



Avicenna Alliance
Association for Predictive Medicine

Survey Report

**A snapshot of current practices and
perceptions of Public & Patient Involvement
(PPI) within the Avicenna Alliance**

May 2023



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1. Contributions

Steven M. Levine, PhD – *Dassault Systèmes – Avicenna Alliance;*

Martha De Cunha-Burgman, MSc – *Edwards Life Sciences – Avicenna Alliance;*

Liesbet Geris, PhD – *University of Liège & KU Leuven – VPH Institute – Avicenna Alliance;*

Raphaëlle Lesage, PhD – *VPH Institute – Avicenna Alliance;*

Thierry Marchal, MSc – *Ansys – Avicenna Alliance;*

Marlène Mengoni, PhD, MSc Eng, FHEA – *University of Leeds, United Kingdom – VPH Institute – Avicenna Alliance;*

Cécile F. Rousseau, PhD – *Voisin Consulting Life Sciences – Avicenna Alliance;*

Alexandre Serigado, M. Sc. – *Voisin Consulting Life Sciences – Avicenna Alliance;*

Bernard Staumont, Ir, PhD – *Université de Liège, Belgium – VPH Institute – Avicenna Alliance;*

Anne Thorez – *Voisin Consulting Life Sciences – Avicenna Alliance;*

Emmanuelle Voisin, PhD – *Voisin Consulting Life Sciences – Avicenna Alliance;*

Cyrille C. Thinnes,  **MBA, DPhil** – *University of Galway & APC Microbiome Cork, Ireland – VPH Institute – Avicenna Alliance.*

on behalf of the Public & Patient Involvement task force of the Avicenna Alliance Policy Development Working Group.

 cyrille.thinnes@universityofgalway.ie

3. Aims

The primary aim of the survey was to **identify current PPI practices and perceptions within the AA** to serve as a guide to the newly established PPI TF for improved targeting of future content and activities in an evidence-based approach. As a secondary aim, the survey was intended to help raise PPI awareness within the AA by catalysing conversations about the topic.

4. PPI Familiarity

Respondents considered themselves rather unfamiliar with PPI practices (average 2.7/5), and also considered PPI to play a rather small part in their daily professional function (average 2.6/5). Comparatively, respondents perceived PPI to be of marginally higher emphasis in their institution’s daily focus (average 2.9/5) (**Figure 1**). Complementing these self-rating questions with a short quiz on categorising different activities by whether they constitute PPI activities (only one of which was, i.e., “having a patient representative on your project steering board”, with others constituting rather ‘engagement’ or ‘outreach’ activities, indicates that the **current PPI understanding is heterogenous, with different interpretations as to what ‘involvement’ means.**

