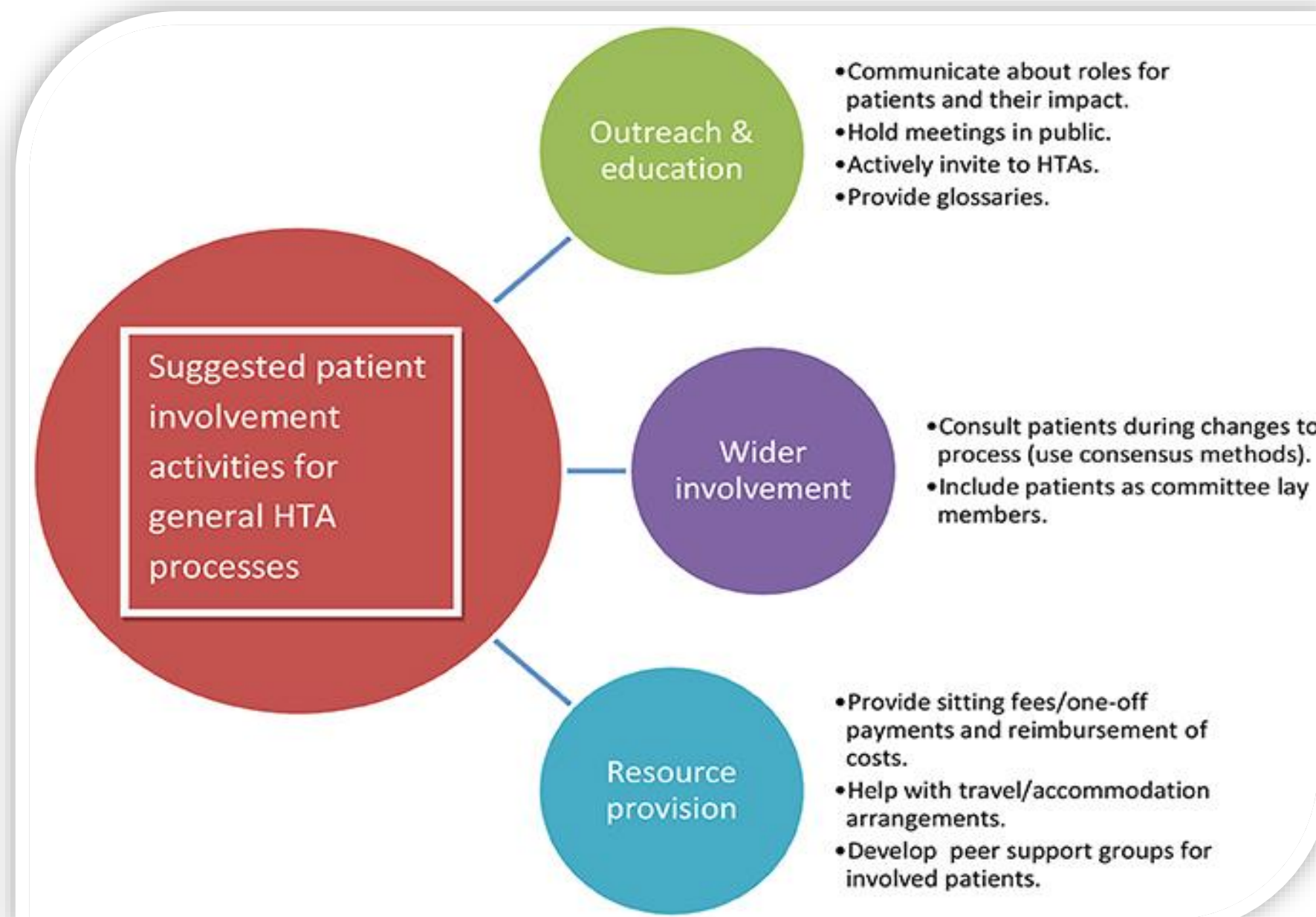


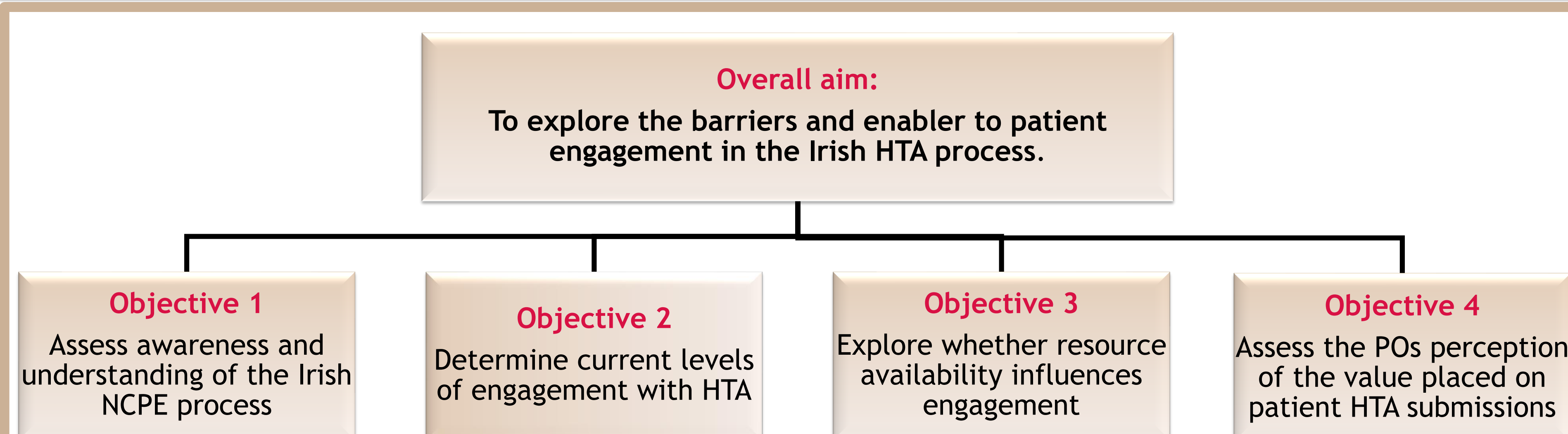
INTRODUCTION

- In recent years, there has been greater focus placed on increasing patient involvement in health technology assessments (HTA).
- In 2011 the European Patient Forum (EPF) conducted an EU wide survey of HTA agencies, decision-makers and patient organisations (POs) to identify good practices and challenges relating to patient involvement in HTA in Europe. Some of the challenges for POs identified by the survey included;
 - HTA was too time/resource intensive;
 - There was a lack of capacity within POs;
 - Lack of transparency regarding decisions;
 - Need for a commitment to equal partnerships.
- Although several hundred POs were contacted across the EU to complete the EPF survey only 23 POs completed it, and only 1 Irish PO participated.
- Furthermore, since the release of the EPF survey report more guidelines have been published across EU agencies. The European Patient's Academy (EUPATI) have also highlighted the need for PO to be involved at all stages throughout the reimbursement process and have outlined ways by which PO engagement can be achieved (see Figure 1).¹
- With the increasing focus on PO involvement in HTAs and with the introduction in 2016 of a "patient submission process" by the Irish National Centre for Pharmacoeconomics (NCPE) in Ireland,² it is important to assess Irish POs engagement with HTA and explore their knowledge and understanding of the current processes in place.

