

OBESITY VOICES:

Patient and Public Involvement & Engagement Hub

A guide for requesting Patient and Public Involvement & Engagement (PPIE) for your activities.

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

Updated: February 2024



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WHAT IS 'OBFSITY VOICES'?

Obesity Voices is a national hub 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 underpinned by the voice of lived experience and support other organisations to do this too. Obesity Voices members share our passion to make a positive difference to people living with or at risk of obesity.

What do Obesity Voices members do?

Our members:

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

How do our Obesity Voices members approach participation in your project?

Our members:

- are passionate about contributing to activities that improve the lives of people living with or at risk of obesity.
- are committed to ensure they add value.
- are open to receiving support and training.
- have expressed interest in multiple areas in the research field of Obesity.
- have no obligation to respond to your project advertisement and if they do it is because they have a passionate interest in your project.

Benefits of Obesity Voices?

- The Obesity Voices Hub provides a large and effective group of potential PPIE Representatives.
- We develop, mentor and support our PPIE members.
- Good examples of PPIE are collected and shared to support our collaborators and we provide informal advice and guidance.
- We offer training opportunities for researchers and our PPIE members.
- We have developed a vibrant community and our members are dynamic and highly responsive to opportunities.

Make a PPIE request

Before submitting a PPIE request, please take the time to read this document. We would like to draw your attention to the "PPIE Process Overview and Checklist" which can be found on page 13. This valuable resource will assist you in preparing the necessary information before filling out our PPIE REQUEST FORM.

INTRODUCTIONS

Welcome

Thank you for your interest in Obesity Voices at the Obesity Institute.

This information pack has been written to help answer any questions you may have about recruiting members of Obesity Voices to work with you on your projects and activities.

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 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 objective 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.



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 simply being a participant in research.

PPIE work can be quite varied, including engagement in the formative stages of projects, the design and implementation of projects and the dissemination of the findings of projects – 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, 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.
- Co-producing curriculum content and approaches to learning, teaching and assessment that incorporate an understanding of the experiences of those living with or at risk of obesity
- Talking to students about lived experience to help them develop into compassionate person-centred professionals.

We ask you to always be clear about what every PPIE activity involves, including how much time will be expected and the nature of the tasks that will be undertaken. Our members can then decide which project/research they would like to get involved with.

"I am honoured to be involved with the Obesity Institute at Leeds Beckett. I began with minimal knowledge of PPIE and how it should effectively work for good collaboration.

Since joining the Institute's PPIE Steering Committee and seeing the Obesity Voices Hub develop, I believe that the Institute is an example of best practise with regards PPIE.

I have learnt a lot, but what I value the most is the respect and honest engagement with all members of the team and truly feeling heard"

Susie Birney

PPIE Steering Committee Member, representative for European Coalition for People Living with Obesity (ECPO) and Irish Coalition for People living with Obesity (ICPO).

BENEFITS OF PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT (PPIE)

There are many reasons why we should involve patients and the public in all our work - here are some benefits:

- Gain different viewpoints, which can help to develop new solutions and improve the design, delivery and impact of our work.
- Ensure our research addresses questions that matter to patients and the public.
- Empower patients and public members living with or at risk of obesity.
- Ensure the work we do is fair, reasonable and realistic for everyone involved.
- 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.
- Help us communicate in plain English, to ensure that what we do and what we find out is clear to everyone.
- Help train our students in becoming compassionate person-centred professionals.
- PPIE members can help share research findings, to ensure there reach and are understood by the public and patients who can benefit from them.

ABOUT OBESITY VOICES HUB

Obesity Voices Hub is the public and patient involvement and engagement hub that supports all the work at the Obesity Institute and can also support others working to improve the lives of people living with, or at risk of obesity. Obesity Voices members are our partners – reflecting the voice of the communities we serve, to ensure the voice of lived experience underpins all our work.

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.
- **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

Obesity Voices Hub is a growing network of 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. We have welcomed anyone who is either at risk of, or has a lived experience of obesity, or who represents or supports people living with obesity, to join the Obesity Voices Hub.

