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# Fair Market Value for Charities in Partnership Work



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## Terms used in this guidance

We recognise the terms used to describe people with lived experience, and those used to describe not-for-profit organisations, are context-dependent and complex.

Different groups may prefer different terminology, and we acknowledge the limitations of language. For the purposes of this guidance we have used terms which we believe will be familiar to the broadest range of people and organisations:

- **Health charity:** an organisation whose primary objectives are philanthropy and social well-being. Other terms that may be used include 'not-for-profit organisation', 'third sector organisation' and 'patient organisation'.
- **Fair Market Value (FMV):** the rate charged or paid to charities for services they provide to other organisations e.g. pharmaceutical companies or research groups.
- **Involvement:** any initiative where a person with lived experience influences decision making, or the design or delivery of an intervention by a charity or other type of organisation. In some settings this is referred to as patient and public involvement, or PPI.
- **People with lived experience:** a person who has first-hand experience of the problem a charity is seeking to address through its work. This term includes service users, patients, carers and family members.

## Partners in this Guidance

The following organisations collaborated on the development of this guidance. The project was funded by these organisations.



### Cancer 52

Cancer52 represents over 115 predominantly small patient support group 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 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

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.

## Executive Summary

# Fair Market Value for Charities in Partnership Work

Charities face increasing demands from all sectors to support patient and public involvement (PPI) and to work in partnerships. Partnership work uses funds and resources. Charities must manage these costs to ensure financial sustainability.

This guidance is designed to help charities and partners calculate Fair Market Value (FMV) when charities decide to work in partnership and to charge for these activities.

Charities have huge value as partners. It is critical this value is understood and recognised in the process of setting FMV. Our aim is to support the independence of charities and increase transparency about payment.

For charities partnership work to continue and grow, there must be fair and transparent payment which contributes to the sustainability of the sector. We urge all partners to implement our recommendations on Fair Market Value.

### Recommendations

**1. Full cost-recovery to support charity sustainability**

Charities need to recover the full cost of their activity including staff costs and central overheads to ensure the sustainability of organisations.

**2. Minimum entry point of £100/€120 per hour for the work of charities**

Patient Focused Medicines Development (PFMD) has developed an FMV calculator for people with lived experience. This rate is a minimum entry fee to be paid to a charity working in partnership.

**3. 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. Recognition of this expertise should mean there is equitable payment.

**4. Market value add-on costs**

When setting FMV the intangible 'brand' benefits of partnering with charities should be taken into account.

**5. Fair contracting**

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

## Growth of Patient and Public Involvement and partnership work

### Purpose

The purpose of this guidance is to help charities and potential partners calculate fair payment for contributions to projects or partnerships. This initiative was led by a coalition of charities and is informed by a series of consultations with a wide range of charities and partner bodies. You can view the full list of partner organisations in the appendix.

### The growth of PPI and partnership work

There is a growing desire from commercial and public sector organisations to actively involve people with lived experience in the development of their activities. This includes all aspects of medicines development, research, service development, health information development and related projects.

This is often referred to as Patient and Public Involvement (PPI). It is encouraged and very much supported by charities.

The importance of offering payment to people with lived experience for their involvement is increasingly recognised. There are several sources of guidance about payment to individual PPI contributors. See the reading list on page 13 for links to this guidance.

### Guidance gap

While there is existing guidance on payment to individuals, this document addresses a guidance gap on FMV payments for charities' contribution to PPI and partnerships.

A survey in 2023 found inconsistencies in FMV rates paid to charities, with some charities receiving no payment for partnership work. The perception is FMV calculations are inconsistent, complex, unfair and lack transparency.

### The cost of supporting PPI and partnership for charities

Charities invest in dedicated staff to support people with lived experience. This includes regular PPI-related communications with their communities and comprehensive plans to ensure the involvement activities are sustainable and beneficial for people with lived experience.

Partnership work takes time and it uses funds and resources. Charities must consider how to manage partnerships and the costs associated with them to ensure their financial sustainability and to maintain their prized independence.

### Managing costs

National charity regulators recognise effective charities incur operational costs and encourage a pragmatic approach to managing these. For example, the Charity Commission states charities' costs must be 'justifiable and in the best interests of the charity'.

It is crucial to ensure the costs of PPI and partnership activities are recovered so charities can provide and develop sustainable and equitable services with patient benefit at the core.

