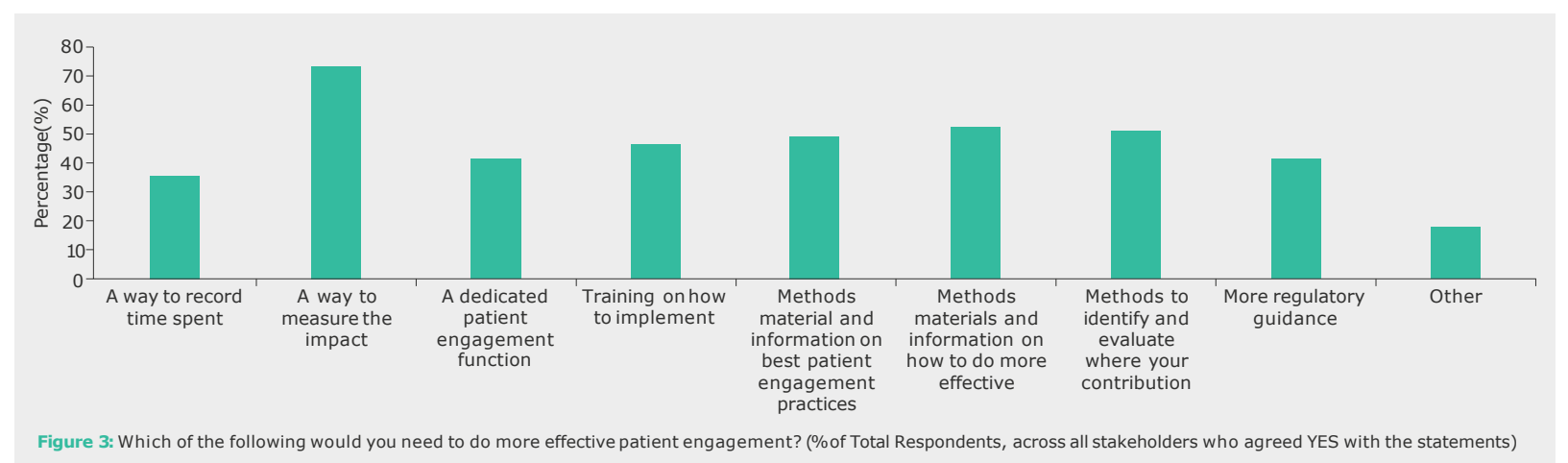


### Top Areas of Need:

The responses indicate that the top areas of need to effectively have patient engagement are:

- Impact measures (**73.1%**)
- Methods materials and information on how to do more effective patient engagement (**50.3%**)
- Methods to identify and evaluate where contribution would be most valuable (**49.2%**)
- Methods material and information on best patient engagement practices (**47.6%**)

These findings align with PARADIGM's ongoing assumptions and the main areas of focus within the project.



**Patient preparedness to engage:** A total of 264 patient organisations/patients noted their perceived level of preparedness and need for support for a number of areas including: internal processes; knowledge; human resources; financial resources and managing competing interests.

The majority of respondents indicated that while they were prepared, they still needed some support for most categories. The exception was financial resources, where the majority noted that they were not prepared and they needed support (**Table 1**).

### Next steps:

- A Delphi process will be employed to gain a more robust sense of patient engagement aspirations from the various stakeholder groups.
- The results will support the co-creation of a suite of tools, guidance's and recommendations to enable a more effective, ethical and sustainable patient engagement framework for all stakeholders.

## Impact and take home message

- Our initial findings confirm that PARADIGM's focus on co-creation of impact measures, tools, guidances and sustainability remain areas of need across stakeholder groups.
- The findings suggest that PARADIGM aims and outputs can potentially be game changing for stakeholders across geographies.
- There is substantial interest to carry out effective and sustainable patient engagement.

## Challenge

- Patient engagement in the medicine R & D process is largely underutilized, despite the benefits of co-creation in delivering health solutions that meet patients defined needs and improve health outcomes.
- There is the lack of a set of consistent, systematic and sustainable metrics that reflect different stakeholders' perspectives on process, outcomes and return on engagement measures.
- Prior initiatives in this area have not routinely included underrepresented groups such as young people, people with dementia and unaffiliated patients, along with a broad group of diverse stakeholders in the co-creation of workable solutions.

## Value of IMI collaboration

PARADIGM consists of 34 public and private partners actively involved in patient engagement. The IMI process enables multi-stakeholder collaborations, which might not otherwise be possible.

PARADIGM brings together patient representatives, biopharmaceutical companies, regulators, health technology assessment organisations, academics and subject matter experts to forge advancement in patient engagement.

PARADIGM will contribute to the co-creation of a sustainable framework that allows for structured, meaningful and ethical patient engagement at three key decision-making points of the medicines lifecycle: prioritisation of research, early dialogue between regulators and HTA and design of clinical trials.

	Not prepared and don't need support	Not prepared and need support	Prepared but need support still	Prepared and don't need support
Internal process	2.3	15.9	54.5	27.3
Knowledge (information and expertise)	1.1	10.2	63.6	25
Human resources	5.7	36.4	44.3	13.6
Financial resources	3.4	47.7	39.8	9.1
Managing competing interests	2.3	26.1	45.5	26.1

**Table 1:** Level of preparedness and need for support of patient organizations/patients to participate in patient engagement (% of Total Respondents)

**PARADIGM is working. Join the movement on LinkedIn, Twitter and PARADIGM Website.**