The wide variety of different projects that Obesity Voices members can get involved with, come from both the Obesity Institute and our trusted partners. Members are informed about opportunities in areas that interest them. Each member then decides which activities they would like to get involved with.



WHAT OBESITY VOICES MEMBERS EXPECT

Payment and Expenses

Obesity Voices member must be offered a fee (minimum of £25/hr) when undertaking an activity with us or our partner organisations. The project funding should also cover or reimburse all reasonable expenses associated with their 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 1).

Accessibility

All our opportunities are accessible, and no one is excluded. Therefore please ensure you can accommodate any accessibility requirements in your project. Please check with members for any access requirements prior to any meetings.

If meetings are held online, you may need to provide training on using Teams or other platforms if required and always provide telephone options for anyone who does not wish to use a computer. Language translators should also be provided where appropriate.

Refreshments

Provide hot drinks and snacks at in-person meetings which last for any longer than 3 hours. If meetings are for a full day or take place over lunch, we kindly ask you to provide either a lunch or reimbursement of expenses (please see Appendix 2). Ensure all dietary requirements are catered for.

Training and Support

All projects will not require specialist knowledge or skills. However, please discuss all tasks in detail, and this will include understanding whether members would like any training to support you in the task(s) for your project. Where training needs are identified, the appropriate training should be provided.

A Positive, Supportive and Listening Environment

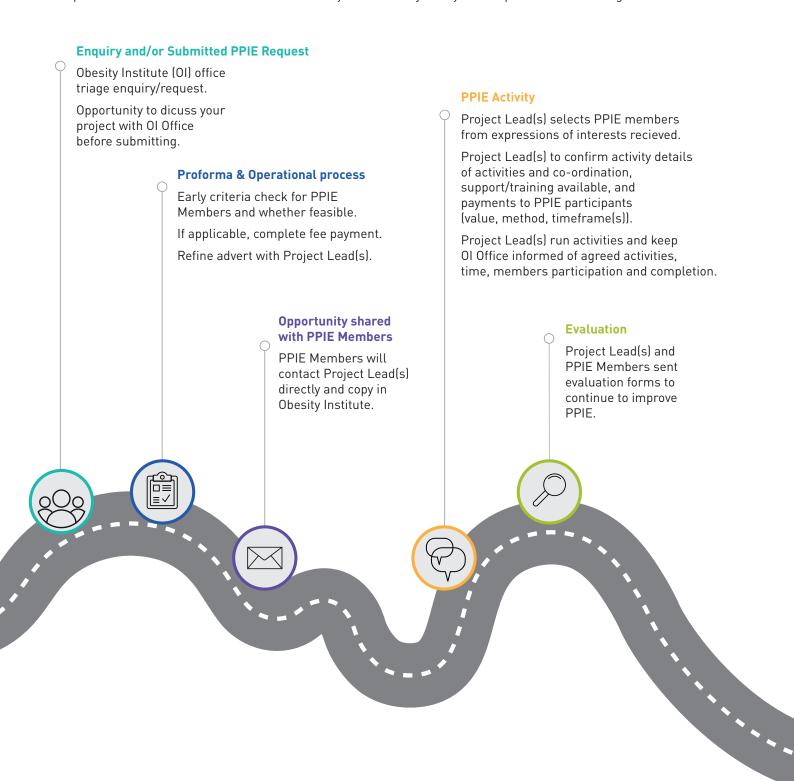
Obesity Voices members are an expert by lived experience, and their views should always be respected and listened to by both the Obesity Institute or partner organisation and other Obesity Voices members.

We hope the projects will provide everyone with an opportunity to meet new people, learn from each other, and help make a difference to the lives of people living with or at risk of obesity.



OBESITY VOICES PPIE ROADMAP

Here at the Obesity Institute, we have taken great care to develop a process that is accessible, fit for purpose and safeguards all our members and partners. We exist to facilitate and improve access to the voice of lived experience and below we have set out the Obesity Voices PPIE journey for our partners and colleagues.





