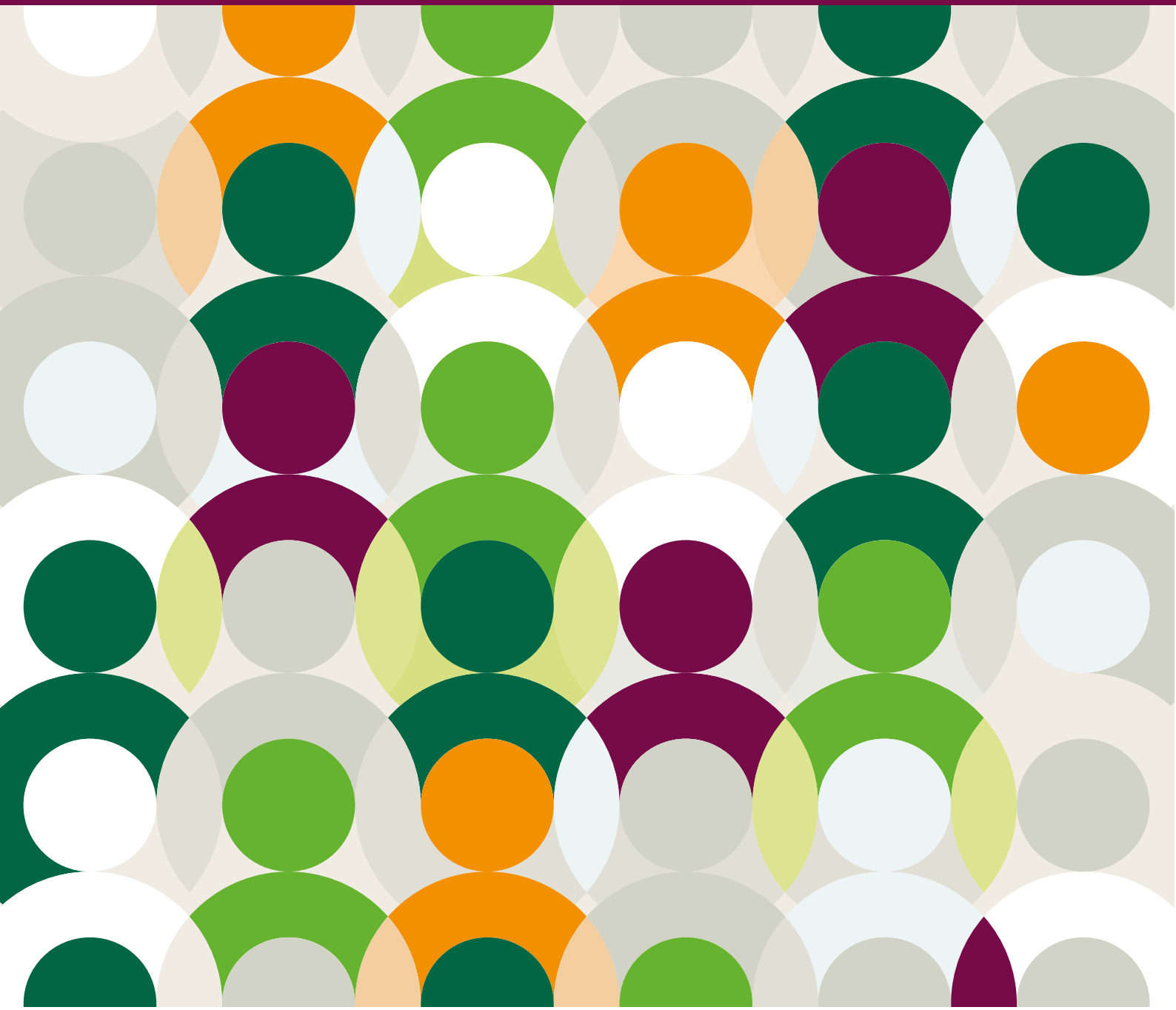
Principles for Reward, Recognition and Support

for Involving People and Communities in the East of England



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Contributors

Rachel Jennings
Dr Su Conquer
Andréa Grobois
Angie Ridley
Tina Starling
The Patients Association
Cambridgeshire and Peterborough Participation and Involvement Network members

1. Background

In order to develop services that are responsive to local needs it is vital that we listen to and provide opportunities for people to share their personal experiences, views and ideas of what it feels like to use them. Acknowledging and valuing the time and contribution that people give, and demonstrating how the insight is used, is fundamental to developing trusted and equitable partnerships.