Fig 1: EUPATI recommendations for patient involvement activities in HTA¹

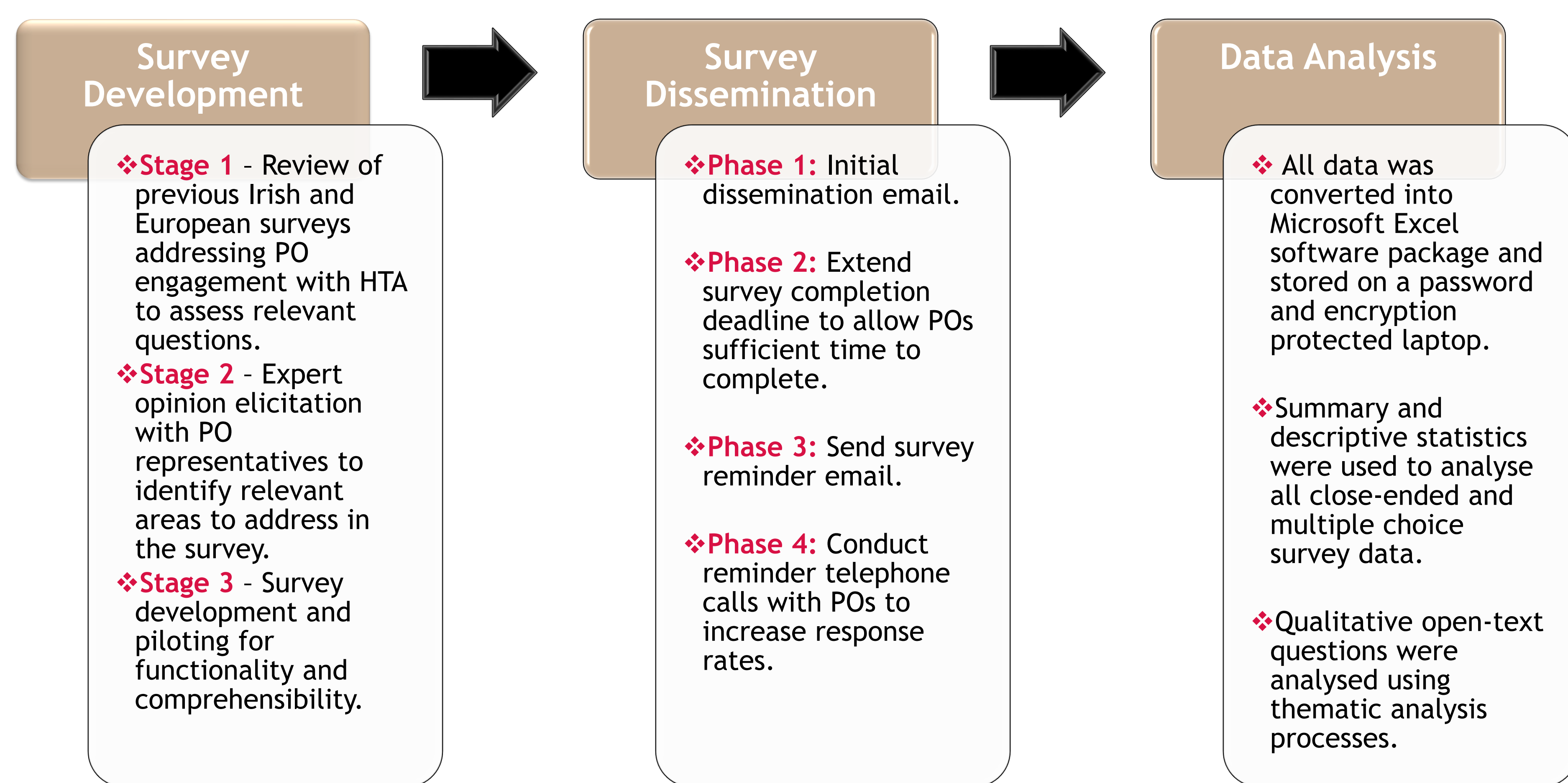


AIMS & OBJECTIVES



METHODS

- A mixed-methods cross-sectional survey was conducted with POs (n=76) across Ireland via online questionnaire. The questionnaire included a range of multiple choice and open text questions to explore POs understanding of and engagement in HTA.
- The online survey was disseminated via email to all POs (n=76) with accessible contact details. Dissemination was conducted via a 4- phase approach to increase response rates.



RESULTS

PO Characteristics

- There were 21 respondents in total, with a 26% response rate. Out of 21 respondents, 2 were from the same PO.
- Based on a coding criteria which included, number of members, annual budget, total weekly hours, and whether the PO had paid and/or volunteer staff the POs were categorised into large or small POs. Of survey respondents 50% were a large PO and 50% were a small PO. See Table 1.
- To note, some POs had few members but had large annual budgets due to charity contributions therefore a combination coding structure was developed.

Table 1: Patient Organisation Characteristics

Characteristics	Response (n=21*)
Number of members	
0-10	14% (n=3)
11-50	10% (n=2)
51-100	5% (n=1)
100+	72% (n=14)
Annual budget**	
€0-€99,000	30% (n=6)
€100,000-€499,999	15% (n=3)
€500,000-€999,999	5% (n=1)
€1,000,000+	40% (n=8)
Size of PO*	
Large PO	50% (n=10)
Small PO	50% (n=10)