THE OBESITY VOICES STEERING COMMITTEE

"I am so pleased to be working with the Obesity institute. As a person living with obesity and also representing residents as a councillor here in Leeds, it is incredibly important to me to be able to engage with this work. The systemic discrimination that people like me face in all manner of areas of life is prolific and having a strong voice of lived experience through this group is imperative to improvements in stigma and health and wellbeing care."

Councillor Hannah Bithell
Obesity & LGBT Champion, Leeds City Council

A PPIE Steering Committee has been established to oversee public and patient involvement and engagement activities across the Obesity Institute. This Steering Committee comprises academics leading in PPIE from the Obesity Institute, people with a lived experience of obesity, our academic partners and representation from obesity related organisations. For more information about our Steering Committee please visit: leedsbeckett.ac.uk/obesity-voices.

Members of the Steering Committee have informed the development of the Obesity Voices Hub and the processes described in this document.

"Working for the Obesity Institute is very important to me because the work/ research they do is inclusive and is reflective of the diverse society in which we live where everyone's voice is heard. My experience so far has been excellent!!"

Dr Jenny TekePPIE Representative

PROFESSIONAL CODE OF CONDUCT

As an Obesity Institute partner and colleague, we ask you to ensure you follow our code of conduct:

- Members are treated as partners in projects and research.
- PPIE activities with Members must be work that is carried out WITH or BY members and not TAKING
 PART in work that is about or for them.
- Activities and opportunities and the level of contribution are always TAILORED to each member's interest and availability.
- Members to be reimbursed adequately and in a timely fashion on terms no less generous than those set out in the PPIE national guidelines
- Appropriately acknowledge member's contribution.
- Demonstrate honesty, care, compassion, collaboration, equality and inclusion.
- Use person first language in all communications and support the Obesity Institute to eliminate weight stigma and bias.
- Feed results of activity back to members supporting the work.
- All member Personal Information will be held in the strictest confidence and in accordance with all Data Privacy Laws.
- Have in place and implement appropriate procedures to deal with complaints from members, and in any event permit members to withdraw from their projects should they no longer wish to participate.

FFFS

In order to maintain the longevity of our Obesity Voices Hub, we have had to introduce a small <u>administration</u> <u>fee of £40</u> is applicable for requests from non-commercial entities. Representatives from commercial, third-sector, or NHS organisations are encouraged to contact <u>obesityinstitute@leedsbeckett.ac.uk</u> to discuss fee options. NB: Our fee does not apply to Leeds Beckett staff and students, or applicants who are working in collaboration with LBU staff.

Following the approval of your request, the fee payment will be requested. You can make the payment easily through our online store. During the payment process, you will be prompted to provide your project title and reference. Upon approval confirmation, your project reference will be provided to you and a link for making the payment will be emailed to you.

PPIE PROCESS OVERVIEW AND CHECKLIST

1. DOES MY ACTIVITY REQUIRE OR BENEFIT FROM PPIE?

If you are unsure or would like to discuss your activity further, please email us at: obesityinstitute@leedsbeckett.ac.uk

2. COMPLETE AND SUBMIT A PPIE REQUEST FORM

Our request form can be found here: PPIE REQUEST FORM

To submit the form, please ensure the following:

Clearly identify the representation you are seeking. Refer to Appendix 2 for a comprehensive list of covered representation categories.
Secure funding to reimburse PPIE members (participants) and cover associated activities as outlined in Appendix 1.
Write the advert in plain English language and third person, simplify information. Refer to Appendix 3 for the example provided.
Propose flexible dates and times for the engagement. We encourage collaboration with PPIE participants to find mutually convenient scheduling options. In instances where project time lines may be tight, please explicitly indicate these constraints in your request.

