



LEEDS BECKETT UNIVERSITY
OBESITY INSTITUTE

OBESITY VOICES:

Patient and Public Involvement & Engagement Hub

Welcome Guide

for Patients and the Public who want
to be involved in advising on and
co-developing research, teaching and
knowledge exchange activities

Obesity Institute:
Improving the lives of people living with, or at risk of obesity



What is 'Obesity Voices'?

Obesity Voices is a group of patients and members of public with a lived experience of obesity, who work with the Obesity Institute and trusted partners to help improve the lives of people living with or at risk of obesity.

Our members ensure everything the Obesity Institute does is driven by the voice of lived experience & supports other organisations to do this too.

No experience or skills required - anyone can join us – all you need is to share our passion to make a positive difference to people living with or at risk of obesity.

What do Obesity Voices members do?

- » They work with us and our trusted partners to ensure the work we do meets the needs of the public & patients we serve.
- » They ensure our work is acceptable, useful & usable.
- » They help us to develop a new generation of compassionate person-centred professionals.
- » They ensure our work is inclusive by providing an opportunity to listen to every voice, not just those who are most often heard.

What are the benefits of becoming an Obesity Voices member?

- » You will have the opportunity to meet new people & contribute to work that improves the lives of people living with or at risk of obesity.
- » You will be paid for your time & your out of pocket expenses.
- » You will receive support & training.
- » You will be provided with many different opportunities to work with the Obesity Institute & our trusted partners, on topics and projects that interest you.
- » You can receive a newsletter twice a year telling you about the work we are doing.
- » There is no obligation – we will tell you about different opportunities, what they involve & the time they should take - you then decide whether or not you would like to get involved.

The Obesity Voices promise:

- » Every member is treated with respect & fairness.
- » We will always offer to pay members for their time & expenses.
- » We will provide appropriate training and support whenever needed.
- » We will always use person first language and work to eliminate weight stigma & bias.
- » We will be clear, open, honest & accountable for everything we do.
- » Any personal information you share with us will always be held in the strictest confidence and never shared with anyone else.
- » We are always happy to answer any questions.

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If you are interested in becoming a member...

Register your interest using the QR tag or contacting

ObesityInstitute@leedsbeckett.ac.uk
or **0113 812 5039 / 0113 812 3199**

You will receive a newsletter twice a year & we will contact you if any opportunities arise in the areas you have expressed an interest in.

This guide provides more detailed information about Obesity Voices and public and patient involvement activity.



INTRODUCTIONS

Welcome

Thank you for your interest in Obesity Voices at Leeds Beckett University's Obesity Institute. This information pack has been written to help answer any questions you may have about getting involved.

About the Obesity Institute

The Obesity Institute at Leeds Beckett University brings together a range of academics from across the University with policy makers, service providers and people with a lived experience of obesity, to work together to develop new ways to improve the lives of people living with, or at risk of obesity. The Institute provides a supportive, inclusive, collaborative environment to directly address the real-world challenges and complexity of obesity. We are committed to delivering compassionate, non-stigmatising, person centred research, teaching and knowledge exchange activities that will make a real and tangible difference to the lives of people living with, or at risk of obesity.

The Obesity Institute has the following values:

Inclusion and collaboration:

We co-develop our research and practice with patient and public involvement, whilst seeking to improve and promote representation, equality, diversity, and inclusion.

Integrity and Transparency:

We aim to foster a culture of openness, compassion, and collaboration within our community.

Excellence and Innovation:

We aim to build on our excellence in applied obesity research and education. We seek to excite and inspire the public, our students and colleagues, academia and industry with disruptive and ground-breaking research, innovation and practice.

Our mission in the Obesity Institute is to ensure that the voices of people with lived experience of obesity underpins everything that we do, and we'd also like to encourage other organisations to do the same too.

"Nothing about us, without us"

Obesity Empowerment Network

What is Patient and Public Involvement and Engagement (PPIE)?