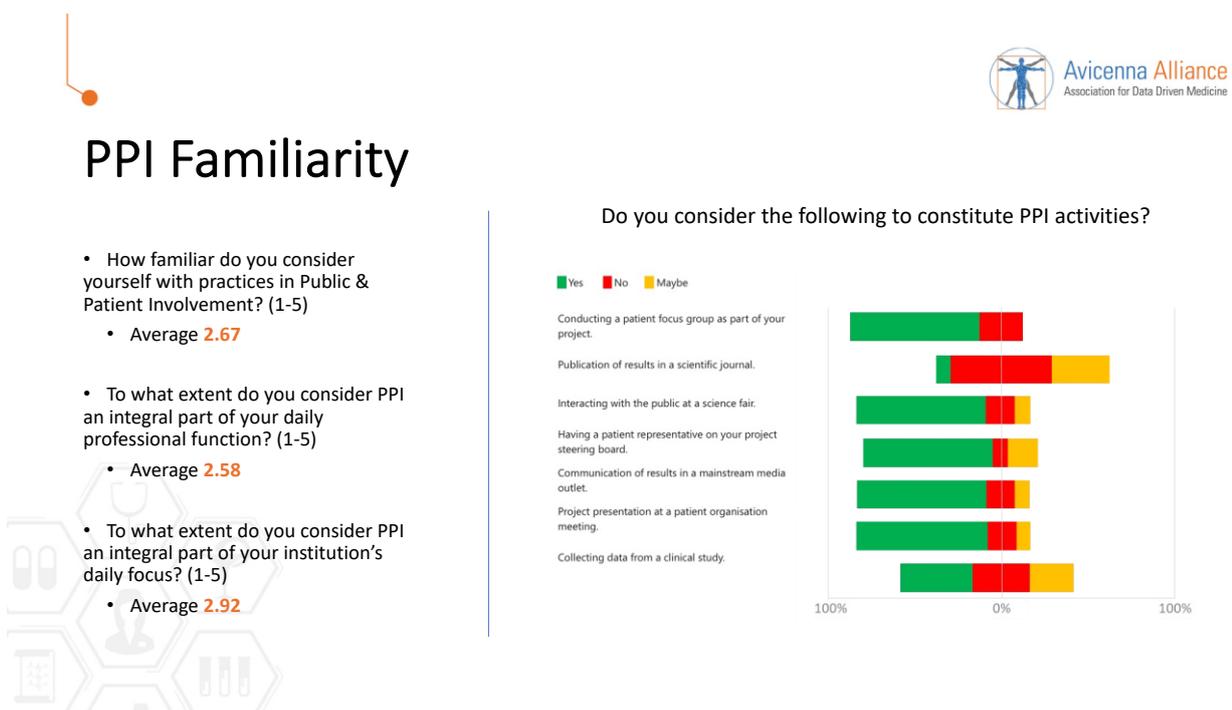


Figure 1: Overview of survey responses relating to PPI familiarity and scope.

5. PPI Awareness

1/3 Survey respondents have previously sought advice on PPI (**Figure 2**). Of all respondents, half would gather PPI advice indirectly, e.g., from their company-internal Public Affairs department. 1/4 would gather the information directly from a patient or PPI group. **1/4 of respondents indicated they do not know where to gain PPI information from.**

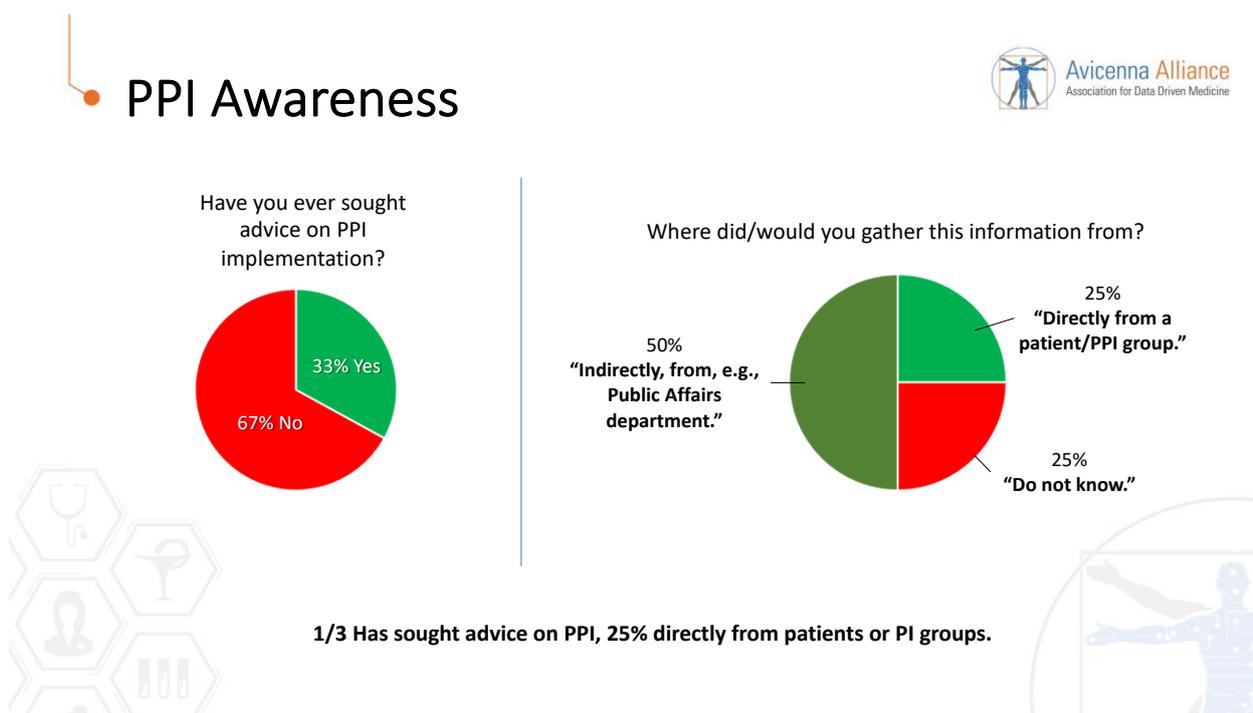


Figure 2: Overview of survey responses relating to PPI advice and support.

