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Tackling inequalities though research coproduction

Louisa Ells, Professor of Obesity

Specialist Academic Advisor to Public Health England

Expert Advisor to NICE

Expert Advisor to NHS England

Public Health
England

Obesity does not affect all groups equally

Obesity is more common among:

- People from more deprived areas
- Older age groups
- Some black and minority ethnic groups
- People with disabilities

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Child obesity inequalities in Europe:

- Socioeconomic inequities in obesity in Europe are widening and the gradient is becoming steeper.
- Women and children in low socioeconomic groups are most vulnerable and inequities in obesity are passed on from generation to generation.
- Pre-pregnancy, pregnancy, infancy and early childhood are critical periods for interventions to reduce obesity inequities.
- Physical activity is important for weight management and overall health, so appropriate policies and interventions should be tailored to different needs and abilities in a range of settings.

obesity-090514 (who.int)

However…

What is less understood is how effective these strategies are in preventing obesity in groups with low socioeconomic status.

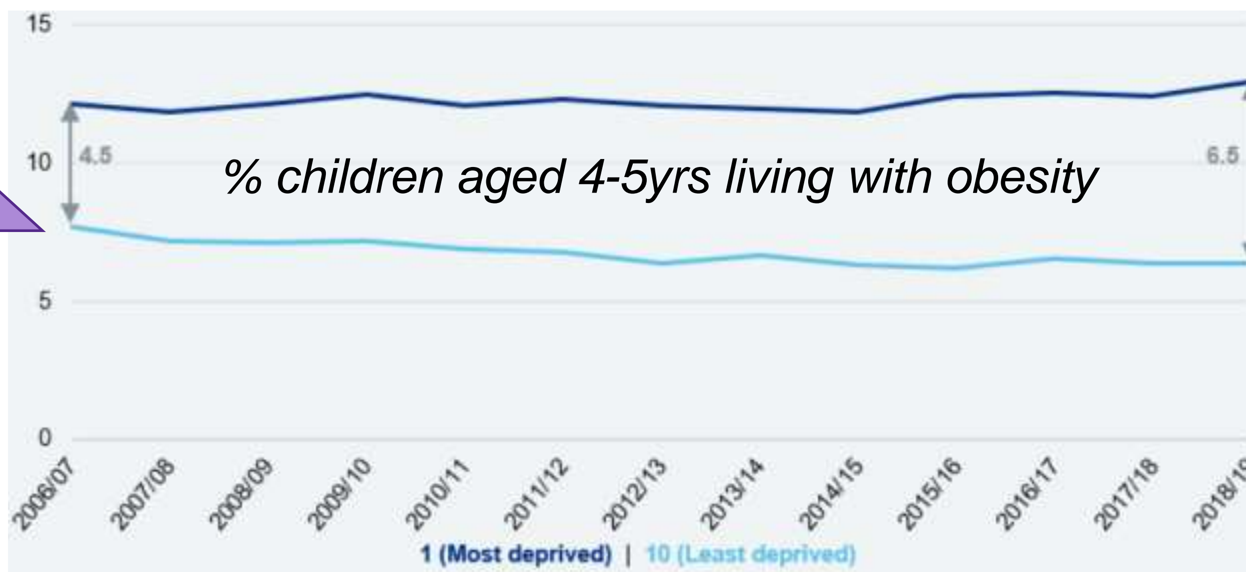
We need to do more to understand:

- Which groups have the highest obesity prevalence?
- Which groups are likely to benefit most from which strategy?
- How can the intervention be crafted to ensure groups with the highest need benefit most?

obesity-090514 (who.int)

If obesity is most prevalent in socially disadvantaged groups, yet interventions are most effective in advantaged groups – obesity inequalities are going to widen – as seen in the English National Child Measurement Programme

