Fair Market Value for Charities in Partnership Work

2026 Survey – report and recommendations

cancer 52
the common voice
for rare & less common cancers

nras
National Rheumatoid Arthritis Society

Charities Research Involvement Group

ArthritisUK

HRCI
Health Research Charities Ireland

Patient Information Forum

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Survey partners

The following organisations collaborated on the development of this survey and report. The project was supported by these organisations.

Arthritis UK

Arthritis UK is the leading arthritis charity, changing lives through research, campaigning and support.

Cancer 52

Cancer52 represents over 100 rare and less common cancer charities with the shared aim of promoting improved diagnosis, treatment and support for those affected by rare and less common cancers.

Charities Research Involvement Group (CRIG)

CRIG is a grouping of charities, our aim is to enable shared learning about the involvement of people with lived experience in health and related research.

Health Research Charities Ireland (HRCI)

HRCI is the national umbrella organisation in Ireland for over 45 charities engaged in health, medical and social care research, collectively representing over 2 million people.

National Rheumatoid Arthritis Society (NRAS)

The National Rheumatoid Arthritis Society (NRAS), is the only patient-led organisation in the UK specialising in rheumatoid arthritis (RA) as well as juvenile idiopathic arthritis (JIA).

Patient Information Forum (PIF)

The Patient Information Forum (PIF) is the independent membership body for people working in health information and support. We are the independent voice of UK health information representing 300 cross-sector organisations.

Towards fairer market value

Partnership Survey 2026

Introduction

In early 2026, the Patient Information Forum, Cancer 52, NRAS and Arthritis UK jointly surveyed patient organisations on their experience of partnership working with the pharmaceutical industry.

The aim was to note any improvement in the experience of fair market value (FMV) payments since our survey in 2023 and the guidance we issued jointly with the Charities Research Involvement Group and Health Research Charities Ireland in 2024.

The survey also sought to identify trends and ongoing tensions in partnership working and priority areas for future partnership work.

Arthritis UK joined the collaboration and we included some questions from their research and report published with partners in 2023: From Transactional to Truly Collaborative: Improving Relationships Between Industry and Patient Organisations.

The respondents

The survey had 17 respondents, compared to 43 in 2023.

All organisations provide information and support.

41% 41% had an annual income between £1m–£5m.

35% 35% had an annual income under £500k.

80% 80% had been established for more than 10 years.

47% 47% had 2–10 employees.

29% 29% had 11–50 employees.

Cancer, auto-immune conditions and children's health were the most common topic areas covered, within a broad range of conditions listed.

Working with industry – true collaboration remains a goal

All the respondents had worked with pharmaceutical companies in the previous year. 59% worked with 5-10 pharmaceutical companies and 41% with up to 5 companies.

Type of engagement

63% 63% in clinical research

56% 56% in post-marketing activity

Engagement with pharma companies spanned medicines development, but focused mostly on clinical research (63%) and post-marketing activity (56%).

The most common project types were patient engagement and representation, clinical trial recruitment and design, and the development of patient information.

This reflects findings from Arthritis UK in 2023. Its survey found industry partners' valued patient perspectives, experience and unmet needs in medicines development and patient involvement in developing outcome measures and end points.

Type of relationship

47% 47% of organisations described their relationship with companies as “one off”

41% 41% had established, ongoing relationships

12% 12% had long-term co-creative partnerships

Most organisations (47%) described their relationship with companies as "one off" interactions. 41% had established, ongoing relationships and 12% had long-term, co-creative partnerships.

This represents little change since 2023. Then 76% of respondents from pharmaceutical companies expressed a desire to have long-term relationships and co-created projects. This suggests more needs to be done to make truly collaborative relationships the norm.

Gradual improvement on FMV

More than half (59%) said said companies define Fair Market Value (FMV) payments but rates varied by company. Only 18% felt FMV was consistent across companies, 47% said FMV rates varied.

Consistency and FMV

18% 18% felt FMV was consistent across companies

47% 47% said FMV rates varied

These figures demonstrate some improvement since 2023, when 90% said FMV rates varied. 25% of respondents said FMV rates had improved since our last survey, but most respondents were unsure if this was the case. One respondent commented:

"Companies are now more willing to listen and take on board feedback from patient organisations; are more aware of the importance of PPI and, for the most part, willing to remunerate based on FMV rates."

"In the past year we comprehensively reviewed our approach to working with companies and developed new policies and processes."