PPIE can take place in research, teaching or knowledge exchange activity. It involves work that is carried out 'with' or 'by' patients or members of the public.

It is important to note that taking part in PPIE activity is very different to taking part in research. PPIE work can be quite varied – some examples of PPIE work are provided below:

- » Speaking to researchers to help them develop research questions that are important to the public and patients.
- » Sharing your views and opinions, in order to develop a research idea or project in a supportive and collaborative environment.
- » Helping to co-develop a research project. This is an approach in which researchers, practitioners and the public work together, sharing knowledge and responsibility from the start to the end of a project.
- » Helping to design resources and tools for people living with or at risk of obesity.
- » Helping researchers write reports on specific health issues relevant to people at risk of or living with obesity, or about different population groups who may be more at risk of developing obesity or obesity related conditions.
- » Helping researchers to understand research findings from a public and patient perspective.
- » Being trained to carry out research yourself, for example observing a health service or carrying out interviews.
- » Presenting research findings at a meeting, writing a blog or producing a podcast or short film about the research you have helped to develop.
- » Talking to students about lived experience to help them develop into compassionate person-centred professionals.

We will always be really clear about what every PPIE activity involves, including how much time will be expected and the tasks that will be undertaken. You can then decide which activities you would like to get involved with.

Why do we Involve Patients and the Public in our work?

There are many reasons why we involve patients and the public in our work - here are just a few:

- » To gain different viewpoints, which can help to develop new solutions and improve the design, delivery and impact of our work.
- » To ensure our research addresses questions that matter to patients and the public.
- » To empower patients and public members living with or at risk of obesity.
- » To ensure the work we do is fair, reasonable and realistic to everyone involved.
- » To build a sense of community through shared experience and challenges, and to ensure we listen and respond to every voice across our broad and diverse communities.
- » To help us communicate in plain English, to ensure that what we do and what we find is clear to everyone.
- » To help train our students in becoming compassionate person-centred professionals.
- » PPIE members can help share research findings, to ensure they reach and are understood by the public and patients who can benefit from them.

ABOUT OBESITY VOICES

Obesity Voices is the public and patient involvement and engagement hub that supports all the work at the Obesity Institute. Obesity Voices members are our partners – reflecting the voice of the communities we serve, to ensure the voice of lived experience underpins all the work we do.

Our ethos is to demonstrate care, compassion, collaboration, equality, and inclusion, with the person at the centre of everything we do. We will use person first language in all our communications and will continue to work to eliminate weight stigma and bias.

The Obesity Voices values

Obesity Voices supports the 6 values and principles for public involvement as set out in INVOLVE (2015) Public involvement in research: values and principles framework, which are:

- 1 **Respect:** Researchers, research organisations and the public respect one another's roles and perspectives.
- 2 **Support:** Researchers, research organisations and the public have access to practical and organisational support to involve and be involved.
- 3 **Transparency:** Researchers, research organisations and the public are clear and open about the aims and scope of involvement in the research.
- 4 **Responsiveness:** Researchers and research organisations actively respond to the input of public members involved in research.
- 5 **Fairness of opportunity:** Researchers and research organisations ensure that public involvement in research is open to individuals and communities without discrimination.
- 6 **Accountability:** Researchers, research organisations and the public are accountable for their involvement in research and to people affected by the research.

The Obesity Voices Hub

We are developing a network of Obesity Voices members to guide, and work with us to ensure we undertake the highest quality work that makes a real and tangible difference to people's lives. There are lots of different opportunities to get involved, depending on what you are interested in, and how much time you can give. We welcome anyone who is either at risk of, or has a lived experience of obesity, or who represent or support people living with obesity, to join the Obesity Voices Hub.