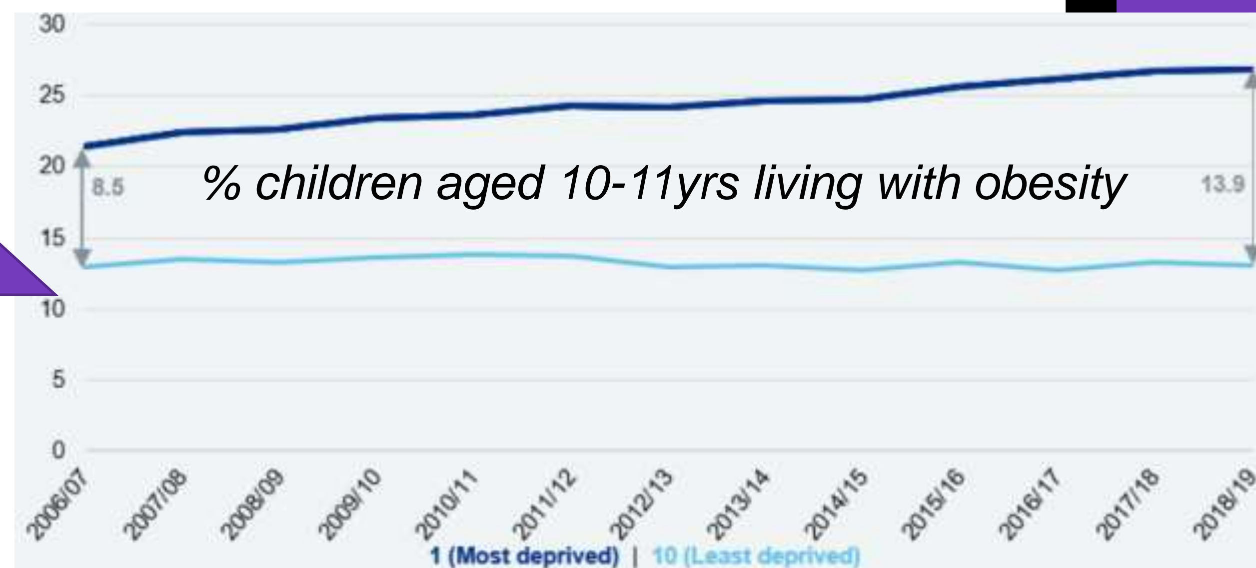
2.1% increase between most and least deprived



Children from the most deprived families and from certain ethnic groups are also more likely to gain or maintain an unhealthy excess weight during primary school!

[Changes in the weight status of children between the first and final years of primary school (publishing.service.gov.uk)]

5.4% increase between most and least deprived



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[Deprivation - NHS Digital]

Social disparities in obesity treatment for children age 3–10 years: A systematic review

- Only 5 out of 81 primary studies directly addressed differential effectiveness of treatment in relation to social disparities, with inconsistent conclusions.
- Interventions need to be culturally and socially sensitive, avoid stigma, encourage motivation, recognize barriers and reinforce opportunities and be achievable within the family's time and financial resources.
- Providing treatments that are attractive, that encourage, support and facilitate repeat attendance, that motivate sustained change, and are achievable within the resources the family can offer, requires a degree of understanding of the children being treated and their families.
- However, it appears from this review that this understanding is rarely attempted, considered or applied.

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Social disparities in obesity treatment for children age 3–10 years: A systematic review - Lobstein - 2021 - Obesity Reviews - Wiley Online Library

Barriers and facilitators to supporting families with children most at risk of developing excess weight - a rapid European review

- Searched for evidence within families: from certain (high risk) ethnic groups, with low socioeconomic status, or intellectual and/or physical disabilities
- The review found that insight into how and why families with the highest risk of developing excess weight, engage [or do not engage] with weight management services remains limited.
- **Weight management programmes, including assessment tools and health promotion materials, should be co-developed with children and their families to ensure they are designed appropriately and tailored.**