Survey respondent

However, the power imbalance between patient organisations and industry remained a concern for some in free text comments:

"They could recognise more appropriately (in financial terms) the amount of work we do on their behalf, especially given the struggles the charity sector is facing at the moment."

"Patient organisations are in general much smaller and less resourced than companies we are working with, meaning that the balance of power is always with the company."

Some organisation have taken steps to address the power imbalance:

"In the past year we comprehensively reviewed our approach to working with companies and developed new policies and processes. Our new approach to working with companies supports our developing work in this area."

Supporting partnership working

Thematic analysis of open-ended questions revealed recurring themes in positive relationships. These include the importance of contact consistency, long-term relationship building, reduced contract complexity and stakeholder engagement. These factors make companies more desirable to work with:

"Ongoing and honest relationships work best. You can tell when the company is ticking a box and when they're actually interested in working with us and patients to improve."

Respondents expressed a desire to continue working with industry in the following areas:

- Engagement activity to promote health equity.
- Patient-centred research and trial design.
- Health information development.

"In the past year we have further developed partnership and collaborative working with companies to include development and support of new services and information."

> **"Ongoing and honest relationships work best. You can tell when the company is ticking a box and when they're actually interested in working with us and patients to improve."**
>
> Survey respondent

Respondents also noted increasing requests from industry for patient organisations to work with multiple sponsors on a single project. New ways of collaborating across organisations and companies are required, to reduce complexity and duplication of effort:

"Having a standardised process or a single portal for applying for grant funding from all companies would make life much easier. It is very time-consuming having to submit the same application to multiple companies in varying formats, with different measures of success."

Handbook on partnership working

PIF partnered with the ABPI to update its handbook on partnership working.

This was published in 2025 and is supported by a library of partnership case studies, demonstrating best practice in partnership working and the positive impacts that result.

Ongoing and new tensions

Contracts remain a key concern.
The main issues were:

- length and complexity (70%)
- affordability of legal review (50%)
- liability clauses (20%).

One respondent suggested companies: ***"Work with their compliance teams to minimise red tape. Use the contracts that patient organisations supply rather than lengthy complex contracts provided by industry."***

Another ongoing tension is patient representation and exclusion from conferences and events:

"The regulations meaning you can only be a 'prescriber' or a 'non-prescriber' create real problems with patient and patient organisation involvement in events and activities. It is often more of a barrier to effective working than a protective system. It feels like there is increasingly strict interpretation of regulations which is limiting access."

New tensions have emerged on funding declarations.

81% supported transparency on declaring industry support but the responses demonstrate uncertainty and practical challenges, particularly in relation to digital projects.

Charities' code concerns

71%

71% – Lack of clarity over how long funding statements must remain in place.

53%

53% – Prominence of funding statements, disproportionate to the funding provided and implying undue influence by the funder.

53%

53% – Requests that funding declarations appear on every page of a website.

29%

29% – Prominence of funding statements on smartphone screens hindering access to content for users and search engines.

There is a perception that recent PMCPA case decisions have added to complexity:

"It's not about companies making it easier, my experience of working with them has been great. They are bound by the code though and rigid application doesn't work for either of us.

"If we were able to add a short 'Funding statement' link to the top of the page that linked out to a page that gave room to describe the relationship more fully that would help. It's really about changing the code so this is possible."

Respondents also mentioned that rules on the promotion of medicines made it harder for them to tackle misinformation on medicines:

"I think there are some frustrations on declarations of funding on projects and some frustration that the code prevents more active tackling of misinformation."

Respondents suggested cross-sector partnership work to advocate for a change to regulations to remove barriers to effective partnership. But this came with a caveat that: ***"any actual or perceived bias in collaborative work is carefully considered".***

Regulatory Framework

The regulatory framework for medicines is complex. The Medicines and Healthcare products Regulatory Agency (MHRA) sets the regulatory framework for medicines in the UK.

The promotion of prescription medicines to the public is prohibited. The definition of promotion is much wider than advertising alone.

The ABPI Code of Practice is a self-regulatory code that regulates the promotion of medicines in line with MHRA rules. Relationships between industry and patient organisations are bound by the ABPI Code and underpinned by UK law.

The ABPI Code is administered by the Prescription Medicines Code of Practice Authority. It operates independently of the ABPI. It provides advice, guidance and training on the ABPI Code. It also rules on complaints made under the Code. Its case reports provide further interpretation of the ABPI Code.

The ABPI Code of Practice will be updated in 2027.