## The value and nature of charities

Charities have huge value as partners. In the health sector they are trusted parties, representing the best interests of people with lived experience. The relationships charities build with their communities take many years. Charities have developed expertise in supporting PPI and in ensuring people with lived experience are effectively informed, supported and have access to a holistic set of services.

Health charities have strong links to clinicians and researchers in their specialist field. Their staff may also have a clinical or research background. Good relationships with the clinical community require effective governance and trust is built over many years. Charities also have expertise in communications, advocacy, event management and other skills of great value to partners.

### Expert and professional

Charity staff have many years of collective expertise in their fields of work. Charity professional roles include chief executives and specialists in communication, policy, involvement and engagement.

Staff often work collaboratively and bring multi-disciplinary expertise to the projects they deliver in partnership.

Health charities are diverse and differ hugely in size, income, the types of disease or health condition and the numbers of people they represent. The broad range of charities operating offers unique and diverse value to partnerships.

### Unique insights

Working with a range of charities allows partners to gain invaluable insights into crucial issues like health inequalities, improving outcomes for partners and patients alike. It is critical this value is understood and recognised in the process of setting FMV for partnership work.

We stress there is no obligation for charities to engage in partnership or charge for their work with partners. They may also adjust their rates depending on the types of partner they are working with.

However, where there is payment it should be consistent, transparent and reflect the true value that charities bring as expert and trusted partners. This will help to make partnership working both feasible and sustainable for charities.

## Recommendations

### Recommendations for calculating Fair Market Value (FMV)

These recommendations are designed to support charities and their partners to establish a more informed and coherent approach to calculating FMV.

#### 1. Full cost-recovery to support charity sustainability

Charities need to recover the full cost of their activity including staff costs and central overheads to ensure the sustainability of the organisations. VAT charges may also apply to some fees and need to be factored into costings and payments.

#### 2. Minimum entry point of £100/€120 per hour for the work of charities\*

Patient Focused Medicines Development (PFMD) has worked on a global scale to develop a FMV calculator for people with lived experience. We consider this a minimum entry fee for to be paid to a charity working in partnership. This could vary depending on the following considerations:

- Type of project: complexity, scope, purpose.
- Type of staff who will contribute to the project: chief executive officer, clinical background, specialist teams, administrators, researchers.
- Type of activity: engagement, involvement, speaker requests.
- Type of partner: start-ups, public bodies, researchers, NHS, national or global commercial.

- Time required: how many hours, days, weeks, months or years.

\*This rate was developed in 2024 and should be adjusted for inflation in future years.

#### 3. Equity of payment with healthcare professionals where this is higher than the PFMD rate

There is growing recognition of the expertise of people with lived experience and the charities representing them. This expertise covers lived experience of the health condition and its treatment, the health system and policy.

Health charities and expert patients sit alongside healthcare professionals on steering groups, advisory boards and conference platforms. Recognition of this expertise should also mean there is equitable payment for time given. Examples are provided below.

| Charity role                                 | Equivalent HCP payment rate                           |
|--|---|
| Charity CEO                                  | Consultant physician                                  |
| Head of Service (PPI, Information, Research) | Senior Physician, Senior Allied HCP, Nurse Consultant |
| Senior charity lead                          | Nurse specialist and Allied HCP                       |



#### 4. Market value add-on costs

When setting FMV the intangible benefits of partnering with charities should be taken into account.

This could be considered as the 'market' or 'brand' value charities bring to a partnership and is beyond the direct staff costs and overheads.

This value includes:

- Credibility gained from being approved to work with a charity.
- Access to support from professional multi-disciplinary teams within charities to deliver end outcomes.
- Unique insights into challenges, opportunities and threats.
- Managing reputational risks throughout the project, protecting participants and being responsible for patient benefit.
- Expert insights into the conditions they support.
- Horizon scanning across their specialty both nationally and internationally.

#### 5. Fair contracting

FMV rates should be agreed at the outset of a project or partnership. Contracting arrangements should be transparent and simplified. Budget should be provided for independent legal review. Payment terms should be 30 days.

## Deciding to work in partnership

The decision to enter paid or unpaid partnerships should reflect a charity's strategic aims and values, the type of partner, type of activity and time required.

Managing partnerships requires governance and transparency. There is a responsibility for charities to ensure all funds they raise are spent appropriately and deliver tangible benefit for their beneficiaries.