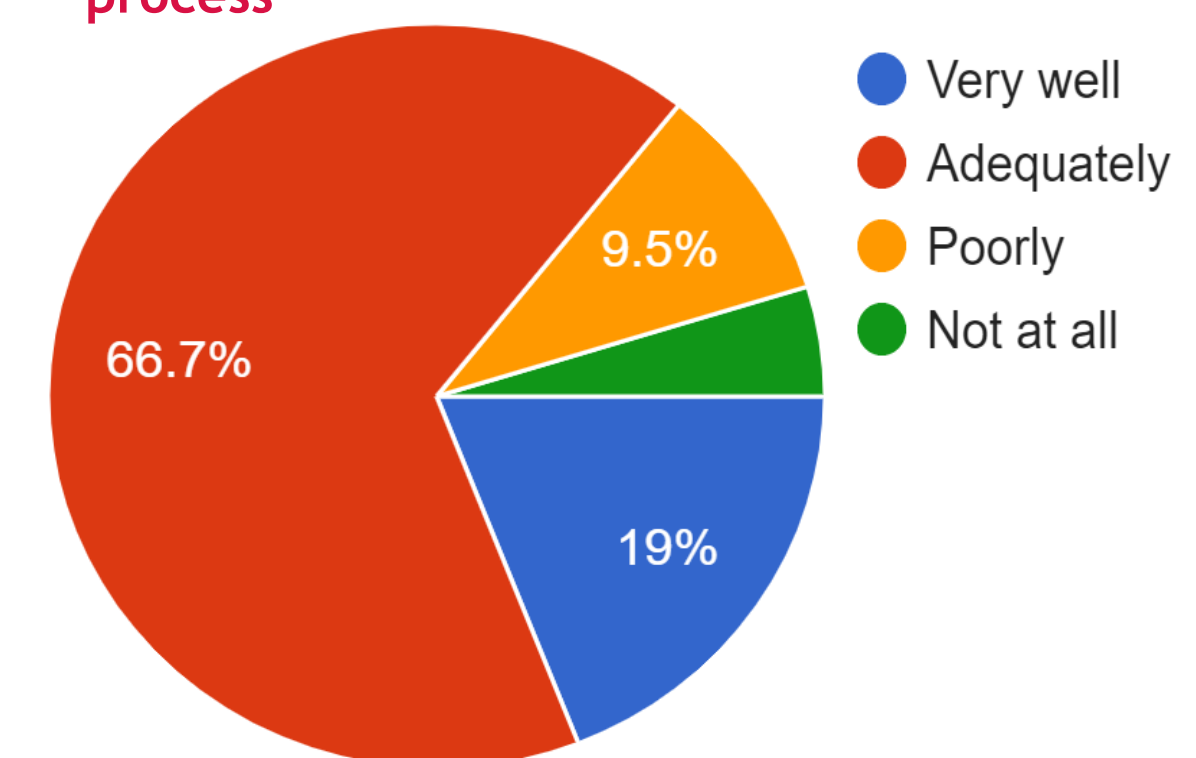
* There were 21 respondents in total two of which were from the same PO

**there were two missing responses for this question

Awareness and understanding

- The majority of respondents (86%) believed they had adequate or a very good understanding of the Irish HTA process (see Figure 2)
- Although the majority believed they had good understanding of the HTA process only 67% were aware of the patient submission process, with 33% stating they were not aware.

Fig 2: How well POs understand the Irish HTA process



Engagement in patient HTA submissions

- 30% of respondents had completed a HTA patient submission, while 70% said they have not completed a patient submission (including those with no relevant HTA available to submit to).
- Of the POs who completed the patient submission, 57% stated that the process was time consuming and significantly impacted on their usual responsibilities and 29% felt they did not have sufficient technical knowledge to provide information. The time it took for POs to complete the patient submission ranged from 21 hours to 250 hours.
- Subgroup analysis showed that for POs where a submission was available to complete, a higher proportion of the large POs completed the submission in comparison to the small POs, 71% versus 25% respectively. However this should be interpreted with caution due to low response numbers. See Table 2.