Conclusion

This survey notes some improvement in the experience of partnership work and FMV since 2023. However inconsistency in approach remains. Those companies that perform best build long-term, collaborative relationships. They are seen as more desirable partners than those that continue to treat patient and public involvement as a "tick-box" exercise.

See our requirements for collaborative relationships on the next page.

Our recommendations on FMV from 2024 remain valid, and have been reviewed and updated for 2026. They focus on what can be achieved within the existing regulatory framework.

We note that a review of the regulatory framework is needed to meet the needs of an increasingly digital information environment and to acknowledge the importance of working with patient organisations and patients as partners.

Key findings from CRIG and HRCI

The Charities Research Involvement Group (CRIG) and Health Research Charities Ireland (HRCI) carried out a separate survey on the impact of the 2024 guidance. This survey focused on the use and effectiveness.

Of CRIG members responding, 75% had used the guidance with others planning to use it. 50% of respondents said the guidance:

- Provided reassurance on charging levels.
- Allowed them to "justify" charges.
- Helped them set charging policy and levels.

"The new NIHR guidance for paying patients seems to have confused researchers. Hopefully the more commonplace it is for charities to charge, the less confusion there will be around patient rates versus our rates for what is essentially a professional service."

Most respondents to the HRCI survey (n=8) had used the guidance but needed broader support for implementation. They recommended the following actions:

- Normalising expectations of FMV payment through awareness and promotion.
- Strengthening negotiating positions through benchmarks and evidence.
- Providing practical tools including charging models and examples.
- Greater clarity, visibility, and practical application of the existing guidance.

FMV recommendations

Full cost-recovery to support charity sustainability
Charities need to recover the full cost of their activity including staff costs and central overheads to to ensure financial sustainability.

Minimum entry point of £120/€140 per hour for the work of charities
Patient Focused Medicines Development (PFMD) has an FMV calculator for people with lived experience. This rate is the entry fee to be paid to a charity working in partnership.

Equity of payment with healthcare professionals where this is higher than the PFMD rate
The staff of health charities sit alongside healthcare professionals on steering groups and conference platforms. There should be equitable payment.

Market value add-on costs
When setting FMV the 'brand' benefits of partnering with charities should be taken into account.

Fair contracting
FMV rates should be agreed at the outset. Contracts should be transparent and simplified. Payment terms should be 30 days.

Grant funding consistency
Improve consistency in the grant application process to support multi-company funding of projects.

Keys to collaboration

Recommendations from Arthritis UK's 2023 report continue to require focus to ensure relationships become fully collaborative. The recommendations are listed below:

Companies and patient orgsanisations

- Develop and support personal relationships
- Develop strategic partnership frameworks
- Build mutual understanding
- Collaborate on code changes to support collaboration

Companies

- Create simple template contracts
- Engage with patients and POs earlier
- Create a single point of contact
- Improve standard operating procedures (SOPs)

Patient organisations

- Build an understanding of the ABPI Code of Practice
- Develop your parameters for an effective partnership

Further reading

Towards Fairer Market Value, published September 2024
pifonline.org.uk/resources/fair-market-value-for-charities-in-partnership-work

Arthritis UK and partners, Transactional to truly collaborative
arthritis-uk.org/media/ksvmgo42/from-transactional-to-truly-collaborative_full-report_arthritis_uk.pdf

PIF and ABPI, Handbook on partnership working between and patient organisations
abpi.org.uk/publications/working-together-a-handbook-for-industry-and-patient-organisation-partnerships-2025

ABPI case study library
abpi.org.uk/partnerships/patient-involvement/charity-industry-partnership-case-study-library

About this report

This survey and report is a collaborative project developed by Arthritis UK, Cancer 52, Charities Research Involvement Group, Health Research Charities Ireland, the National Rheumatoid Arthritis Society and the Patient Information Forum.

The guidance is a follow up to a survey published in 2023 and tracks progress on partnership since the publication of new guidance in 2024 and 2025, (see further reading).

It makes recommendations on setting fair market value rates for charities working in cross-sector partnerships and supporting patient and public involvement activities.

Acknowledgements

With thanks to the following people for their contributions in the writing and editing of this resource:
Gemma Winsor – Research Involvement Manager, Arthritis UK
Chris Walden – CEO, Cancer 52
Bec Hanley – Charities Research Involvement Group
Dr Avril Kennan – CEO, Health Research Charities Ireland
Peter Foxton – CEO, NRAS
Sophie Randall – Director, PIF