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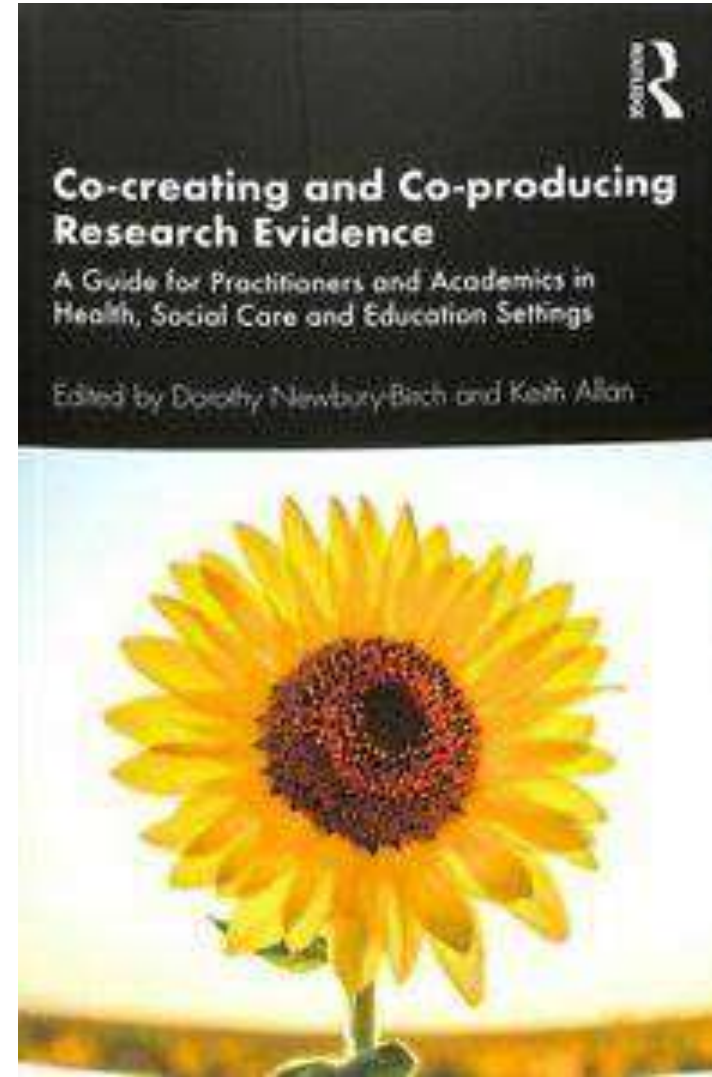
Supporting families with children most at risk of developing excess weight (publishing.service.gov.uk)

How can coproduction and PPI help?

What is co-production?

- ‘Sharing information and decision making between service users and providers, which when effectively applied can improve services and enable service users to be become more effective agents of change’
- Increasingly being used to bring together academics, policy makers, practitioners and service users to provide high quality research that has a real and tangible public benefit.



*McGeechan GJ, **Ells LJ,** Giles EL (2019) CHAPTER 2: CO-PRODUCTION: THE ACADEMIC PERSPECTIVE In Newbury-Birch D, Allan K (Eds). Co-creating and Co-producing Research Evidence: A Guide for Practitioners and Academics in Health, Social Care and Education Settings. Routledge*

What is PPI – Patient and Public Involvement?

- Is part of the co-design process where members of the public are actively involved in research.
- These activities recognise that people with lived-experiences contribute additional expertise: providing invaluable, novel insights.

NIHR INVOLVE (www.invo.org.uk) define PPI as: “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, or ‘about” them.

- Creating a truly person-centred approach

- **Putting people at the heart of what we do to develop, deliver and evaluate services and research with the populations that most need them!**

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What does involving service users bring?

- A new and different perspective
- Improves the quality of your service or research
- Makes the research or service more relevant to the service user

PPI coproduction & inequalities:

PPI coproduction can be particularly helpful in tackling inequalities as it can:

- Provide an opportunity to hear the voice of least heard communities who are often subject to the greatest health inequalities.
- Listening to the voice of communities suffering most from inequalities can help to understand:
  - What are the best communication mechanisms for the community.
  - What do communities feel they need (so often this is at odds with what researchers or policy makers are providing)
  - What do they think about current services, and how they can be improved.

  HOWEVER – it's not just about listening, it's also about working together to co-design services, interventions or research, so the communities we most want to support most feel a sense of ownership and engagement.

Tackling inequalities is about working with communities most in need and not continuing to just do on to them!

