

# **EUROCARERS' GUIDANCE FOR ETHICAL INVOLVEMENT OF CARERS** and Carer Organisations in Research

**A Eurocarers' Position Paper**



June 2026

# OBJECTIVES: what this document aims to achieve

The aim of this document is to **define a clear set of principles** that guide Eurocarers **to ensure fair involvement of carer organisations and individual carers in research activities**. In particular, it makes the ethical case for research institutions to fairly remunerate carers and carer organisations for their time and overheads.

**Eurocarers encourages all members to actively uphold these principles when engaging in research.** While Eurocarers is not in a position to mandate or monitor their implementation, these principles are intended to represent a shared ethical standard across the network and secretariat.



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# BACKGROUND: why this document was created

Eurocarers' goal is to achieve meaningful results for carers. This is done, among other things, through well-implemented cooperation between research and carer organisations, in the form of research projects. Ensuring **strong and fair cooperation in research** is one of the key priorities of the network.

**This set of guidelines is an important tool for Eurocarers to grow stronger in this area and to better support the inclusion of the carers' perspective in research.** It is also in line with the growing importance of **participatory research**, that aims to co-create research on products and services with their intended users.

The need to set out principles for fair involvement of carer organisations and individual carers in research was brought to the attention of the Eurocarers Board in November 2024 by two members, yet representing the sentiments of the other carer organisations that are part of the network.

In a letter to the Board, they explained that often their involvement in research activities does not feel like a cooperation, but rather is perceived as an alibi to increase the chances of obtaining funding. They summarised the difficulties experienced by carer organisations as follows:

- Carer organisations and individual carers are not involved from the start of the research process, they are added 'as an afterthought';
- Requests to contribute to funding applications are advanced very late and with a short time to reflect or respond;
- Carer organisations and individual carers are expected to assist in finding research participants, but there are (mostly) no resources set aside to compensate for their time and effort.

**In many cases, researchers in this field share a strong commitment toward involving carers but often underestimate the resources needed by carers and carers organisations.**

# PROCESS: how this document was created

This set of principles was redacted by the Eurocarers Secretariat and Board, in consultation and collaboration with its members, especially the Eurocarers Research Working Group (ERWG).

The following steps were taken:

**Bilateral discussion with members  
that raised the issue to the Board**  
November 2024

**Group discussion and feedback  
session at ERWG meeting**  
October 2025

**Consultation with the Eurocarers  
Board and Executive Director**  
January 2026

**Consultation with all  
members of the ERWG**  
March 2026

**Discussion at the Eurocarers Annual  
General Assembly**  
May 2026

# DEFINITIONS

## Research involvement

This document sets out principles for fair **research involvement of carer organisations** and individual carers. Research involvement is different from research participation.<sup>1</sup>

### Research involvement

Involvement is defined as **research being carried out 'with' or 'by' members of the public** rather than 'about' or 'for' them. It is an **active partnership** between patients, carers and members of the public with researchers.

Involvement implies **sharing responsibilities for the entire process and outcomes of the research**. Carer organisations and individual carers are **co-owners** of the research activities, with clear and distinct roles.

Examples of how carer organisations and individual carers might get involved in research include:

- As joint grant holders, co-applicants or consortium partners on a research project;
- As members of a project advisory or steering group;
- Identifying research priorities;
- Commenting on and developing patient information leaflets or other research materials;
- Identifying and recruiting research participants;
- Commenting on and developing digital/technical devices with researchers;
- Carrying out research (i.e. interviews and focus groups) as carer researchers, in line with a participatory research approach.

## Carer organisations and individual carers

This document outlines common ethical principles that refer to the involvement of both individual carers and carer organisations. However, it is important that their involvement in research raises different practical considerations and arrangements.

**Individual carers** typically contribute expertise that is grounded in their lived experience of caring. Their involvement may include participation in advisory groups, consultation processes and co-design activities. This contribution represents valuable expertise and should be recognised and compensated appropriately within research funding applications.

In contrast, **carer organisations** contribute institutional expertise, organisational infrastructure and professional staff time. They may facilitate access to carer communities, support recruitment, contribute to dissemination activities or provide strategic input into research design, interpretations and recommendations. Their involvement often requires the allocation of organisational resources and should be recognised through formal partnership agreements and appropriate financial compensation within research funding applications.

