

# Patient and carer involvement (PI) in Real World Data & Evidence generation (RWDEG): Findings from industry

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## Introduction

Studies have shown a mis-match between patient priorities and those of academia and the pharmaceutical industry, meaning some drugs come to market presenting little value to patients <sup>1</sup>

Real World Data and Evidence (RWDE) is needed to supplement data derived from clinical trials and patient and carer involvement (PI) in this process is not well defined.

Involving patients and carers as partners, is essential in order to produce high quality, relevant evidence that reflects the priorities of patients and is disseminated and communicated in an accessible way. This will result in a more informed and accountable research agenda with a greater impact on healthcare.

## The main objective of this work was to understand:

1. Why, when and how Pfizer UK currently involve patients and carers in RWDEG
2. What were the benefits and challenges
3. What improvements were needed

## Methods

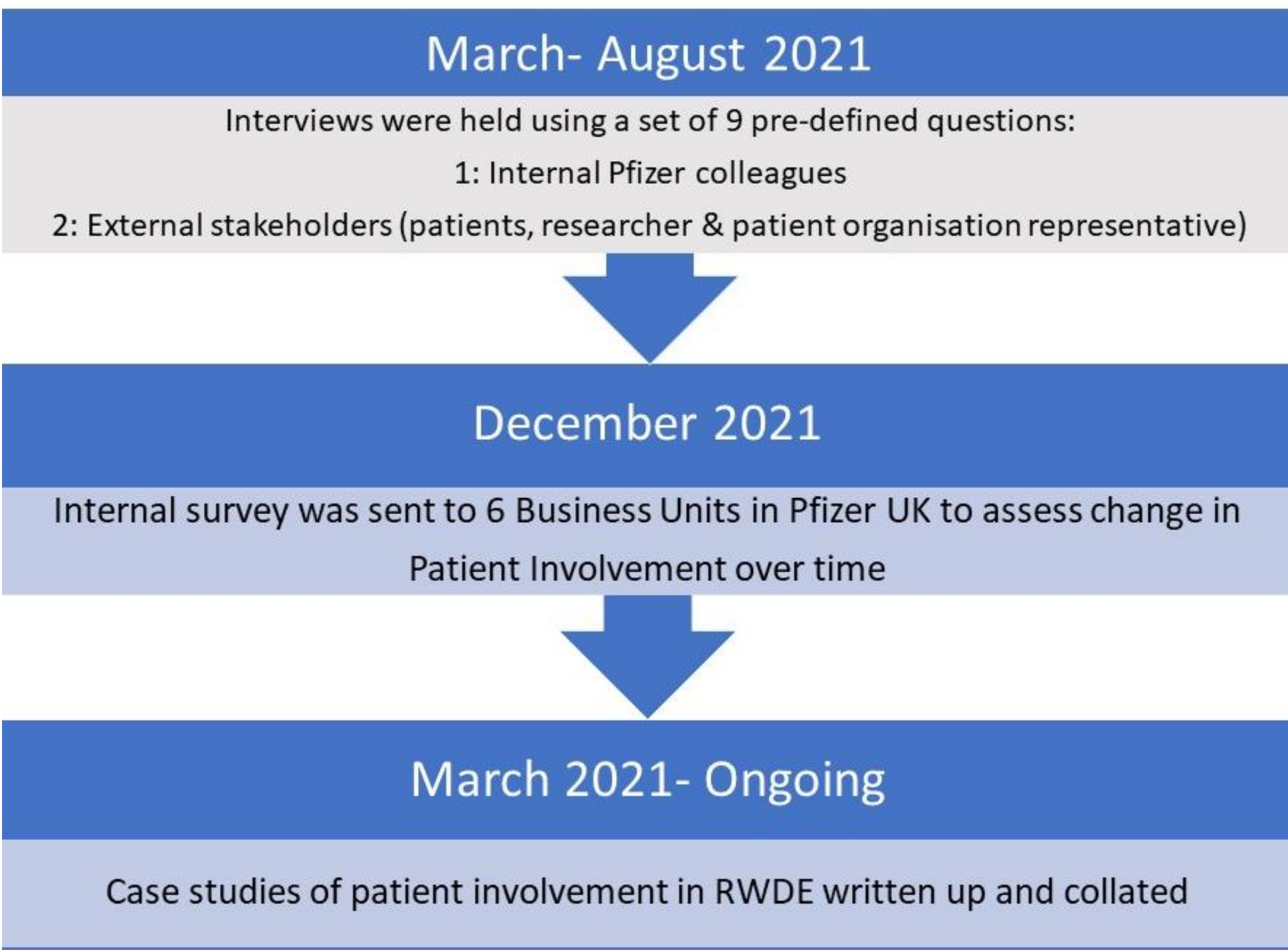


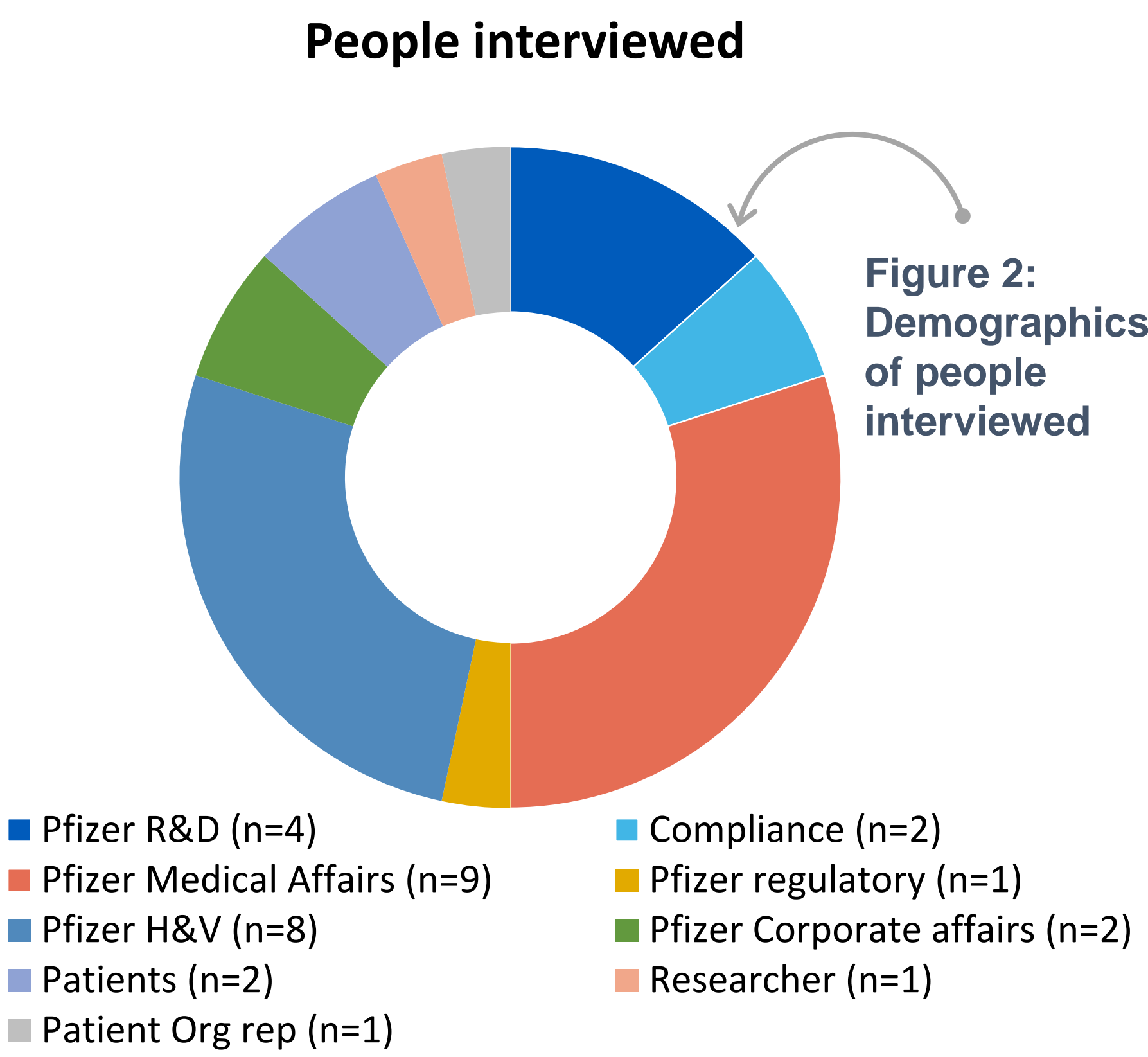
Figure 1: Main methods of the study

- Figure 1 outlines main methods of the study.
- Results were summarised and themes were drawn out from open ended questions analysis.

