

Including the voice of lived experience in policy making

Summary

Introduction

This document is an output of the Equalities workstream of the [VCFSE Accord](#), led by the [Greater Manchester Equality Alliance \(GM=EqAl\)](#) who have developed a set of principles to ensure the voice of lived experience is heard in policymaking, together with remuneration arrangements.

Who is this document for?

It aims to support Greater Manchester public sector colleagues to include the voice of lived experience in policy making.

The guidance is not aimed at those carrying out standard public consultation and engagement activities, nor is it meant to be an exhaustive toolkit. We welcome dialogue and feedback to continue the development of the guidance.

What do we mean by 'lived experience'?

Lived experience belongs to people who have gained knowledge through direct, first-hand involvement in everyday events¹.

How does it fit into Greater Manchester's ambitions?

Greater Manchester (GM) has ambitions as a city-region to do things differently; the GM Strategy states that GM will 'involve people in the decisions we make and actions we take'. It is vital that practice reflects reality, and that services are designed to meet the needs of the population. This guidance aims to support this by ensuring direct, and first-hand experiences are leading the development of policy.

Summary of Key principles

The following is a set of clear principles and considerations that policymakers can adopt when considering including the voice of lived experience in their work:

1. Policy makers should actively devolve power and control/authority to people with lived experience
2. People with lived experience are not treated as advisors or consultants but have similar roles and powers as statutory partner
3. Lived experience is given the same authority and recognition as learned experience
4. Project/policy leads are enabled to share power and authority with participants and empowered to devolve decision making within project
5. Equity that goes beyond individual projects and where people with lived experience are as involved in setting the agenda as they are in identifying the solutions
6. People with lived experience are remunerated at the appropriate level for the type of involvement they have and their own personal circumstances

¹ Chandler D, Munday R (2016) A Dictionary of Media and Communication. Oxford: Oxford University Press.

7. Project/policy leads enabled to provide remuneration by appropriate payment processes being created or where this isn't possible to seek this support from other external stakeholders
8. Project/policy leads to seek support from the Department for Work and Pensions (DWP)/ Job Centre Plus staff where they are remunerating someone who's circumstances might be affected by being in receipt of income, regardless of method of payment
9. Commitment to make all situations where someone with lived experience is involved in projects/activities, as inclusive and accessible as possible, using guidance that has been developed by partners to support this.

Best practice for involving people with lived experience

The following table is taken from a [report](#) produced by Health and Social Care Alliance Scotland following a study of programmes of people with lived experience.

Best practice	Examples
Meaningful levels of involvement	<ul style="list-style-type: none"> • As early in the process as possible • Inclusion of people with lived experience in all the steps of decision-making (design, implementation, delivery and evaluation) • Listening and implementation • Co-production and collaboration • Feedback and follow-up • Embed inclusive practices and spaces in design and budgets
Clear expectations and communication throughout	<ul style="list-style-type: none"> • Clear roles • Having a common goal and clear expectations • Clear communication
Training and support for participants	<ul style="list-style-type: none"> • Help participants prepare for tasks • Accessibility – there are numerous resources around all types of accessibility – understand the needs of participants and use appropriate resources • Online and/or offline engagement and in multiple forms (diversity of options) • Tailored emotional and practical support • Links to benefits and/or self assessment advice for people in receipt of remuneration
Appropriate and well-trained staff and networks	<ul style="list-style-type: none"> • Training for staff working in policy and services • Ensure staff can properly support participants • Create trust with appropriate skills • Build relationship with existing networks
Ensure sufficient funding and resources are in place and secure necessary authority to delegate these as the project requires	<ul style="list-style-type: none"> • Effectively planned • Budget for expenses such as training, support, remuneration, out of pocket expenses , venue • Clear timeline • Produce Templates and documents for remuneration • Clarity on what proportion of budget and work will be owned/led by people with lived experience (this could be decided through a co-production process)
Value participants as individuals and reflect their needs	<ul style="list-style-type: none"> • Different experiences and perspectives – diversity of thought • Listen to individuals, collaborate together • Value lived experience at the same level as learned experience • Meet people where they are – • While people with lived experience bring a great deal of knowledge and expertise, they may not have experience of operating in a highly professionalised or technical working environment and may need specific training or support
Create a trusting and welcoming environment	<ul style="list-style-type: none"> • Minimise harm • Safe space • Inclusive language and spaces - see our inclusive language guidance. • Be open and willing to listen • Acknowledge challenges, power imbalances from the start and seek to address them wherever possible