Recognising these different forms of contributions helps ensure that individual carers nor carer organisations are placed at disadvantage as a result of their involvement in research.

# SET OF PRINCIPLES endorsed by Eurocarers

## 1. Research should compensate carer organisations and carers fairly

Research organisations and researchers should take all the necessary steps to ensure that the involvement of carer organisations and individual carers in research is **fair and equitable**. This means paying attention that their time, knowledge and resources are adequately valued, on par with other research partners. Carer organisations and individual carers should not be financially worse off as a result of being involved in research activities relevant for the Network, and they need to be **compensated** for their time and overhead costs.

Compensation should be **monetary whenever possible**. However, there might be circumstances where there is no budget available, particularly to cover the cost of developing a research proposal, or in smaller research projects with limited funding. In these cases, research involvement can still be acknowledged and handled transparently through **in-kind contributions**.

## 2. Research should value the intellectual input of carer organisations and carers

Research activities that aim to involve carer organisations and individual carers should be conceived and developed in collaboration with them from an early stage, following the principles of **co-production and co-creation**. In practice, this means that carer organisations and individual carers should be involved as **joint grant holders, co-applicants or consortium partners** on a given research project.

This ensures that their **intellectual input** can shape the whole research process, their work and knowledge are fairly compensated by research grants, and they are informed about and able to **exploit the research results**.

## 5. Research produced by carers and carer organisations is valuable and valued

When engaging in research projects, researchers should value the expertise and evidence of organisations that are both research- and carer-focused.

## 3. Research co-production should be the default

**Co-production with care organisations and with carers** should be the default, and Eurocarers members are committed to champion it so that it becomes **common practice**.

Different arrangements, such as involving organisations or individuals at a later stage (i.e. when the project has already been conceptualised) should be the exception and are to be limited as much as possible.

## 6. Co-producing research with carers and carer organisations improves quality

Fair financial compensation is not only a matter of equity, it also **signals value**. In research practice, activities that are budgeted and financially recognised tend to receive clearer planning, stronger accountability and greater institutional priority. Conversely, when involvement is unpaid or informal, it risks being marginalised or treated as inconsequential. Ensuring adequate compensation therefore **strengthens research quality as a whole**. This set

## 4. Managing instances when co-production is not possible with fairness

In those (ideally) **exceptional cases** when carer organisations and individual carers are asked to contribute to a research project that has already been developed without their involvement, all the **costs** that they sustain **should be covered**, and their work should be **compensated with a fair rate** (or other in-kind compensation).<sup>2</sup>

Caveat: Researchers should be aware that it is not always possible to compensate research involvement if this expense was not factored into the funding application, due to administrative and financial constraints. For this reason, it is extremely important not to treat the involvement of carer organisation as an afterthought, and to always prioritise a co-production and co-payment approach.

of principles offers guidance on how to move away from unethical involvement of carer organisations and individual carers in research. In order for research to take place in an equitable manner, however, these principles need to be **translated and applied to negotiations and relations at the local level**.

# TRANSLATING PRINCIPLES INTO PRACTICE: some examples and resources

## Early engagement during grant development

Researchers should seek to involve carers and carer organisations in the early stages of project development, ideally before a funding proposal is submitted. Early engagement allows sufficient time to define meaningful roles and to ensure that appropriate resources are included in the project budget.

### For example:

- Consulting carers and carer organisations when **defining research questions or identifying priority topics**;
- Involving carers or carer organisations in **shaping study design, recruitment strategies, interpretation of findings or dissemination plans**;
- Clarifying the type, scale and time frame of involvement expected, and **assessing what carers and carer organisations have capacity for**;
- Clarifying how the contribution of carers and carer organisations will be **recognised from an intellectual property point of view** (i.e. inclusion as authors) and how research outcomes and outputs will be shared with people who took part.

These discussions enable the research team to budget appropriately for involvement activities, and choose the most suitable contractual arrangement.

## Budgeting for organisational capacity

If carer organisations have agreed to play an active role in research projects, their involvement should be reflected in the project budget.

### For example:

- Staff time should be allocated for **participation in project meetings, advisory or steering committees**;
- Staff time and resources should be allocated to **carry out research tasks**;
- Resources should be allocated for **communication and dissemination activities**.

## Navigating contractual arrangements

Research projects are governed by contractual agreements between the funder (i.e. grant-making institutions, philanthropy entities, donors) and the funding recipients (i.e. the project consortium). There are several possible types of contracts, depending on the type of research and on the country.