Engagement leads from Integrated Care Boards (ICBs) and NHS providers in the East of England (EoE) have worked collaboratively with other partners in local authorities, research organisations and the voluntary and community sector to address this issue and produce guidance that can be used to support the involvement of people in services that work for them and our communities.

Supported by funding from the regional NHSE team and the Patients Association, we have sought to develop a system-wide approach to how we involve, support and recognise people with lived experience and to consider the most effective ways that we share that insight with system partners. Recognising that whilst a blanket approach to policy implementation would not be appropriate, these are a common set of principles and ways of working that all system partners can learn from and adopt.

This document provides clear guidance and options for how to support and recognise the contributions of people with lived experience who take part in involvement activities and promoting best practice when thinking about remuneration. It provides examples of best practice and tools to enable people to participate and have their voices heard and in doing so, achieve a level of consistency across organisations supporting the creation of a culture of co-production across the East of England.

People and communities in the East of England deserve a consistent and fair approach that recognises the experience they have gained through lived experience. As Integrated Care Systems (ICSs) working with partners across the NHS, local government, research and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sectors, we are committed to genuine partnerships with people who have lived experience.

We need to make sure every voice is heard and acted upon. We should support people to grow and develop, trust in our shared ability to respond to their experience, and ensure that contributions are recognised and valued everywhere.

2. Insight

The Patients Association was commissioned by NHS England's Eastern regional team to find out what patients, carers, and the public think about involvement activities. They did this through a national survey with 622 responses. They also ran a focus group with five people from different backgrounds, all living in the East of England.

The research identified 5 key findings:

1. Patients get involved because they want their experiences to be heard and to make a difference for others.
2. While payment isn't the main reason most patients share their experience, it helps to increase involvement and engagement, especially for those from marginalised and underrepresented groups. Fair payment shows that their experiences and contributions are valued.
3. Good involvement treats patients as partners. It values their contributions, ensures that their voices are heard, and keeps them informed about how their feedback is used to improve care.
4. Poor involvement feels like a box-ticking exercise. It excludes patients, ignores their contributions and lacks transparency. Patients may feel dismissed and never see the impact of their input.
5. Inclusivity matters. Involvement opportunities should focus on being accessible to all by addressing barriers, be they social, cultural, physical, financial or other. If only certain voices are heard, services may overlook the needs of marginalised and underrepresented groups, worsening health inequalities.

Based on these findings, the report made five recommendations for developing the guidance:

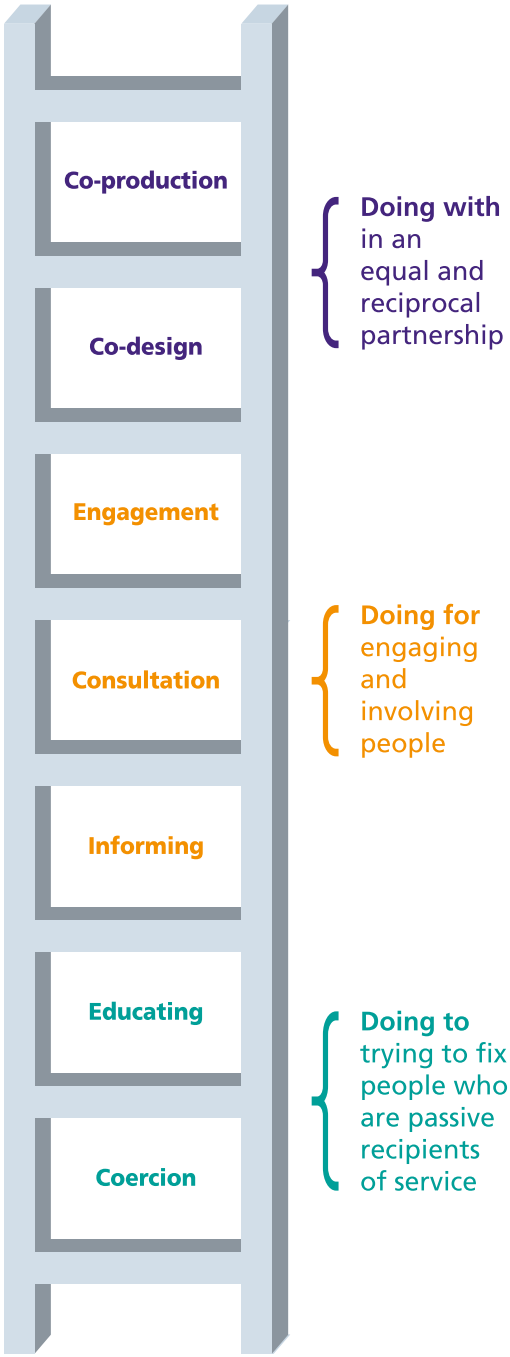
1. Ensure guidance on reward, recognition and remuneration is holistic
2. Prioritise inclusivity and accessibility in patient involvement to tackle health inequalities
3. Emphasise the creation of safe and empowering environments for patient feedback
4. Strengthen patient partnership in practice and champion its adaptation across systems
5. Simplify processes and minimise barriers to patient involvement

The report said guidance should take a broad view and recognise what motivates people. It should encourage wider participation, especially from marginalised and underrepresented communities. The aim is to improve statutory services by offering opportunities that are easy to access and inclusive.

the patients association
Listening to patients, speaking up for change.

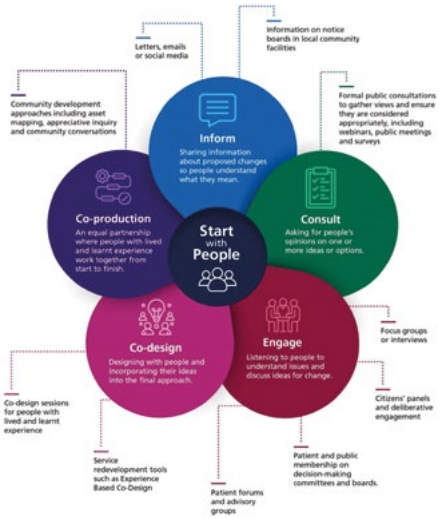
3. Involvement and co-production

Involvement is an umbrella term for co-production, engagement and participation; each providing different forms of valuable insight. It is important to be clear on what type of involvement you are seeking to do, in order to have a shared understanding and expectations of what you are hoping to achieve.



The Care Act 2014 outlines the concept of co-production in its statutory guidance. The guidance defines co-production and suggests that it should be integral to implementing the Care Act. In particular, co-production should be used to develop preventative, strength-based services, support assessment, shape the local care market, and plan information and advice services.