Additionally, provide a simplified, plain-language summary of your project in third person. Include details on how PPIE members will contribute and the intended objectives of the project. To aid PPIE members in decision-making and understanding the discussions, consider providing sample questions, preferably three or more. We have provided an example advert in Appendix 3, to guide you.

We will respond to every request within 10 working days.

3. OBESITY VOICES TRIAGE & APPROVAL PROCESS

- We will review the information and details you have provided and may come back to you to seek additional clarification.
- We will tell you how many Obesity Voices Hub members fit your criteria.
- Fee payment will be requested upon approval, if applicable.
- ☐ Convenient online payment process: For easy payment submission. You'll be prompted to input your project title and reference (provided by Obesity Institute office) during the process.
- We will work with you to create the advert for your activities.
- We will advertise your project to members who have specified the same interests as you have specified on the PPIE Request Form

4. PPIE EXPRESSION OF INTEREST: PROJECT ADVERT

- We will inform you when your project has been advertised to our members.
- Members will express interest in your project directly with you or your assigned contact.
- Please contact all members who have expressed an interest in your project, to inform them if they have been successful or unsuccessful.
- We encourage you to speak with members before making your selection(s).

- We recommend a minimum of 2 PPIE members per activity.
- If you require assistance in making selections, please get in touch.
- Ensure you have reimbursements process set up, to ensure you can reimburse members on time.

5. POST EXPRESSION OF INTEREST DEADLINE ACTIVITIES

Within ten working days post deadline, please update us with the following:

- $\ \square$ How many members responded with expression of interest?
- ☐ Confirm if the activity/activities have been confirmed, shares dates and times
- ☐ If the Obesity Voices Team can offer any support to the recruited PPIE Representatives

We ask you to please keep us updated if there are any changes with the project or member participation. This is so we can support our members and keep our records updated.

6. COMPLETION OF PPIE ACTIVITY

- ☐ Please let us know when the PPIE activity has ended
- Please complete our evaluation form here:
 Obesity Voices: PPIE Request Evaluation Form

PLEASE BE AWARE THAT ANY VIEWS OR FEEDBACK PROVIDED BY OUR OBESITY VOICES HUB MEMBER(S) ARE THEIRS ALONE AND DO NOT REPRESENT THE VIEWS OF THE OBESITY INSTITUTE AND/OR LEEDS BECKETT UNIVERSITY.

CONTACT US

Obesity Voices at the Obesity Institute
Leeds Beckett University

Email: obesityinstitute@leedsbeckett.ac.uk
Tel: 0113 812 5039 or 0113 812 9389

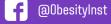
Find out more: leedsbeckett.ac.uk/obesityinstitute

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APPENDIX 1: GUIDANCE FOR PPIE PAYMENTS

PPIE members and public contributors are involved in a range of tasks which can be identified as PPIE. Such activities 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 required will depend on the volume and nature of the activity.

A member of your project team should advise Obesity Voices member(s) of the nature of the task/activity and the fee (also known as an honorarium payment) this work will attract. The project team's PPIE administrator should oversee this process and answer any queries raised by members in the first instance. Project teams clarify what fees will be offered when inviting Obesity Voices member(s) to take part in work. It is up to the Obesity Voices Hub member to decide if they want to take part, and if they wish to accept any payment that is offered. If members choose to accept the fee offered for participation in PPIE activities, the project team should guide member(s) through the process within their organisation to ensure payment is made promptly.

The Obesity Institute/Obesity Voices hub is not responsible for ensuring reimbursement. Payments and reimbursements are the responsibility of the Project Lead(s) under the requirements of our professional code of conduct.

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 Obesity Voice members work full time in the public sector they may, by exception, still be entitled to payment of a fee provided that they confirm to the project group in writing that:

• Member's paid employment is unrelated to the activity being asked of you

and

• Members intend to undertake the activity in their free time, such as through taking annual leave or outside 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. We will only support requests from partners/individuals who comply with this guidance. The payment rates listed here are a guide only and a minimum expectation. Fees will only be required when the public contributor is involved in tasks as part of PPIE activity.