There is a wide variety of different projects that Obesity Voices members can get involved with, with both the Obesity Institute and our trusted partners (these are other organisations who have signed up to values of Obesity Voices). Every member is informed about opportunities in areas that interest them. Each member then decides which activities to get involved with. No experience or skills are required to become a member – just an interest in improving the lives of people living with or at risk of obesity. Any work undertaken by Obesity Voices members will be fully supported and training will be provided if required. All members are paid for their time and out of pocket expenses. The only thing we will ask is that every member follows our Code of Conduct (Appendix 1).

The Obesity Voices Steering Committee

This group has been formed to ensure public and patient involvement and engagement is embedded within all of the Obesity Institute's activities. The steering group meet every three months and any member of the network can express an interest in attending one of these meetings or receiving public versions of minutes of meetings. If a member wishes to join this group they should contact the Obesity Voices: obesityinstitute@leedsbeckett.ac.uk





WHAT OBESITY VOICES MEMBERS CAN EXPECT

Payment and Expenses

As an Obesity Voices member, you will be offered a fee (minimum of £25/hr) when you undertake an activity with us or our partner organisations. We will also cover or reimburse all reasonable expenses associated with your involvement. This might include the costs of travel, internet access, accommodation, subsistence, alternative childcare or caring arrangements.

Further information about PPIE payment can be found in the Payment of Fees section (Appendix 2).

Accessibility

We are committed to ensuring all our opportunities are accessible and no one is excluded. We will ensure we can accommodate any accessibility requirements. Please let us know of any access requirements prior to any meetings.

If meetings are held online, we will provide you with training on using Teams if required and will always provide telephone options for anyone who does not wish to use a computer. Language translators can also be provided.

Refreshments

You can expect hot drinks and snacks at meetings which last for any longer than 3 hours. If meetings are for a full day or take place over lunch, we will also provide either a lunch or reimbursement of expenses (please see Appendix 2). All dietary requirements will be catered for.

Training and Support

For all Obesity Voices activities no specialist knowledge or skills are required. However, we will discuss all tasks with you in detail, and this will include understanding whether you would like any training to support you in the task/s. Where training needs are identified, the appropriate training will be provided.

A Positive, Supportive and Listening Environment

As an Obesity Voices Member you are an expert by lived experience, and your views should always be respected and listened to by both Obesity Institute (or partner organisation) and other Obesity Voices members. You will always be supported in your activity by peers and the activity organiser. We hope it will provide an opportunity to meet new people, learn, and help make a difference to the lives of people living with or at risk of obesity.

FREQUENTLY ASKED QUESTIONS

1. Do I need any qualifications to be involved?

NO. We would like to hear from people with a range of experiences and backgrounds. You do not need any specific qualifications or skills to become a member. If a specific project is looking for people with a particular experience or background this will be made clear when you are told about the opportunity.

2. How often do I need to be involved?

There are no requirements about the length of involvement or how regularly you are involved. We value all involvement, no matter how large or small.

3. Can carers / family members get involved?

YES. Carers / family members will often have an interest in, and an appreciation of, lived experience, and so we would encourage them to also get involved.

4. What do I do if I have a bad experience during an activity I was involved with?

We hope all Obesity Voices members have positive experiences. However, if you are unhappy with any aspect of the PPIE activity you are involved with, please contact the project coordinator for the individual project you are working on. We may also contact you separately from time to time to seek feedback on your general experiences as an Obesity Voices member.

5. Can I leave at any time?

YES. Involvement in PPIE activities is entirely voluntary, and you can leave at any time without giving a reason.

6. Where are meetings held?

Most meetings will be held online or over the phone to begin with. We will give you guidance and training on how to access these meetings.

On occasion we (or our trusted partners) may run events in different locations and this will be made clear on the information provided, and any travel and or accommodation arranged if required.

7. How and when will I be paid?

How much you will be paid, and how you will be paid will be arranged with you prior to you undertaking your activities. We will always ensure prompt payment after each activity and ask the same of our trusted partners, however some payment methods may take longer than others, but this will be explained and agreed with you prior to you starting.