PPI essentials:

- Taking time to build a good mutually respectful relationship
- Ensuring appropriate funding is available to pay people for their time (and promptly)
- Good open communication (no hierarchy)
- Training for researchers and PPI members so every is clear about expectations and is equipped with the skills required
- Evaluation: celebrate what worked well and learn from what didn't
- PPI involvement in EVERY stage of the research…

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Inequalities and coproduction: the importance of reach, cultural awareness, stigma & weight bias

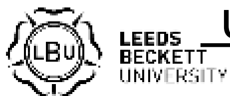
- Reach out to communities, rather than rely on them coming to you. Think about community hubs, religious institutes, and work alongside trusted community champions or leaders, or recruit staff from your target communities.
- Don't rely on good literacy, use innovative communication and engagement – understand what works for your target population – what communications mechanisms are used within the community.
- Always use non-stigmatising person first language i.e. people living with obesity rather than obese people.

People-First Language - Obesity Action Coalition

- Unfortunately, weight stigma exists in healthcare and research settings.
- Negative attitudes about individuals with excess weight have been reported by physicians, nurses, dietitians, psychologists and medical students.
- Research shows that even healthcare professionals who specialize in the treatment of obesity hold negative attitudes.

Understanding Obesity Stigma Brochure - Obesity Action Coalition

  - Think about your own and your team's weight bias which can be explicit or implicit



useful implicit bias test: https://implicit.harvard.edu/implicit/takeatest.html

How we have used coproduction and PPI to develop inequalities research…

Developing the use of technology in ethnically diverse communities – a research proposal development

Aim: To develop an intelligent avatar enabled electronic Buddy (e-Buddy) to enable and empower families from ethnically diverse communities to take part in health research.

Rationale: Ethnically diverse communities often do not engage in health research which is leading to widening inequalities. We were interested to know if using technology could help.

However in order to develop a research proposal that was tailored to community need, we needed to codevelop the proposal.

Coproduction activity:

- We worked with two local community champions who helped us to recruit 12 parents and young people from ethnically diverse families living in one of our most socio-economically deprived areas in the North East of England.
- We asked the PPI members what time, day and venue would suit them (they chose to meet on a Saturday morning, to avoid clashes with school and religious commitments, they asked to meet in the University so that their young people can see that University is accessible to them)
- We made the workshop fun and interactive, with lots of practical exercises
- We also provided:
    - Refreshments and lunch tailored to dietary preferences
    - Provided transport to and from the workshop venue
    - Offered every family a shopping voucher as a thank you for their time

Key findings from the workshop:

- There is an urgent need for more research within this community:

“I want research about me and my community”.

- Research areas that communities felt were important were related to mental health, diet and activity.
- Community members identified a number of barriers to taking part in research:

“there is a disconnect between the community and those who make the decisions”,

“often language is a barrier”, “people don’t feel comfortable taking part”, “time to participate is an issue as is travel, cost and caring responsibilities”.

- Community members felt an e-assistant could help to engage the community in research as it would provide a space to discuss culturally taboo topics such as mental health. However, participants felt that to be successful it must be: free, age appropriate, have clear governance and data protection, different language options and be personalisable (so it can be culturally appropriate).
- Community members felt an e-assistant could also be useful in helping members to also access health information.

These findings shaped the application and two families continued to work with us as co-investigators.

PPI evaluation - CRITICAL

Evaluation of any coproduction activity is critical to ensure we reproduce what works well and learn from what didn't.

A summary of the workshop anonymous feedback:

- 100% of participants enjoyed the workshop.
- Aspects of the workshop that participants particularly enjoyed were the informal and friendly nature, the structure of the workshop and variety of discussions.
- 100% of participants felt listened to and felt they were able to express their views.
- No participants felt we could have done anything better, the only feedback was can we invite more community members as it was felt to be a beneficial morning.
- Members expressed an interest in continuing to work with the team.

Back2Basics co-production:

Aim: To co-develop the Australian Back2Basics programme so it meets the needs of local families

Rationale: The back2basics programme was successfully piloted in remote areas Australia. North Yorkshire is a rural county in England that can suffer from socio-economics and rurality inequities. Therefore the County Council want to explore whether it could provide a feasible support programme for families who would like weight management support.