6. PPI Resources

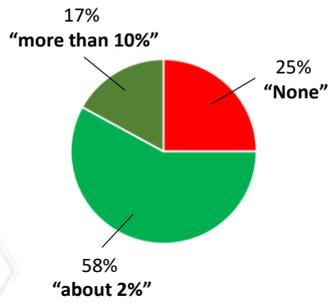
Survey participants answered questions in relation to their allocated PPI resources, i.e., time and money. 87% of participants spent $\leq 2\%$ of their time on average on PPI activities over the past year, with 25% none at all. **60% felt their PPI time allocation was too little (Figure 3).**

58% of respondents have allocated no budget at all to PPI activities over the last year. **2/3 respondents who have spent budget on PPI activities experienced their allocation to have been too little.** When spending PPI budget, the top 3 categories were communication, travel, and salaries (**Figure 4**).

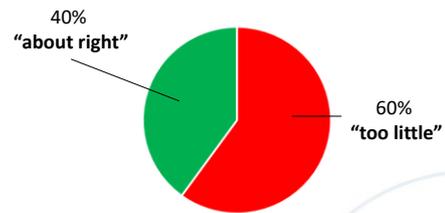
PPI Resources – Time



About what % of your time have you spent on average on PPI activities over the last year?



If any time spent, did you experience this to be:



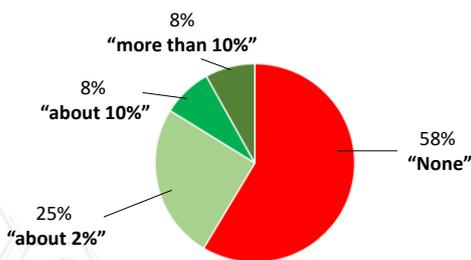
87% Spent 2% or less on PPI, 60% felt it was too little.

Figure 3: Overview of survey responses relating to PPI time resources.

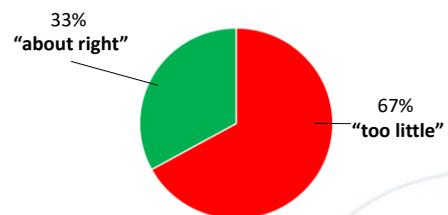
PPI Resources – Money



About what % of budget have you allocated to PPI activities over the last year?



If any budget spent, did you experience this to be:



Top 3 PPI budget categories: communication, travel, salaries.
 67% felt the budget was too little.

Figure 4: Overview of survey responses relating to PPI financial resources.

7. PPI Incentives

Assessing potential incentives for PPI, both internal and external to AA members’ institutions, about **half of the survey respondents were unaware of any PPI incentives**. Survey participants also indicated that there are fewer internal incentives (the top incentive being an evaluation requirement) compared to external ones (the top external incentive being a funding requirement) (Figure 5). Participants indicated that they consider PPI to be a worthwhile pursuit as an integral project part (average 3.8/5) (Figure 6).

