

Towards fairer market value

The Patient Information Forum, Cancer52 and NRAS jointly surveyed patient organisations on their experience of 'fair market value' (FMV) payments.

FMV is the rate set by pharmaceutical companies for the work of patients and the staff of patient organisations. There is a perception in patient organisations that FMV rates are inconsistent and sometimes less than fair. The survey was designed to capture the experience of patient organisations.

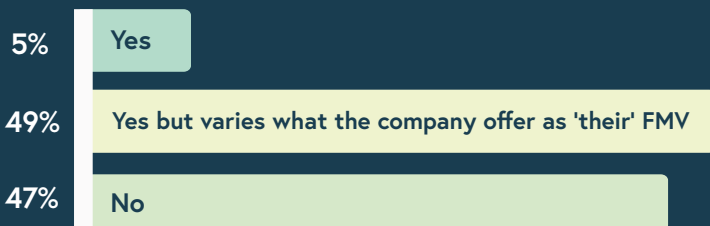
Working with industry

All of the organisations had worked with the pharmaceutical industry in the last year. 56% had worked with up to 5 companies, 44% had worked with more than 5 companies. 54% had experienced fair market value payments, 44% had not. Of those that had experienced FMV payments, 90% said they varied company to company.

The respondents

- The survey ran throughout March 2023 and 43 organisations responded.
- 47% had an annual income of less than £500,000, 23% between £500k-£1m, 23% between £1m-£5m and 8% more than £10m.
- 80% had been established for more than 10 years.
- 84% employed fewer than 50 people.
- The top 3 conditions represented were cancer, musculoskeletal and autoimmune disorders.
- Overall more than 20 conditions were represented.

Q7. Do pharmaceutical companies and their agencies define 'fair market value' for your time?



Organisations were more likely to charge for patient and expert patient time than for staff time. Only 60% of organisations charged for staff time.

23% provided the time of their CEO 'purely voluntary' and 19% answered not applicable (N/A). For senior staff, 21% provided time voluntarily and 21% answered N/A.

Q11. Percentage of organisations providing time and services on a voluntary basis to industry



Organisations with the lowest income were most likely to charge and those with the highest income least likely.

Only 37% of organisations charged for utilising their contact data for industry projects.

Perceptions of fair market value and the impact on charities

- 70% of organisations felt FMV payments were inconsistent.
- 84% felt a fair market value rate card developed by the sector would be helpful.
- 2 organisations provided their own rate cards.

Q9. Do you think fair market value is consistent company to company?



Q10. Would an FMV rate card set by patient organisations be useful?



'These figures vary between what different industry partners offer and so we are somewhat beholden to them. They can vary considerably.'

In free text comments organisations mentioned key concerns. These included:

- The need to recover the full cost of staff time
- Time required to complete work often being underestimated
- Low payments meaning they cannot invest time in recruiting from more diverse patient populations
- The need to cover full expenses for patients and carers.

Experience of FMV

Free text comments

'We try to quote on a project by project basis but if it is an advisory group then the rates are set and sometimes these are unpaid. We have seen FMV rates changed mid-project.'

'We've never agreed a rate internally (I know, it's on my list...) so this has been entirely down to what each pharma has put in our agreement.'

'Sometimes they have the rate they pay. Sometimes they ask our rate. I've been informed our rate was too high and too low! I've had situations where a doctor/HCP on same project has been paid more than the patient/group.'

'The current rates and approaches do not encourage more diverse patient populations or charities to spend time on this – not because they don't want to but because there is no capacity to do so.'

Broader concerns

Free text comments

'We think it is also important to consider the costs to the participant and their carers, who may lose working time for participation.'

'They set the hourly rate and the time involved but often the time involved is way more than they are paying for.'

'Their agencies gain access to peer support groups without asking us or acknowledging our work in providing and curating the space.'

"We have just started using our Fair Market Value Policy. One company was surprised we had this, and thought that instigating a project was 'payment' enough."

Approaches to payment

Free text comments

'For staff time, we cost based on salary of the individual at the required level for the work, plus on costs, calculated against the time taken to do the agreed tasks. This would vary across the charity, as we would want to claim our full costs back.'

'We don't currently charge, rather rely on sponsorship support for our activities and projects as we feel this is a better relationship building tactic and better than charging an hourly rate. However, we also work very closely with the NHS and for free - a rate card for this would be incredibly useful.'

'For a recent project that required extensive knowledge and really thoughtful prep another trustee and I were paid £225/hr, which struck me as generous. A rate card might have discouraged them from paying us that much. But a rate card might make us more confident about asking to be paid.'

Next steps

1. To share these findings with members of the ABPI and industry colleagues.
2. Convene a working group of patient organisations to develop a 'rate card' for use by charities working with industry.
3. Ask pharmaceutical companies to adopt the 'rate card'.
4. In the meantime, when negotiating with industry partners, patient organisations should refer to PFMD's [Global principles for remunerating the patient community](#) and its [FMV toolkit](#), alongside the [ABPI code of practice](#).