When it comes to **EU-funded projects**, there are two main types of contractual arrangements that can be used to govern research involvement:

- **Funding beneficiaries** play a major role in a project consortium (i.e. they are responsible for a Work Package or several tasks), co-sign the grant agreement, are legally responsible for the successful implementation of the grant, and must comply with reporting rules.
- **Affiliated entities** are not direct funding beneficiaries (i.e. they do not sign the grant agreement), but are involved in ad-hoc tasks of a research project in light of long-standing pre-existing relationship with one of the beneficiaries. The arrangement must be clearly defined in the project proposal, and is formalised in the grant agreement that all beneficiaries sign. These entities are paid from the budget allocated to the beneficiary they are affiliated to.

## Leveraging funder requirements for Patient and Public Involvement (PPI)

In several countries, research funders increasingly expect meaningful involvement of patients, carers and the public in research, in line with PPI principles. For example, the Irish Health Research Board requires applicants to describe public involvement in research proposals and recognises that the nature and extent of involvement will vary depending on the context of each study.

**Funder requirements can encourage researchers to plan involvement more systematically and to allocate appropriate resources for it within grant proposals.**

# 'HOW TO' GUIDE

## for handling exceptional cases with fairness

This section provides guidance for situations where **carers or carer organisations are invited to be involved in research after a project has already been designed or funded**, without their involvement. Whilst this situation should ideally be avoided, it may occur in practice. The guidance below outlines how researchers can handle these situations in a fair and transparent way.

### What to do before contacting carer organisations and individual carers

- Develop a clear policy on payments, which includes:
  - Payment rates to be offered;
  - Clear explanations on what expenses may be reimbursed or covered, and how the expense claim process works;
  - Specific procedures designed for individuals who receive state benefits;<sup>3</sup>
- Seek advice from your organisation or institution's finance and human resource departments to clarify how payments can be made, and what are the potential administrative constraints;
- Do not underestimate the budget for research involvement – ensure that you have sufficient resources to coordinate and support involvement throughout the research process, and that you can cover all necessary costs.

### What to do at the first point of contact

- Consult with carer organisations and individual carers about how they would like to receive payment (monetary or in-kind) or receive acknowledgement for their contributions;
- Conversations around compensation should take place at the first point of contact, when you contact carer organisations and individual carers with a request to be involved in research activities. At the outset, make sure to explain what they are being asked to do and what they are being offered in return, how they will be paid, how their involvement will be acknowledged, and what actions they need to take;
- Offer payment at a level that is commensurate with the nature and demands of the activity and is fair when compared to other members of the research team, to acknowledge the value placed on research involvement;
- Where possible, be flexible when offering payment and recognition, as the individual's circumstances should be taken into account;
- Where possible, design timelines and deadlines that are compatible with the workload of carer organisations and individual carers;

- Make sure to process all reimbursement of expenses promptly. Where possible, pay for expenses in advance to avoid carer organisations struggling with cash flow issues and having to wait for reimbursement;
- Offer support to carer organisations and individual carers in the form of documentary evidence of any payment, so that they have information to provide to tax or benefits authorities, if needed.

# 'HOW TO' GUIDE

## for handling exceptional cases with fairness

### What to do at the end of the research process

- Promptly share research outcomes and findings with the carer organisations and individual carers that were involved in the research process, in an accessible and timely manner.
- Raise the visibility of carer organisations and carers, when presenting research findings.

### What should be compensated: check-list of common costs associated with research involvement

Not all costs might apply to all situations. This check-list should be consulted to assess what is needed on a case-by-case basis.

#### A. Payment and reward (direct compensation for involvement):

- Monetary payment
- Vouchers
- Fee, donation or gift to a group or network
- Funding for additional training or learning
- Honorary appointment

#### B. Reimbursement of expenses incurred for research involvement:

##### STAFF INVOLVED IN RESEARCH ACTIVITIES

- Travel
- Remote/home working costs
- Subsistence
- Childcare
- Carer costs (i.e. replacement care, respite care)
- Personal assistants
- Overnight accommodation

##### SERVICES AND GOODS PURCHASED TO CARRY OUT RESEARCH ACTIVITIES:

- Finding research participants (advertising cost)
- Training and learning costs
- Venues and catering
- Equipment and books
- Conference fees
- Administrative support
- Public involvement of coordinator and/ or community engagement lead
- Independent facilitator
- Peer researchers/ interviewers
- Disclosure and Barring Service
- Language translation and interpretation

## Payment rates

Rates of payment are context-dependent. Some countries, regions, or even national hospitals might have guidelines (e.g. for patient involvement, for carer involvement) on rates that are appropriate for specific contexts.