8. I receive benefits, how will being involved affect this?

If you receive benefits, any Obesity Voices payments can affect your benefits, and you will need to check what this means for you. More information and support on this can be found on:

[nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392](https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392)

or by calling the NIHR Centre for Engagement and Dissemination: 020 884 37117.



CONTACT

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LS6 3QS

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Phone:
0113 812 5039
0113 812 3199

Website:
leedsbeckett.ac.uk/research/obesity-institute

Twitter:
twitter.com/ObesityInst

LinkedIn:
linkedin.com/company/obesityinst

You can call or email the Obesity Voices Administrator at any time to discuss Obesity Voices activities, sign up to our mailing list or for any other questions relating to events and activities. Alternatively, you can sign up to our mailing list directly at this website address.

APPENDIX 1:

Code of conduct for PPIE members

In order to provide active and positive engagement between researchers and PPIE Members, the Obesity Institute PPIE Steering Committee have agreed a code of conduct when reviewing, advising and consulting with researchers. This document sets out our overarching values for the Obesity Institute and the standards of behaviours expected by PPIE Members when consulting on research.

The Code of Conduct is to be signed by volunteers participating in PPIE activities such as focus groups or reviewing confidential information such as grant applications.

The purpose is to:

- » Give assurance to PPIE members.
- » Give credibility to the group and ensure a professional understanding of the confidential nature of the material to be discussed and reviewed.
- » Give assurance to researchers.

PPIE Members agree to work in partnership with researchers to identify, design, prioritise, conduct and disseminate patient focused research that is relevant, ethical and will make a difference to patient care.

INCLUSION, EQUALITY AND DIVERSITY

We are strongly committed to the promotion of equality and diversity for PPIE Members and staff. PPIE Members' behaviour and attitudes must be consistent with the aims and values of the Obesity Institute; to support inclusion, diversity and equity for all.

RESPECT

PPIE Members must treat each other, researchers and others they come into contact with when volunteering in their role with respect and courtesy at all times. PPIE members must respect different opinions and experiences - listening to and recognising the value of others' contributions to discussions. We ask that feedback is constructive and conducive to improving the quality of our research.

CONFIDENTIALITY

PPIE members must respect the status of confidential issues they read and discuss. They are bound to maintain the status of this material and any information shared by researchers or other PPIE members.

PPIE members should abide by the following confidentiality statement at all times:

Unless stated otherwise, all pre-award materials – including funding bids and research proposals are confidential and should not be discussed outside the confines of the PPIE Research Groups. PPIE members will be notified when such materials are no longer confidential, at which point they may be discussed freely outside of the PPIE Research Group. When PPIE members are involved in post-award activity – i.e., active, ongoing research – they will be informed at the start of their involvement whether anything is confidential and when it ceases to be so. The nature of the PPIE Research Groups mean that personal stories and experiences may be shared at group meetings. PPIE Members should not share these stories outside of the group in a way that includes any identifiable information.

INTEGRITY AND TRANSPARENCY

PPIE Members are required to use their knowledge, expertise, and experience to give the best advice they can. PPIE members should act in an individual capacity and not as a representative of any group, organisation or individual. PPIE members must not accept gifts or hospitality which



are aimed at compromising their neutrality.

COMMITMENT

PPIE members should prepare for meetings to ensure they add value to any PPIE activities. We will send you the necessary information at least 2 weeks prior to any meetings. PPIE members should inform the PPIE Administrator if they are unable to attend.

CONFLICTS OF INTEREST

PPIE members should identify and promptly declare any actual, potential or perceived conflicts affecting them. If you hear something within a focus group which you feel would be a conflict of interest for you, please make the researcher aware. A conflict of interest could be working for or being involved in activities, organisations or funders related to the research, or being involved as a participant in a research trial directly related to the research you are discussing. If you are unsure, please raise this with the PPIE Administrator or the researcher.

OPENNESS AND ACCOUNTABILITY

PPIE members must be open, responsive and accountable to each other, members of staff and researchers.