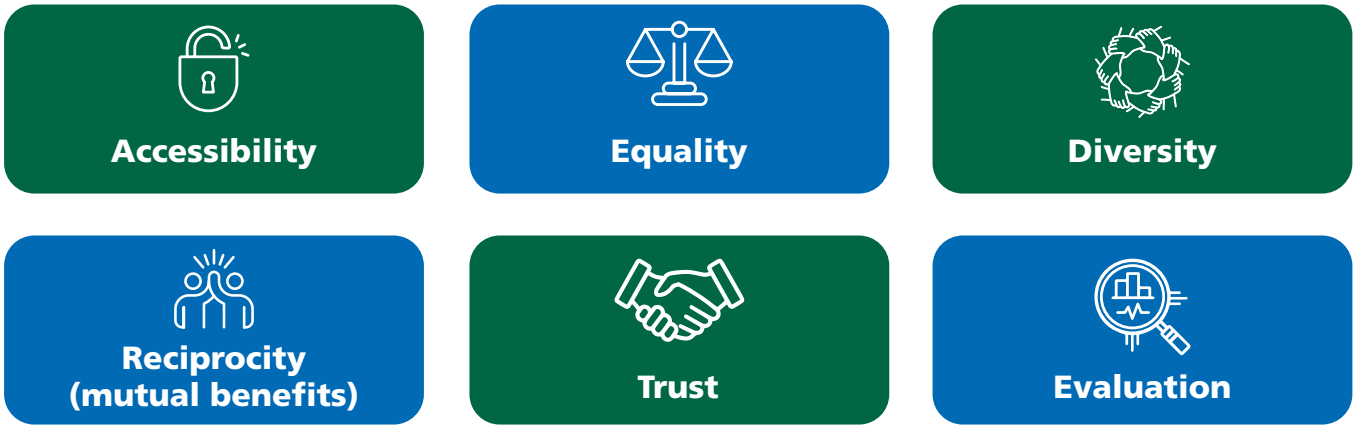
The ladder of co-production describes a series of seven approaches to involve people, across a spectrum. It is designed to support greater understanding of the various stages of access and inclusion, with the higher the ladder the greater the involvement, but it is important to acknowledge that different scenarios will call for different levels of involvement.



NHS England's Statutory Guidance to Working in Partnership with People and Communities sets out a variety of approaches to working with people and communities, acknowledging that no 'one size fits all'. The options for doing so will vary depending on the context and objectives, and there needs to be flexibility depending on the aims and scale of the programme.

> ***"Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.***
> *The Coalition for Personalised Care, 2022*

To co-produce effectively, everyone's contribution should be treated equally, and everybody needs to feel equally valued. It is important to understand and be guided by principles of co-production.



Co-production activities may be organised and attended by people as part of their job, causing disparity between professionals with 'learned' experience and those bringing their 'lived' experience. Because of this, people with lived experience can feel like their contribution is less valuable than those being paid. This can result in people believing that their contributions will have less value in the decision-making process.

Many organisations understand this and seek to recognise and reward people's contribution to say thank you for their time, skills and experience. Remuneration can enable a greater diversity of voice, but it is complex and can inadvertently have a negative impact on a person's financial situation if they receive benefits, and for some vulnerable groups, being left to navigate complex tax implications alone doesn't align to the commitment of valuing people's contributions.

The range of Co's across the continuum of co-production

- **[CO]-DESIGN** ➤ Survey creation, Service specification, Co-production planning
- **[CO]-CREATE** ➤ Principles, Accessible information, Stakeholder mapping
- **[CO]-FACILITATION** ➤ Agenda setting, Shared decision making, Chairing meetings
- **[CO]-EVALUATION** ➤ Agreeing KPIs, Survey analysis, Recommendations
- **[CO]-DELIVERY** ➤ Peer support Training, Encourage service uptake, Reduce barriers, Increase trust, Upskill the community

4. The principles

Provide a safe & welcoming environment. The best experiences of involvement take place in what feels like a **safe environment** where there is an **openness** and willingness to share because those in charge ensure they feel **listened to**, **valued**, and that their experience will potentially make a difference.

"People need to feel that what they're involved in will make a difference. They want to find out if it has changed anything. You've got to feel as though it's worthwhile"

Inclusivity matters. Involvement opportunities should focus on being **accessible to all** by **addressing barriers**, be they social, cultural, physical, financial or other. If only certain voices are heard, services may overlook the needs of marginalised and underrepresented groups, worsening health inequalities.

"This includes technical support, such as help with setting up the platform and ensuring accessibility features like screen readers or captioning"

Representation. It is important to **consider who is and who isn't participating**. People who have shared their experiences can feel dismissed or unheard, but there is a wider issue about who isn't engaging in the first place. What is the system missing, and what is the impact of this missing data on efforts to improve services, meet the needs of people and communities and in particular, address health inequalities.

"As someone from a marginalised group, I feel it's important to give my lived experience and amplify the voices of those in my community. We are often labelled as 'hard to reach' but the reality is that we are 'easy to ignore'"

Involvement with meaning. People's involvement can often feel transactional; that they are invited to share their experience because there is a policy stating that it should happen, but then they never hear from the service again. People can be left feeling somewhat exploited. With no idea if what they said was used or how, or if it made a difference to how services are designed and delivered, therefore ensure there is a widely communicated **plan for feedback and follow up**.