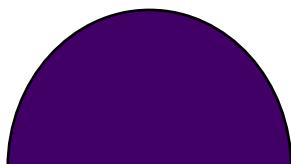
Remuneration

- **Expenses should be covered at a minimum.** This refers to any reasonable cost incurred during involvement work that is deemed necessary and related to the tasks performed.
- **Service user involvement** is any activity that is designed to improve statutory services and is carried out with or by people with lived experience. This payment will be treated as earnings but it should not be considered employment. Where an individual is in receipt of benefits, it is best practice to inform the Job Centre before the work begins to be sure there are no unintended consequences.
- An **honorarium payment** is ideal for use in situations which would otherwise be classified as unpaid volunteering. These payments should be infrequent and over a short period of time. There is no formal contract of employment and payment will only be made for attendance at an eligible activity. The work is done on a voluntary basis, paid as recognition for time given.

How to pay: Remuneration is normally made in the form of BACS transfer to the individual. If they prefer payment in the form of shopping vouchers, it's good practice to accommodate.

Recommended remuneration levels

Level of commitment	Expected minimum remuneration level	Mechanism to deliver	Considerations
One off meeting with open invite	Travel expenses covered	Petty cash/bank transfer on the day	Organiser to produce template to keep record of payments and store receipts
Regular attendance in short term, time-limited process e.g. 3 monthly meetings as part of co-design group	High street vouchers/gift card/raffle prizes PLUS travel expenses	Vouchers given out on the day and travel expenses arranged as above	As above. Organiser to purchase vouchers in advance Take advice on what is a reasonable amount. For those in receipt of benefits, gift cards should still be declared as income unless they are given as a thank you gift rather than as payment – this must be made explicitly clear to avoid any doubt
Ongoing long term membership/attendance of expert advisors/co-production group/lived experience group	Hourly payment for attendance and prep time. Minimum suggested rate is £11.50 (real living wage at time of writing) but ideally £150/day or £75/half day (as set out in NHS guidance) OR use Bursary mechanism	Create a standard BACS form to enable standing payment Benefits declaration form including information about where to seek advice should be provided	As above. Rate of payment should be clear from outset and whether this includes prep time rather than just attendance in sessions. Check with DWP that you are following any necessary steps they require for those claiming benefits and in receipt of payment for involvement



Additional Resources

- GM Equality Alliance Inclusive language guidance: www.vcfseleadershipgm.org.uk/resources/gm-eqal-inclusive-language-guidance
- A range of resources covering creating accessible PDFs, accessible events, using plain English, and more: www.makethingsaccessible.com/guides/1/
- Engaging people with lived experience, Health and Social Care Alliance Scotland: www.alliance-scotland.org.uk/blog/news/new-report-engaging-people-with-lived-experience
- A Handy Guide to Facilitation (NHS): www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/2010_handy_guide_to_facilitation_final_low-res_1.pdf
- Social Care Institute for Excellence (SCIE) Resources for Co-production: www.scie.org.uk/co-production/
- Inclusive participatory approaches: A facilitator's guide - <https://cgspace.cgiar.org/server/api/core/bitstreams/e2018b1d-59db-46c0-8a0d-debcb64feef6/content>
- Paying for Involvement and why it matters (The Social Change Agency): thesocialchangeagency.org/blog/paying-for-involvement-why-it-matters/
- Entitled To – benefits advice: www.entitledto.co.uk/
- Citizen's Advice Bureau: www.citizensadvice.org.uk/
- Turn to Us – helping people with financial security: www.turn2us.org.uk/
- Lived Experience Fair Remuneration campaign: www.basw.co.uk/social-workers-union/lived-experience-fair-remuneration
- Universal Credit information from the UK Government: www.gov.uk/universal-credit

Read the full document: www.vcfseleadershipgm.org.uk/resources/including-lived-experience