APPENDIX 2: Payment of Fees

PPIE Members and public contributors may be involved in a range of tasks. This may include participating in an advisory or focus group, becoming an external reviewer, undertaking community outreach activities, participating in interview panels, co-delivering training, or a longer-term but time limited activity, such as a project advisor. The payment offered will depend on the volume and nature of the particular activity.

A member of staff will advise you of the nature of the task, the fee (also known as an honorarium payment) this will attract and issue the claim form. The PPIE administrator will oversee this process and any queries should be raised with this person in the first instance. We will make clear what fees, if any, will be offered when inviting you to take part in our work. It is up to you to decide if you want to take part, and if you want to accept any payment that is offered. If you choose to accept the fee offered to you for participation in research activities, we will ask you to fill in and return a claims form.

1.1. Who is Eligible for a Fee?

We offer a fee to public contributors who:

- » are a member of the public
- and*
- » are being asked to provide a public perspective
- and*
- » are not in receipt of a full-time salary from public funds

If you work full time in the public sector you may, by exception, still be entitled to payment of a fee provided that you confirm to us in writing that:

- » your paid employment is unrelated to the activity being asked of you
- and*
- » you intend to undertake the activity in your free time, such as through taking annual leave or outside your normal working hours

Payment Rates

The Obesity Institute supports the NIHR payment guidance for public involvement. Detailed information about this guidance can be found here:

[nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392](https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392)

We will also seek to work with trusted partners who also seek to comply with this guidance.

The table below summarises payment rates in line with this guidance.

Meetings and Advisory Groups		
Short activity	Involvement in a brief task or activity requiring little to no preparation, e.g., short teleconference, or reviewing a brief document such as a leaflet or information card (a total of one hour of activity or less).	£25
	Involvement in a task/activity that is likely to require some preparation, e.g., a short conference with related papers to read in advance (a total of 2 hours of activity or less).	£50
Half day activity (including reasonable preparation activities)		£75
Full day activity (including reasonable preparation activities)		£150
Full day activity (that requires substantial preparation)		£300

The payment rates listed here are a guide only and will vary by project. Fees will only be offered when the public contributor is involved in tasks as part of research activity.

Tasks including reviewing project proposals or funding bids may not attract an honorarium payment, as those research projects will not yet have attached funding. If we are able to obtain funding for these activities, you will of course be offered a reward for your involvement.

Please note that these fees are in addition to the expenses you can claim.

1.4. Tax and National Insurance

You are personally responsible for any income tax or National Insurance contribution liability resulting from accepting payments for participating in research activities. You will need to declare any payments you receive to HMRC. HMRC states that you do not have to pay tax or National insurance contributions on money you receive to reimburse you for any reasonable expenses you incur in taking part in research activities. Any money you receive beyond this (such as fees you except for specific tasks) may be liable for tax and NIC. Further information can be found on the HMRC website.

Obesity Voices Hub/Obesity Institute (Leeds Beckett University) cannot provide financial advice. Information on where to go for financial advice can be found in section 4 below.

1.5. Advice if you receive state benefits

If you are receiving state benefits, any payment of fees and expenses to you may affect your benefit claim. You should notify Jobcentre Plus of any paid or voluntary activity before you undertake it. You may also need permission to undertake any paid activity. Benefit conditions are complex and limits on payments that can be received without impacting benefits vary widely.

Obesity Voices Hub/Obesity Institute (Leeds Beckett University) is not able to offer expert advice about this issue, but we can support you in the process of getting advice. Information on where to go for financial advice can be found in section 4 below.

1.6. Advice if you receive a retirement pension

Any earnings you receive in retirement count as taxable income along with income from your State Pension, personal or occupational pensions, and taxable benefits. Any money that you earn after State Pension age may affect income-related benefits such as Pension Credit, Housing Benefit and Council Tax Support. Obesity Voices Hub/Obesity Institute (Leeds Beckett University)

is not able to offer advice on how payment for involvement may affect you in retirement.