"I loved receiving the publication I was involved in and seeing myself there. It gave me a real sense of worth and value that I had contributed to something"

Reward & Remuneration. Good involvement is **recognition and respect of participants and their experiences**. Remuneration is a practical way of demonstrating that what is being shared (and the person sharing it) is important and will contribute to the development of health and care services. Offering some form of reward or remuneration can improve access and participation, particularly among those from marginalised or underrepresented communities. It does so by acting as an incentive and **addressing financial barriers** which may otherwise prevent someone from taking part.

"I had an amazing time, everyone shared their opinion, it was respectful and inclusive and we got paid for our time."

5. Putting the principles into practice

77% of survey respondents said their motivation for sharing their experience was to 'improve health and care services for others', with 61% saying that they wanted their experience (positive or negative) to be recognised by the service provider. There is a clear willingness among people to share their experiences to help improve services. However, we must recognise and address the barriers that can prevent this, and ensure the right considerations and support are in place to enable meaningful involvement.

The framework for working with people with lived experience is built around six core elements that should be considered when designing co-production approaches. While not all will be applied in every case, all should be consciously considered.

Wellbeing

- Strong relationships built on **trust** and **respect** are the foundation for positive involvement and co-production
- Create a safe environment where people feel confident and able to share their experiences. Establishing rules about what is acceptable and how people should behave towards each other will support participants to feel comfortable and confident in sharing their thoughts and experiences.
- There should be **clear communication** about what is happening and why, and clarity on how what people share will be used before, during and after the project.
- There should be clarity on the roles and responsibilities of those involved and **clearly defined expectations**.
- Good practice is to provide training for lived experience involvement and providing pastoral support pre, during and post involvement.

Inclusion

- **Ask directly and proactively what people need** to ensure the involvement is accessible to them and address their requirements prior to the start.
- **Be proactive with communications**. Send information such as questions that will be asked and documents they need to review in advance, with consideration for whether easy read, translations or hard copies are required. For those who have difficulty processing information quickly, this can help them to prepare and engage fully with the session, providing better quality feedback than they might otherwise be able to.
- Ensure that all communication uses **plain English without jargon** and acronyms and provide a glossary for terminology that is necessary.
- Both online and in-person meetings can present accessibility issues and thereby impact the opportunities for groups experiencing health inequalities to participate. Therefore you should actively promote to the public that you are **open to addressing accessibility issues** and specific needs should be identified as part of the recruitment process. This includes being mindful of assistance people may need who have caring responsibilities for either young children or other family members.
- Also consider opportunities for partial involvement such as contributing by email rather than having to attend meetings.

Representation

- It is important to think about underrepresented groups. If those with the worst experiences of services are not engaged in involvement initiatives designed to improve services, then we risk preserving or worsening health inequalities by failing to learn from and address the needs of the most vulnerable. **Carrying out an Equalities and Health Inequalities Impact Assessment** at the start of the project will help to identify particular groups that should be actively targeted.
- There should be a **genuine openness and transparency** and a willingness to address participation barriers and seek out diverse voices and experiences.
- Work with an initial group to **ensure diverse perspectives are participating** and act as a group to involve missing voices as early on as possible.
- **Work in partnership with community champions and trusted leaders** who can help facilitate access to underrepresented groups.

Support

- The health, safety and wellbeing of individuals with lived experience must be prioritised when involving them in engagement, coproduction and participatory projects. Pastoral support can ensure meaningful and sustained participation and should align to the following principles:
    - **Person-Centred:** Pastoral support must be individualised, taking into account the person's specific health and wellbeing challenges, experiences, preferences, and beliefs and should involve having a named lead offering support before, during and after involvement.
    - **Empathy and Compassion:** Providers should offer a safe space for individuals to express themselves freely, be heard with empathy, and feel supported throughout their journey and take a trauma informed approach to working with people.