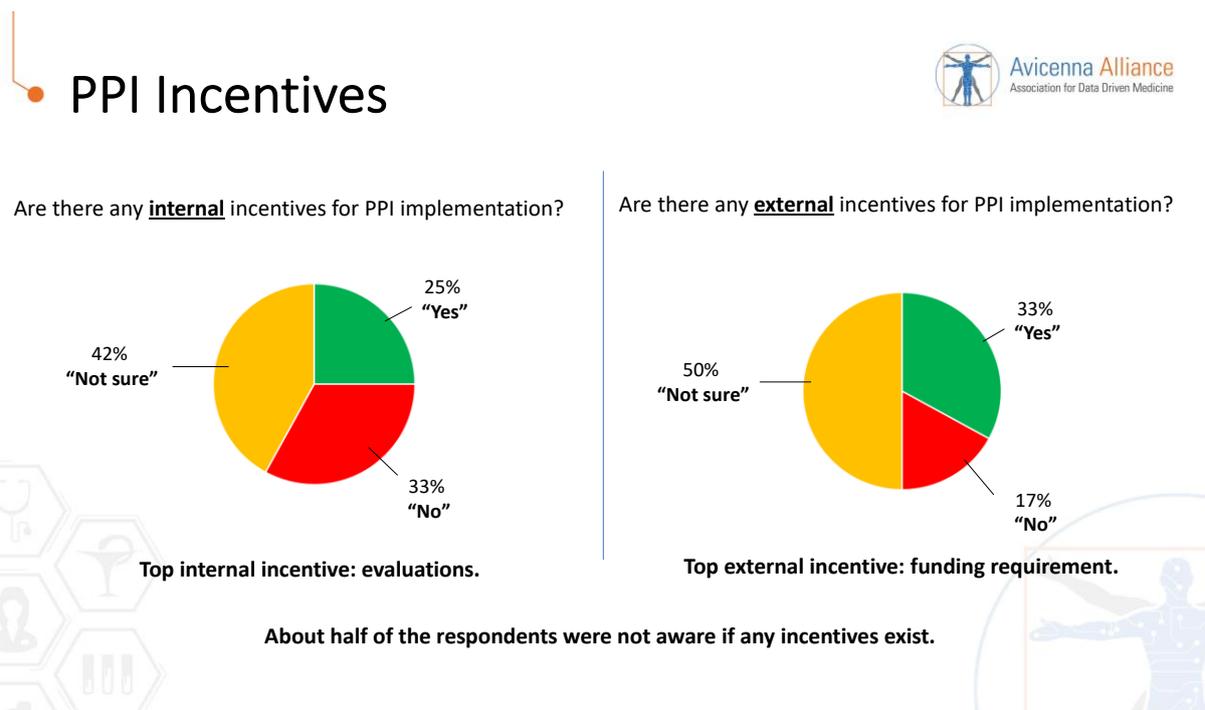


Figure 5: Overview of survey responses relating to internal and external incentives for PPI implementation.

8. Conclusions and Actions

From the survey evaluation, we interpret that:

1. The external PPI environment may change faster than the institutional awareness among AA members.
Action: Enable AA members to adopt a proactive PPI approach to maintain and foster a competitive edge.
2. AA members generally consider PPI to be a worthwhile pursuit and are open to emerging opportunities.
Action: Adopt a research lifecycle approach to systematically identify PPI opportunities.
3. PPI support & incentives are relatively low among AA members.
Action: Provide guidance internally within AA capacity and establish relationships/touch points with competent PPI institutions beyond the AA.
4. PPI perceptions are heterogenous among AA members.
Action: Facilitate a coherent & unified PPI language across the AA, in line with international PPI leaders.
5. PPI awareness is relatively low among AA members.
Action: Establish & develop the AA PPI TF identity and involve AA members such to become ambassadors for PPI best practices for *in silico* medicine through, e.g., publications, workshops, and advocacy.

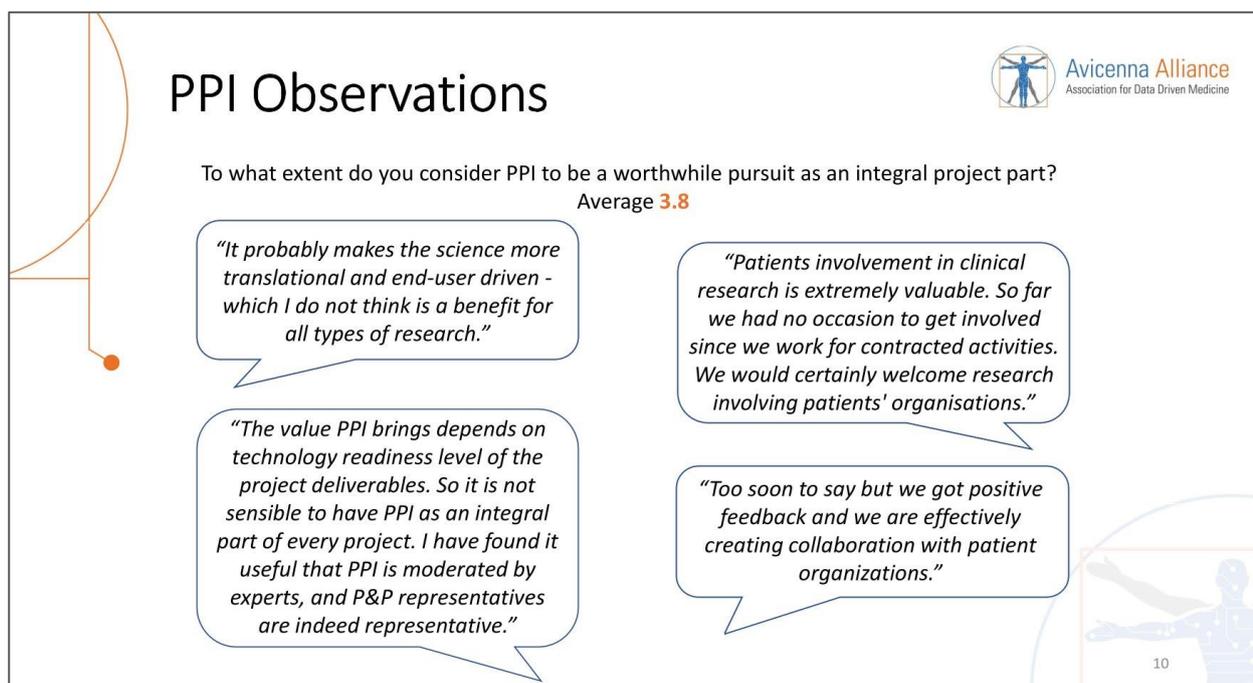


Figure 6: Overview of survey responses relating to PPI general perceptions.

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