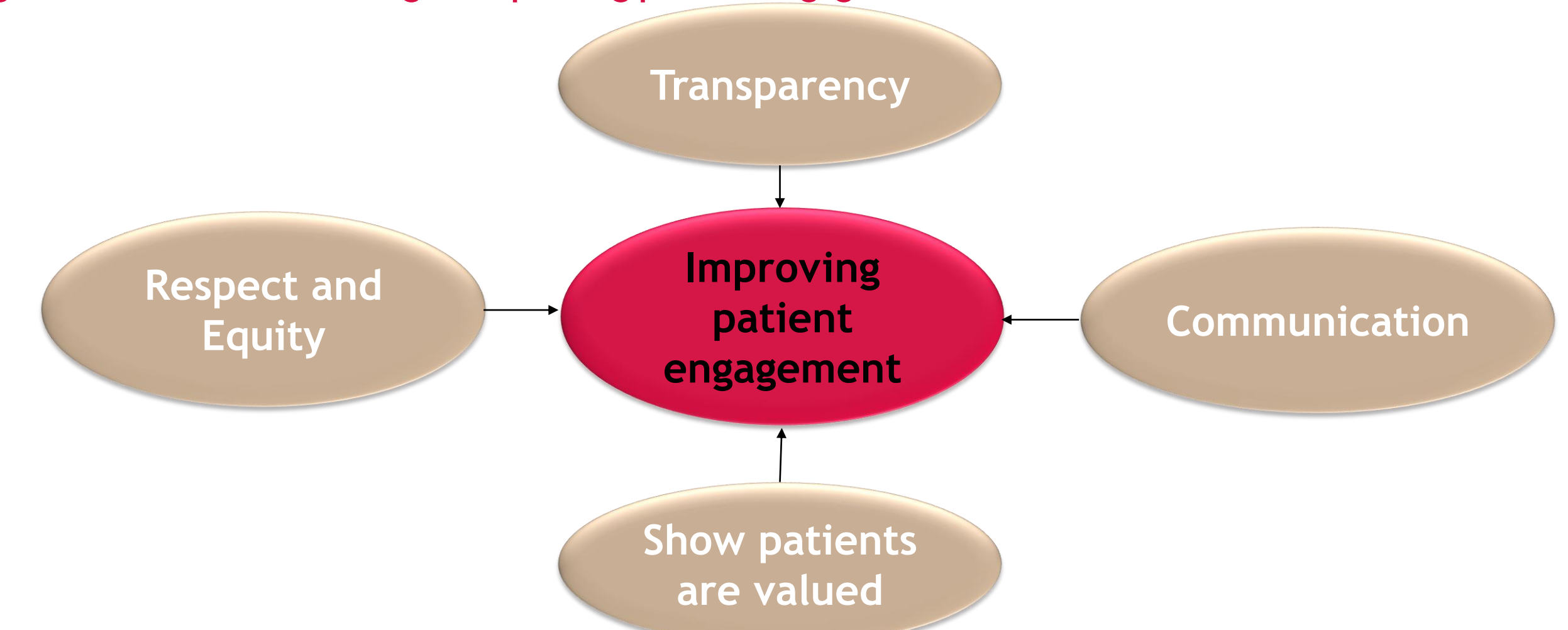
Table 2: Difference between submissions made by large and small patient organisations

PO Size	N	Patient submission available (N)	Patient submission completed	Reasons given by POs for not completing a relevant HTA submission
Large PO	n=10	n=7	n=5 (71%)	• Not aware a submission was available (n=2, 29%)
Small PO	n=10	n=4	n=1 (25%)	• Too time consuming (n=1, 25%) • Missing (n=2, 50%)

Improving PO engagement:

- In open-text questions POs were asked how patient engagement could be improved. Four key themes were identified; increase transparency regarding the process; improve communication channels via a NCPE PO representative; demonstrate equity to POs regardless of size or disease area; and value patient input by increasing clarity on how patient submissions are weighted;. See Figure 3.

Fig 3: Themes drawn relating to improving patient engagement in HTA



CONCLUSIONS AND RECOMMENDATIONS

- Overall the perceived understanding by the PO's of the Irish HTA process was high, however still a number of POs were not aware of the NCPE patient submission process.
- Engagement with the patient submission template was low at 30%, however background research shows that only 50% of respondents had a relevant HTA they could submit to since 2016. Submissions rates were higher for larger POs, however there were also more relevant HTAs available for larger POs.
- Of the POs that did complete a patient submission, the majority found it time consuming and challenging, with POs stating it took up to 250 hours to complete.
- Key recommendations identified from the survey include; provide POs with clarity on how patient submissions are assessed; increase training opportunities and improve communication channels; and finally ensure an equitable system is in place so that rare disease POs are adequately supported to make patient submissions.

References:

- Guidance for patient involvement. EUPATI. <https://www.eupati.eu/health-technology-assessment/guidance-for-patient-involvement-in-hta/>
- NCPE Patient Submission overview. <http://www.ncpe.ie/for-patients/patient-submission-process-overview/>

Acknowledgements; We would like to take this opportunity to thank all the patient organisations who submitted responses and the MRCG Ireland for their support.