Your pension provider or impartial advice organisations can tell you how earnings may affect your pension or Pension Credit. Contact information for relevant advice organisations can be found in section 4 below.

2. Other Benefits and Support We Offer

2.1. Communication and Support Needs

To support public contributors, we are able to provide information in alternative languages and formats at meetings and events where needed. This will include the provision of information in alternative formats such as easy read or braille, and in alternative / community languages. Please notify the project team in advance of your needs.

Where the costs or methods of involvement are a barrier to you in ways not specified in this policy, please discuss your needs with the PPIE coordinator. Reasonable adjustments will be considered on a case-by-case basis.

3. Learning and Development

Occasionally we may ask you to voluntarily attend an event because it might be beneficial for you in your role as a public contributor or recognise the contribution that you have made. In which case we will offer an honorarium payment for your attendance and reimburse any associated costs.

Exceptionally we may agree that you can attend a training or learning event, such as a conference, for which we will pay any event fees and any associated expenses.

4. Financial Advice

Money Advice Service

Free and impartial money advice service set up by the government.

Telephone: 0800 138 7777

Website: moneyadviceservice.org.uk/en

Citizens Advice

An advocacy service that provides free, independent and confidential services for people who need independent advocacy support.

Telephone: 0808 278 7820 | Website: citizensadvice.org.uk/

Pensions Advisory Service

Free and impartial guidance to help people with workplace and personal pensions.

Telephone: 0800 011 3797 | Website: www.pensionsadvisoryservice.org.uk

Gov.uk

Information from the government about state benefits, tax and National Insurance.

Website: www.gov.uk

NIHR, National Institute for Health Research

Website: www.nihr.ac.uk

5. Further Information

If you have any questions or concerns about claiming fees and expenses, please raise them with the Patient and Public Involvement Administrator.

6. Frequently Asked Questions

» Do I have to claim for anything?

No, it's completely up to you whether you claim for your expenses, fees, both or neither.

» Can I claim a fee for one activity and not another?

Yes, you can choose to claim no fees, a fee for some activities and not for others, or all the fees we have offered you.

» Can I ask for a lower fee?

We are unable to change the fee amount we offer you based on your preference.

» Can I donate my fee to a charity?

You are free to do as you wish with any monies, we pay you. However, we are unable to donate to charity on your behalf.

» Does all PPIE activity attract a fee?

Yes – we will ensure that you receive payment for all PPIE activity. This will be discussed.

APPENDIX 3: Useful definitions and abbreviations

Term or abbreviation	Definition
Chairperson	The chair or chairperson of the group facilitates participation and discussion within the group, provides leadership and works in collaboration with the coordinator.
Co-Applicant	A person who is involved in the development of a funding application, and who has some responsibility in the delivery of the study if it is funded.
Co-Chairperson	The co-chair of the group assists the chairperson and coordinator with facilitating participation and discussion within the group and providing leadership.
LBU	Leeds Beckett University
National Institute for Health Research (NIHR)	The NIHR works in collaboration with the NHS, universities, local government, and members of the public to deliver and enable health research.
Patient and Public Involvement and Engagement (PPIE) research Group	A group that facilitates patients and members of the public in contributing to how research is designed, conducted, and disseminated.
Patient and Public Involvement and Engagement (PPIE Member) or Public Contributor	A patient or member of the public involved in the group who is representative of the views and concerns of members of the public, patients, service users and carers. They advise on the direction of research, contribute to discussion, and share experiences and views, with the aim of improving research and making it relevant and useful.
Service User	A broad term used to describe a person receiving or using (or has received or used) a health care service.
The NIHR Centre for Engagement and Dissemination (CED)	The NIHR Centre for Engagement and Dissemination (CED). This centre builds on the work of INVOLVE and leads to make the NIHR's health and care research representative, relevant and ready for use.



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