There are a number of elements charities should consider when agreeing to work with a partner. See the appendix for guides to help with this decision-making process.

The following should be taken into account when considering opportunities to partner and to decide if charging would be appropriate.

- **Alignment on purpose and goals**

The charity should consider how its strategic aims and values align with the goal of the project or research proposal.

- **The type of partner**

There are a range of partners that may want to work with including:

- Small start-up companies with low funds.
- Larger commercial and profit-making organisations.
- Public bodies.
- Universities.
- Research agencies.
- National health services.

- **The type of proposed activity**

The type of activity charities might be asked to contribute to includes:

- One-off requests.
- Complex long-term projects.
- Strategic advice.
- Review of patient information.
- Advisory boards.
- Research design and recruitment.

- **Governance and transparency**

Charities must communicate and disclose all payments. See the appendix for good practice guidance to help manage this reporting process. There should also be due consideration of ethics including confidentiality of patient information and GDPR, managing contracts and reporting public benefit.

## The role of partners

There are many examples of charity partnerships with researchers, public bodies, commercial pharmaceutical companies and other organisations. These can benefit both parties and contribute to improving outcomes for people living with health conditions.

However, there are also bad experiences. These have impacted negatively on charities and mean they no longer want to engage in partnerships.

Negative experiences include funding being promised and then taken away with little notice, leaving the charity with costs and no end results for their communities. Charities also report long and complex contracting with delayed payments placing pressure on financial management.

During the consultation on this guidance we heard loud and clear that FMV is not only the work of the charity sector. It is also about how partners improve relationships and support partnership working by providing respectful and informed terms of engagement.

### Three steps to fairer partnerships

We suggest partners consider the following in their processes and approaches to charities:

#### 1. Support our key recommendations

PPI payment and relationship building has moved on considerably. But there remains a gap in terms of what partners expect of charities and the payment they offer to them.

We urge funders to support these recommendations:

- An entry level minimum payment for charities equivalent to the PFMD rates for people with lived experience.
- Equivalence with healthcare professionals (HCPs) rates for senior staff.
- Transparency and disclosure on how FMV calculations are arrived at.
- Improved contracting arrangements and payment terms.

#### 2. Work internally with local and global teams

Partnership projects and research often happen on a large scale involving several countries. They can be initiated outside the country where the partnership is occurring. Internal FMV processes are not in the public domain and are impossible for charities to influence and change.

We need named internal champions and advocates to work with the charity sector to ensure there is consistency and informed approaches to setting FMV levels.

#### 3. Support and share this guidance

The best partnerships will always be a blend of responsibilities held by those involved. Please support this guidance and share with your networks and leaders.

## Conclusion

Charities are invaluable partners in involvement activities in all sectors. However, for this to continue and grow, there must be fair and transparent practice which recognises the value and expertise of charities and contributes to the sustainability of the sector.

We urge all partner organisations and charities to engage with this guidance and implement the recommendations on Fair Market Value.

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## Appendix 1 – Organisations participating in the consultation process

### 1. Fair Market Value Survey, 2023

[pifonline.org.uk/resources/publications/fair-market-value-survey-findings](https://pifonline.org.uk/resources/publications/fair-market-value-survey-findings)

### 2. Interview participants, 2024

Association of the British Pharmaceutical Industry  
AstraZeneca  
Bowel Research UK  
Breakthrough Cancer Research Ireland  
British Heart Foundation  
British Society for Immunology  
Cardiomyopathy UK  
Cleft Lip and Palate Association  
Cystic Fibrosis Trust  
Health Research Board Ireland  
Maynooth University Ireland  
National Institute for Health and Care Research  
Psoriasis and Psoriatic Arthritis Alliance (PAPAA)  
Scleroderma and Raynaud's UK

### 3. Workshop participants, 2024

The Alzheimer Society of Ireland  
Association of the British Pharmaceutical Industry  
Asthma and Lung UK  
Blood Cancer UK  
British Liver Trust  
Cancer 52  
Cardiomyopathy UK  
Charities Research Involvement Group  
Cleft Lip and Palate Association  
Cystic Fibrosis Trust  
Epilepsy Research Institute UK  
Fight Bladder Cancer  
Health Research Charities Ireland  
H E A R T UK  
Irish Lung Fibrosis Association  
Johnson & Johnson Innovative Medicine  
National Institute for Health and Care Research  
National Rheumatoid Arthritis Association  
Parkinson's UK  
Patient Information Forum  
Takeda  
Versus Arthritis