- **Confidentiality:** Confidentiality must be maintained at all times, respecting the individual's right to privacy and ensuring that sensitive health information is protected.
- **Holistic Approach:** Support should be provided before, during and after engagement activity, with a named contact for questions or concerns. Particular consideration should be given when discussing sensitive or emotionally challenging topics. Providers should consider not only the physical and mental health needs of individuals but also their spiritual, emotional, and social well-being.
- **Inclusivity and Non-Discrimination:** Activities should be accessible and inclusive, with proactive steps taken to remove barriers and address power imbalances that may prevent people from participating fully. Involvement should be respectful, fair and free from discrimination, with clarity about how this is achieved in practice.

Feedback

- People and communities should be **treated as equal partners in involvement**, recognise them as experts in their own experience and ensure their voices help to shape decisions that lead to tangible improvements in health and care services. Ensure they are kept informed of the impact of their contributions and provide ongoing opportunities for meaningful engagement.
- One of the biggest complaints from survey respondents was the lack of follow up by health and care services to inform them what has changed. It can create apathy among participants when they think their contribution hasn't made a difference or has been discounted because they are not kept informed and make them less likely to engage again.
- It may take some time for decisions or feedback to be readily available but it is important to maintain contact and provide progress updates to sustain the relationships. It should be an iterative process to confirm understanding and sense-check proposed actions rather than a one off "you said, we did" approach.
- Advocate for integrated and consistent practices that embed partnership with people and communities in involvement across all ICSs. **Share best practice, collaborate with stakeholders** and build a culture that not only values the views of people and communities but also meaningfully acts on it to drive continuous improvements in health and care service

Reward

- It is important to **understand the motivation for people taking part** in involvement activities. Seeing an improvement in services is likely to be the motivating factor and largest 'reward' however, receiving a form of remuneration might help to remove barriers for some underserved communities.
- Out of pocket expenses. **People should not be at a financial disadvantage for taking part in involvement activities**, therefore offering to reimburse out of pocket expenses should be standard allowing people to accept or decline the offer.

- Remuneration should be **proportionate to both the demands on participants but also that activity's importance in terms of influencing improvements to health and care services**. Setting out expectations alongside rates of remuneration would help potential participants to decide whether the compensation received is worth what would be expected of them if they took part. This level of transparency supports informed consent around involvement and addresses some of the power imbalance that is inherent in the process.
- Where possible there should be **flexibility with participants offered a choice in how they are remunerated**, different options for remuneration might increase the number of applicants and the likelihood of them coming from diverse backgrounds.
- Simplified processes. The **remuneration process must be as simple and swift as possible and proportionate to the value of the remuneration**. It is important to consider what information is necessary as bureaucracy will create barriers and could reduce the likelihood of people from certain groups or communities sharing their experiences. If this happens, then the benefits of offering remuneration to increase diversity in the first place are reduced. If processes are complex, direct support should be given to people to complete the necessary forms and instigating reimbursement should be a high priority activity.
- Reward and recognition focuses on non-financial forms of recognition for the involvement work that people do. It provides an alternative way of **recognising people for their dedication, hard work, and contributions** which may be more favourable to meet people's personal or financial needs. It can take the form of formal public acknowledgement, personal and career development opportunities such as opportunities for training, or access to social events. They should be in addition to informal recognitions such as verbal and written thank you in the form of emails, cards or notes and as with financial rewards should be proportionate.
- Some people may choose to decline offers of reward and remuneration which of course should not have any detrimental impact on them still being involved in activities.

Mapping of policies and payment rates took place across a wide range of partners across Cambridgeshire, Peterborough, Suffolk and North East Essex, including NHS, Local Authority, research and VCFSE organisations. There was significant disparities between organisations which demonstrates the diversity of organisational policies and the challenges of achieving consistency.

Mental health providers often had the most comprehensive policies and procedures and scales of remuneration in contrast to other organisations that do not have a remuneration policy or had policies that only supported out of pocket expenses. Many Engagements Leads recognised the importance of reward and recognition but had no budget to support this and were concerned about the implication on benefits.