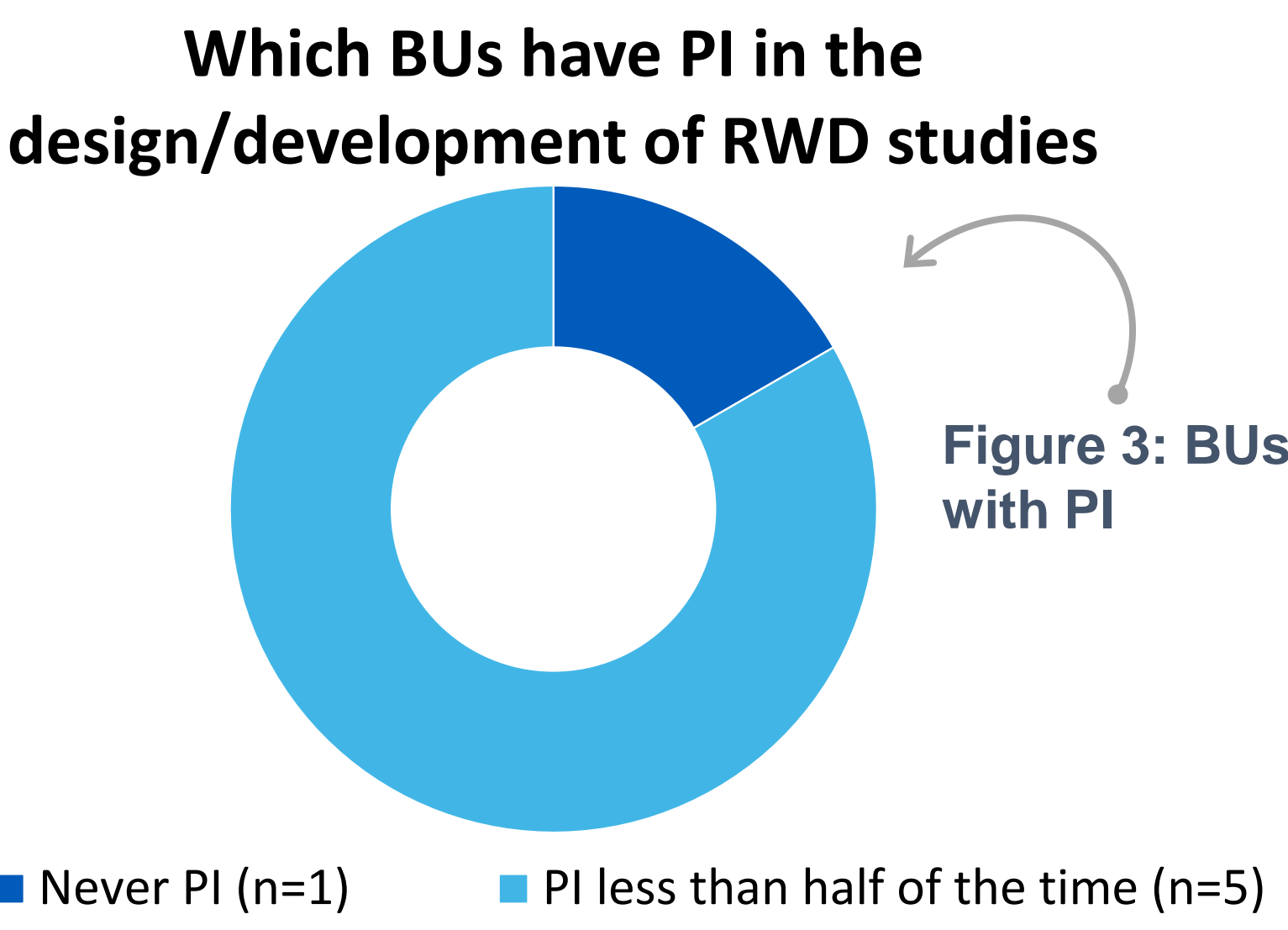
- **Interview questions focused on:** What type of RWDE studies were being conducted, how the patient voice was currently incorporated, what were the benefits and challenges of PI, how could this be done more effectively and what areas should be prioritised and improved.