**Researchers should always refer to guidelines that are applicable to their specific context and situation.**

Below is a non-exhaustive list of examples from some specific contexts. They can be used as inspiration in those cases where more specific rates are not available, but they should always be revised and adapted.



### AUSTRIA

- The Ludwig Boltzmann Gesellschaft Open Innovation in Science Centre published rate guidelines for involving citizens and stakeholders in research in Austria. The document is available [HERE](#).



### BELGIUM

- The Belgian Association of Research Ethics Committees (BAREC) published guidance on fair compensation of subjects for their participation in clinical research in Belgium. The document includes rates that are appropriate for the Belgian context, and can be used for research involvement compensation as well. The document is available [HERE](#).



### IRELAND

- A coalition of Irish health charities published guidance on fair market value for charities involved in partnership work. The document is available [HERE](#), and provides practical recommendations for calculating Fair Market Value, including suggested rates (p.8).



### NORWAY

- The Norwegian Regional Health Authorities published national guidelines for user involvement in research (document available [HERE](#)), and a similar document was also produced by VID University College in Oslo (document available [HERE](#)).
- The Norwegian Agency for Public and Financial Management (DFØ) published national government rates for travel and meals within Norway. The document is available [HERE](#).



### THE NETHERLANDS

- The funding organisation ZonMw (mostly active in the field of health research) published guidelines with suggested rates for compensations and reimbursements for specific target groups and target group organisations involved in the research projects they fund. The resources are available [HERE](#).



### UNITED KINGDOM

- NIHR published detailed suggested rates for members of the public involved in research. The document is available [HERE](#).
- The NIHR rates have been recently reviewed and updated by the Centre for Care, adjusted for inflation in 2025. The document is available [HERE](#).

# References

This position paper was inspired by selected sources, that systematise ethical standards in this domain:

1. Care Alliance Ireland. (2021). Public and Patient involvement. A guide for Non-for-Profit and Community Groups New to Research. Retrieved from: [https://www.carealliance.ie/userfiles/files/PPI\\_Guide\\_NPF.pdf](https://www.carealliance.ie/userfiles/files/PPI_Guide_NPF.pdf)
2. UK National Institute for Health and Care Research. (2024a). Briefing notes for researchers - public involvement in NHS, health and social care research. Retrieved from <https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research#tab-256881>
3. UK National Institute for Health and Care Research. (2024b). Payment guidance for members of the public considering involvement in research. Retrieved from <https://www.nihr.ac.uk/payment-guidance-members-public-considering-involvement-research>
4. UK National Institute for Health and Care Research. (2025). Payment guidance for researchers and professionals involving people in research. Retrieved from <https://www.nihr.ac.uk/payment-guidance-researchers-and-professionals>

These resources were a useful starting point to establish baseline definitions and principles. However, the content of this position paper was later refined by the Eurocarers Secretariat and Research Working Group to suit the needs and circumstances of carer organisations and individual carers across different contexts in Europe.

# Endnotes

1. This position paper is not about carers as research participants. The term 'research participation' indicates instances when research is conducted 'about' or 'for' carers (i.e. carers are the topic that is being studied). Examples include carers being recruited to a clinical trial, completing a questionnaire, or participating in an interview/focus group. When it comes to participation in research, reimbursement of expenses is encouraged as a good practice. In line with principles outlined in the first section of this document, research participants should also not be financially worse off as a result of their participation in research. Payment above the reimbursement of expenses (for study participants' time, skills or expertise) can be offered if subject to ethical approval. Where payments are allowed, these need to follow local legislation and cannot be the sole inducement to take part in a research study. This is to ensure that the validity of research findings is not compromised by participants having a vested interest (i.e. financial interest) motivating their participation.
2. See Section "How to" guide for handling exceptional cases with fairness" for some practical tips on how to proceed in these (ideally) exceptional cases.
3. Receiving this kind of payment can have implications for people receiving any form of benefits. It is very important that people receiving state benefits get expert advice prior to accepting any form of payment"



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