It is important to have a consistent approach to remuneration, being mindful of setting a precedent or expectations for involvement that need to be maintained to build trusted relationships rather than risk being seen to favour or value some involvement activities over others.

For further information, guidance and links to good practice on remuneration and benefits please refer to the Reward, Recognition and Support for Involving People and Communities Toolbox.

6. Working with the Voluntary, Community, Faith and Social Enterprise Sector

The Voluntary, Community, Faith and Social Enterprise (VCFSE) sector is an essential partner in understanding the experiences, priorities and needs of local people and communities - particularly those from underserved communities.

VCFSE organisations hold well established, trusted relationships with communities and often act as the eyes, ears and voice of the people they support. Many organisations are rooted in lived experience, with co-production embedded in how they design and deliver services. As such, the VCFSE sector should be recognised not only for its delivery role but for the strategic insight, intelligence and system leadership it can contribute.

The VCFSE sector is operating under considerable pressure: increasing demand, rising complexity, reduced funding, and workforce and volunteer pressures. Requests for involvement activities inevitably draw organisations away from frontline delivery. This means statutory partners must be proportionate, intentional and fair in how they engage the sector – and realistic about the impacts of their asks.

Before involving VCFSE partners, be clear on the purpose

- Are you asking them to contribute expertise from their specific area of work or to act as a representative voice for the wider VCFSE sector? These are different roles and require different expectations, support and structures.
- Be clear about who you need to involve, is it a senior representative to support strategic development or operational insight from frontline delivery?
- Be clear about what form of involvement is actually needed: A default model of having a 'VCFSE rep on a board' can be ineffective, tokenistic, and resource-intensive for organisations. It can also create capacity barriers that exclude smaller groups. Co-design appropriate mechanisms together – whether that's time-limited task groups, targeted engagement, insight sessions, community listening approaches, or project-based collaboration.
- With approximately 500,000 VCFSE sector organisations in England, it is important to work with a breadth of VCFSE organisations in your area, to truly benefit from the diversity of views and insight, rather than approaching the same small number of organisations each time. Diversity of voice, scale, geography and community connection should be a deliberate design principle.

Remuneration

It is good practice to remunerate VCFSE sector partners for their involvement if the ask sits outside the scope of their commissioned or contracted deliverables. **Involvement is not free capacity, and goodwill is not a sustainable engagement model.**

- Budget for remuneration should be included within each project.
- Remuneration should apply to both individuals and VCFSE sector partners where appropriate.
- Payment processes should be simple, timely and proportionate.

VCFSE Alliances exist within most ICBs and provide a credible route for system-wide dialogue with the sector. They should be used to co-develop local approaches to reimbursement, including shared principles, policies and processes that work for both statutory organisations and VCFSE partners.

7. Next steps...

This document provides principles and ways of working to inform local policies and processes. A rigid, blanket approach would go against the very nature of co-design, collaboration and community-led practice. However there is a clear ambition for statutory organisations across the east of England to align their organisational approaches with this guidance.

A more joined-up, collaborative way of working – supported by a cross-system community of practice - will enable organisations to share learning, reduce duplication and navigate system change in a way that keeps people and communities genuinely at the heart of service development and delivery.

Toolbox of resources and help

Reward, Recognition and Support for Involving People and Communities.

Further information regarding remuneration

People Receiving State Benefits

People on benefits can take part in involvement activities, but they must continue to meet all benefit conditions. They should inform the office that pays their benefits about:

- How often they take part
- What the activity involves
- Whether they receive expenses
- Any additional payments
- Anything else they are given (even if not money)

Any reasonable expenses will not usually affect the amount of benefit a person gets. Claimants should keep receipts and claim forms to show these payments are not income.

Payments beyond reasonable expenses (e.g. involvement payments) may reduce or stop benefits.

It is vital that people on benefits get expert advice from a benefits advisor regarding their personal circumstances. Breach of benefit conditions can result in an individual's benefit being stopped or sanctions applied, sometimes for long periods. This can have huge consequences for individuals, potentially causing them significant financial hardship and personal distress.

