# Shaping Our Lives Statement on Involvement Payments

Last updated: 16th December 2022

Shaping Our Lives supports and promotes making involvement payments to people who share their experiences of using health and social care services; or who share their experiences of discrimination, oppression, and exclusion. We think that these experiences are invaluable in improving services, systems, and societal structures and should be valued in the same way as someone who is usually engaged through work to provide or influence them. Other forms of reward and recognition can also be offered and are often overlooked, such as access to resources, training opportunities, or facilities.

1. People who take part in involvement activities should always be able to choose not to accept an involvement payment or accept a lower payment. They should always be made aware that accepting involvement payments may affect their entitlement to welfare benefits, tax, pensions, and so on. The amount offered for involvement should be regularly reviewed and adjusted in line with inflation.
2. Expenses, reasonable adjustments, and access and support requirements are essential for equity. Support costs include the cost of informal and formal carers, both to assist people to take part, and to support a dependent when someone is taking part and they usually care for someone. Expenses, reasonable adjustments, and access and support requirements should not be considered as an involvement payment. These costs should be included in an involvement activity budget as a separate budget line.

Shaping Our Lives acknowledges that, on some occasions, it may not be possible to offer an involvement payment. This may be because the organisation organising the involvement does not have access to any funding and often this includes students studying for a PhD. In this case, we encourage organisers to think of other forms of reward and recognition. Lastly, it is fundamental that organisers are transparent and make this known to individuals from the start.

Involvement payments should be considered for any involvement activity. Involvement activities are often called consultations, engagement, involvement, or co-production.

The following definitions have been adapted from the National Institute for Health and Care Research (NIHR), and could apply in a range of settings such as research, education, service provision, commissioning and community and voluntary sector organisations. The organisations organising these activities might be a health or social care provider, a charity or other non-profit making organisation, a regulator, a research body, or an educational establishment.

**Involvement =** activities being carried out with or by members of the public; rather than activities done to, for, or about them. It is an active partnership between service users, carers and members of the public with those running services etc.

**Engagement =** where information and knowledge is provided and shared with service users, carers and members of the public.

**Co-production =** an approach where those organising the involvement work together with service users, carers and members of the public, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. It recognises that service users, carers and the public have skills, knowledge and experience of equal importance.

**Consultation =** Consultation is when you ask members of the public for their views and use these views to inform your decision making. Consultation can be about any aspect of research, services or policy.

**Participation =**  where people take part in involvement activities, for example, completing a questionnaire or participating in a focus group.