	Meetings and Advisory Groups	
prep docu	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
activity	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 expectation of tasks including reviewing project proposals or funding bids is expected to attract an honorarium and ideally should be paid from project development funds, or deferred where such funds are not available until project bids have secured appropriate funding (in any event all work completed by the Obesity Voices member must be paid for). Please note that these fees are in addition to the expenses Obesity Voices members can claim.

APPENDIX 2: OUR CATEGORIES OF REPRESENTATION

To ensure we have PPIE members that match the area of representation your project requires please review and select from the following:

- Young adults (18-34 years)
- Adults (35-64 years)
- Older adults (65+ years)
- Adolescents
- Bariatric surgery
- Black, Asian and Minority ethnic communities
- Communities living in poverty
- Dietary interventions
- Digital support services (e-health)
- Lesbian, Gay, Transgender communities
- Mens health
- New drug therapy
- · People living with cancer
- People living with diabetes
- People living with emotional or disordered eating
- People living with heart disease
- People living with liver disease
- People living with mental illness
- People living with muscular skeletal conditions
- People living with obesity and skin conditions
- People living with polycystic ovary syndrome
- · People living with respiratory disease
- People living with sleep apnoea
- · People with neurodiversity
- Physical activity interventions
- Preschool children
- Primary school aged children
- Psychological/talking therapies
- Student teaching
- Tackling stigma and weight bias
- Women during and after pregnancy
- I'm interested in any opportunity

We encourage you to be as specific as possible – our members are very active, and opportunities can attract over 50 responses if they are too broad.



APPENDIX 3: EXAMPLE ADVERT

ABOUT THE PROJECT:

Ann Example is a Senior Research Fellow in the Obesity Institute at Leeds Beckett University. Ann would like to recruit 8 Obesity Voices Members to share their lived experience within an online discussion group.

Ann is researching what improvements can be made within schools, when discussing weight, healthy living and eating. Ann hopes this research will be used to improve practice within schools and improve early eating behaviours, understanding and mental health for young children.

Ann is preparing a grant application and would like PPIE input from parents and teachers of young children to inform

- What is not going well in current practice?
- What they feel current teaching impact?
- What could be done better and how?

WHAT'S INVOLVED:

Ann and two other colleagues would like 8 Obesity Voices Members to join them in a discussion group on the topics listed below and above. The discussion will be recorded, to allow Ann to use extracts to support an application for NIHR (National Institute for Health Research) funding.

Discussion topics will include:

- How young people perceive weight and healthy living and eating.
- How we might go about addressing that difference.
- Do economic inequalities impact perceptions.
- Perceptions of challenges and things to think about, particularly when working with people who have disadvantages
- Delivery proposals and discussion around ideas
- The role of PPIE in proposed work.

There will be two discussion group meetings, date and time to be agreed with participants:

- 1. <u>Discussion group 1</u> will be for 2-hours during April 2024. Will include a brief presentation (10mins) from Ann regarding background and proposed work followed by a group discussion.
- 2. <u>Discussion group 2</u> will be for 1-hour during June 2024. Will be to discuss the application, dissemination and time-scales.

PPIE PAYMENT:

Payments for this opportunity will be paid with Love to Shop vouchers of £25 per hour (£75 in total).

TO GET INVOLVED:

If you are interested in taking part, please contact **Ann Example, a.example@lbu.ac.uk by email, deadline is Friday 12th January, 1:00pm**. To help Ann with their recruitment selection please provide a couple of sentences about why you would be suitable for this project.

Following your expression of interest in the project, Ann will contact you directly following the deadline to discuss the project and your involvement in more detail.





OBESITY VOICES

Email: obesityinstitute@leedsbeckett.ac.uk
Tel: 0113 812 5039 or 0113 812 3189

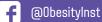
leedsbeckett.ac.uk/obesityinstitute

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OBESITY VOICES HUB

You can find out more and register as a member by visiting: **leedsbeckett.cc.uk/obesityvoices**