The National Institute for Health Research (NIHR) provides extensive guidance for researchers and professionals (Dec 2025).

Payment guidance for researchers and professionals | NIHR

Understanding How Payments Affect Benefits

Benefits calculators can help involvement partners work out how any involvement payment will impact their benefits.

Benefits calculators - GOV.UK

Income Tax and National Insurance

People may need to pay tax or nation insurance (NI) on involvement payments depending on their income, employment status, retirement status, or benefits. It is their responsibility to check with HMRC if unsure.

People Receiving Health Insurance Payments

Those receiving income from medical insurance (e.g. while on sick leave) should check their policy. Accepting involvement payments may breach terms and risk future payouts. They should contact their employer or insurer if unsure.

Further guidance on payments

Several organisations provide guidance on paying people for involvement, including:

- **Disability Rights UK** (Jun 2025)

Service user involvement and payments: how they affect benefits | Disability Rights UK

- **Social Care Institute for Excellence (SCIE)** (Jan 2023)

Paying people who receive benefits: Co-production - SCIE

These cover issues such as working with marginalised groups and the impact of payments on benefits and employment.

National Guidance on Monetary Remuneration

NHS England (NHSE) has recently updated its policy on working with people and communities. The guidance is produced for NHSE employees and is not intended for ICBs or other NHS providers however it is often the case that many NHS organisations refer to this policy when developing their own local guidance. The policy relates to roles such as Patient and Public Voice (PPV) partners in relation to activities that includes engagement, participation, involvement, co-production and consultation. The policy highlights that reimbursing expenses and offering involvement payments to PPV Partners can help remove barriers to involvement. Payment rates are:

- £150 per day (over 4 hours)
- £75 per half day (4 hours or less)

The policy emphasises:

- No one should be out of pocket
- All reasonable expenses must be reimbursed
- Consideration should be given to equality, safeguarding, and accessibility

National Institute for Health and Care Research (NIHR) It is worth noting that research activity generally attracts a different rate of pay which is often dependant on the funding linked to the study. NIHR sets activity based rates, for example:

- **£13.80** – reviewing an abstract (<30 minutes)
- **£27.50** – involvement in a task, requires no preparation e.g a focus group (approx. 1 hour)
- **£55** – involvement in a task requiring preparation (approx. 2 hours)
- **£82.50** – involvement that requires preparation (half a day)
- **£165** – Involvement in meetings/committees (full day meeting)
- **£330** - Involvement in meetings/committees that requires substantial preparation e.g. chairing a meeting (full-day meeting)

Payment guidance for researchers and professionals | NIHR (Dec 2025)

Cancer Research UK have an extensive patient research toolkit that sets out rates of reimbursement for expenses, and payment for participation in involvement activities including interviews, focus groups, patient representatives and patient advisory panels on the basis of time contributed: -

- **£80** per day
- **£50** per half day
- **£30** for short sessions (20 mins–2 hours)
- **£5** virtual activity allowance

Budgeting for your involvement activities | Cancer Research UK

Co-production with Children and Young People

The National Institute for Health Research (NIHR) guidance emphasises:

- Age appropriate recognition (e.g., vouchers, certificates, experiences)
- Co designing recognition with young people
- Safeguarding and parental consent

Buttle UK highlight:

- Living Wage for young people
- Alternatives for those with No Recourse to Public Funds
- Support for participation (travel, childcare, data, food)
- Youth led recognition design

Co-production - Buttle

National guidance on non-monetary remuneration options

Non-monetary gifts are used to recognise voluntary contributions where monetary payment is not requested or not possible. Examples may include:

- Certificates or letters of appreciation
- Small tokens of appreciation
- Access to facilities
- Training opportunities
- Opportunities to attend conferences or events
- Donations to charities

These options help avoid unintended impacts on welfare benefits or tax status. Reimbursed expenses are not considered income and do not affect benefits

Food and Drink as Recognition

Food and drink can be used as non monetary appreciation and help create a welcoming environment and reduce participation barriers such as:

- Free meals or snacks
- Restaurant vouchers
- Event catering
- Small perks like coffee cards