## Results

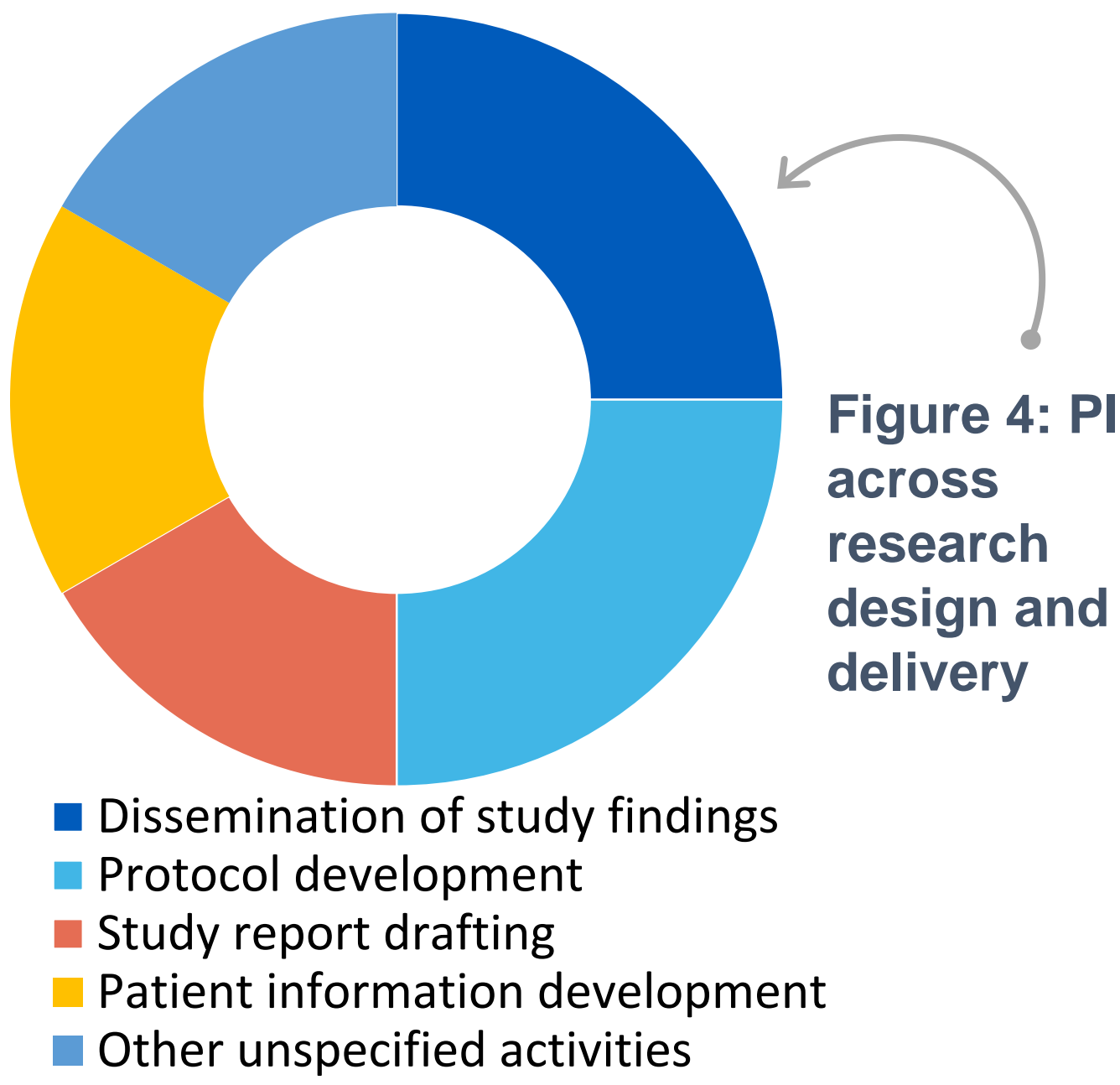
Thirty individuals residing in the United Kingdom; Pfizer colleagues, patients, a researcher and a patient organisation representative were interviewed (figure 2).



- Everybody commented that patients and carers should be involved as early as possible.
- 42% of colleagues had worked directly with patients or carers and of the 58% that hadn't, either their job didn't mandate it (67%) or they had not had an opportunity to do so (33%)
- **The follow up survey** was completed by 6 Business units (BUs) and showed that 87% of BUs had some patient involvement activities (figure 3). Most commonly during protocol development and dissemination of study findings (figure 4)



## Common areas for patient involvement



Benefits	Challenges
Getting a broader view on priority endpoints	Lack of colleague experience
Incorporation of Plain Language Summaries & open access publishing	Compliance hurdles
Developing evidence that is patient centric	Lack of clear guidance
Building mutual trust	Extra costs and time
	Ensuring a diverse group of people

Table 1: Benefits and challenges of PI

Its important to have an ambassador to keep meaningful PI on everyone's agenda

Ongoing evaluation of feedback to inform process and measuring impact is paramount

## Conclusions and future work

- This work identified there was a need for a more systematic approach for PI in RWDE generation within Pfizer UK
- In order to implement PI in a meaningful way, suitable and co-created frameworks are needed
- Acting upon this, further work is ongoing working with patients and carers to co-create the frameworks and resources needed to enable meaningful PI.

## References

1. Crowe, S., et al., *Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch*. Res Involv Engagem, 2015. 1: p. 2

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