## Further reading

### Payment to individual PPI contributors

- Payment Guidance for Researchers and Professionals [nih.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392](https://nih.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392)
- PFMD Global principles for remunerating the patient community for interactions with the pharmaceutical industry [pemsuite.org/wp-content/uploads/2022/05/PFMD\\_Global-Principles-for-remunerating-the-patient-community-for-interactions-with-the-pharmaceutical-industry\\_v06\\_without-logo-1.pdf](https://pemsuite.org/wp-content/uploads/2022/05/PFMD_Global-Principles-for-remunerating-the-patient-community-for-interactions-with-the-pharmaceutical-industry_v06_without-logo-1.pdf)

### Considerations for partnership working

- HRCI / PPI Ignite Network – Charities & Researchers Partnering Guide [hrci.ie/hrci-ppi-ignite-network-charities-researchers-partnering-guide](https://hrci.ie/hrci-ppi-ignite-network-charities-researchers-partnering-guide)
- Coalition of Charities (Versus Arthritis and partners) and Pfizer: From Transactional to Truly Collaborative: Improving Relationships between Industry and Patient Organisations [versusarthritis.org/media/25662/improving-relationships-industry-patient-executive-summary.pdf](https://versusarthritis.org/media/25662/improving-relationships-industry-patient-executive-summary.pdf)
- WECAN Guiding principles for reasonable agreements between patient advocates and pharmaceutical companies [wecanadvocate.eu/rapp](https://wecanadvocate.eu/rapp)
- ABPI sourcebook: principles of working together, relevant clauses in the Code. [abpi.org.uk/partnerships/working-with-patient-organisations/working-with-patients-and-patient-organisations-2022-sourcebook-for-industry](https://abpi.org.uk/partnerships/working-with-patient-organisations/working-with-patients-and-patient-organisations-2022-sourcebook-for-industry)

- ABPI best practice guidance: supporting patient organisations to report industry funding [abpi.org.uk/publications/best-practice-guidance-supporting-patient-organisations-to-report-industry-funding](https://abpi.org.uk/publications/best-practice-guidance-supporting-patient-organisations-to-report-industry-funding)
- AMRC: An essential partnership: a guide to charities working together with industry [amrc.org.uk/Handlers/Download.ashx?IDMF=fa2c3b7c-8184-45c4-87a2-e6d1b8a6888f](https://amrc.org.uk/Handlers/Download.ashx?IDMF=fa2c3b7c-8184-45c4-87a2-e6d1b8a6888f)
- EFPIA: Working together with Patient Groups (Sept 2017) / Working together with patient organisations (Sept 2023) [efpia.eu/publications/downloads/efpia/working-together-with-patient-groups](https://efpia.eu/publications/downloads/efpia/working-together-with-patient-groups)

### Fair Market Value

- Patient Focused Medicines Development (PFMD) tools to support fair remuneration of the patient community for interactions with the pharmaceutical industry [pemsuite.org/fmv](https://pemsuite.org/fmv)
- Global Principles for remunerating the patient community for interactions [PFMD\\_Global-Principles-for-remunerating-the-patient-community-for-interactions-with-the-pharmaceutical-industry.pdf](https://pemsuite.org/wp-content/uploads/2022/05/PFMD_Global-Principles-for-remunerating-the-patient-community-for-interactions-with-the-pharmaceutical-industry.pdf) (pemsuite.org)
- National Health Council (US) Patient Compensation Tools [nationalhealthcouncil.org/additional-resources/patient-compensation-tools](https://nationalhealthcouncil.org/additional-resources/patient-compensation-tools)
- CASS Business School – Cost recovery, tools for success: doing the rights things and doing them right. [bayes.city.ac.uk/\\_\\_\\_data/assets/pdf\\_file/0008/422828/CCE-Cost-Recovery-Guide-Final-Version.pdf](https://bayes.city.ac.uk/___data/assets/pdf_file/0008/422828/CCE-Cost-Recovery-Guide-Final-Version.pdf)

## About the guidance

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

The guidance was developed following a consultation exercise in the summer of 2024 with a range of stakeholders.

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

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