Coproduction activity:

Shirley Adu-Ntiamoah (as part of her PhD research) worked with 5 families with a lived experience of child weight management programmes, to determine:

- What a healthy lifestyle meant to families in North Yorkshire
- What resources they had previously used and/or would like to use online to stay healthy.
- What e-health medium would they prefer to use for their dietetic consultations
- What other apps or resources would help families in to stay healthy
- What families perceive to be the pros and cons of support over the internet.
- How the original B2B programme content and resources should be tailored to meet the needs of families in North Yorkshire

Given current COVID-19 restrictions, Shirley undertook two short telephone sessions with each family and provided them with shopping vouchers as a thank you for their time.

How coproduction influenced the programme: Original B2B vs New B2B

Remote video calls
(20 min:wk 1and 4)
Supported by 12 wks:
- Website
- Texts
- Facebook group

Remote 2x30min video calls

Supported by 12 wks:
- Website
- Texts
- Facebook group
- What's App group
- You tube channel (Conversations with your dietitian)
- One extra 30 call for families that need extra support

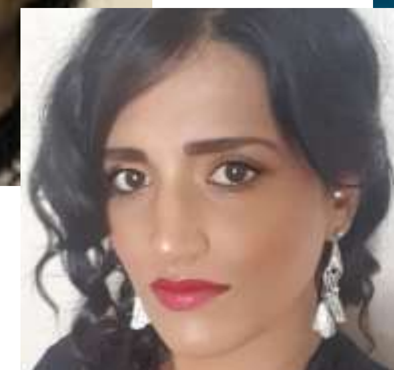
Additional website content:
- Physical activity
- Oral health
- Mental health (Kids and adults)
- Financial support

Evaluating the NHS Low Calorie Diet programme: the central role of our PPI group

Aim: to undertake a qualitative and economic evaluation of the new NHS low calorie diet programme within broad and diverse communities

Coproduction activities:

- co-developed the grant application (Ken Clare – Co-I)
- co-develop of the study protocol and supporting website
- co-develop all patient facing materials (surveys, interview schedules, information sheets…)
- Undertake participant interviews and follow ups
- Co-produce lay summaries, podcasts and blogs
- Work with the creative design team on the patient films, illustrated journals, and talking heads.
- Co-present findings at local, national and international meetings and conferences
- Co-author all study documentation.



Low Calorie Diet PPI group logistics:

- We applied for a small grant (~£500) to pay for group members time during the application development.
- We recruited a diverse PPI group to ensure representation from broad and diverse communities with a lived experience of obesity and or type 2 diabetes.
- We worked with participants to select a remote meeting session (Teams) that was easily accessible to the whole group (with options to dial in, and send paperwork for any members who did not have access to or wish to use a PC/tablet to join).
- Participants chose whether or not to use their cameras in group meetings.
- Meeting dates are arranged around members availability and there is always the option for a follow up call for anyone who couldn't attend on the day.
- We have costed into the grant group members time (£20/hr – INVOLVE rates), as well as all travel, conference fees and subsistence.
- We have worked with the group to understand training needs and are preparing a comprehensive programme of bespoke training.
- We evaluate each session and feedback to date has been excellent:

  "I thought the session was well managed and you got through a lot of content."

  "I really like that you explained the study so that we were able to understand it, also you asked questions after each section to get our input. You was clear and I now have a very good understanding of the project."

  "All members felt valued."

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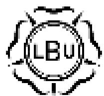
Impact so far…

- The group requested an extensive critique of behaviour change components of the service and an increase in the number of session observations, in reflection of the groups previous poor experiences in terms of long term behaviour change support in Low Calorie Diet programmes.
- The health care professional staff interviews and staff focus groups will ask about how person centred approaches were delivered, as requested by the group, and deemed important for success.
- The study participant survey has been codesigned and extensively modified and optimised by the PPI group to ensure it is accessible, useable and meaningful to participants.
- The PPI group developed the study participant incentives, and have helped codevelop different methodologies and tools (e.g. translators, online and phone data collection, freephone numbers and increasing website accessibility) to ensure inclusion is maximised.
- The PPI group have codeveloped all study public facing materials (e.g. consent forms, invites, PIS).
- The PPI group has codeveloped (and will co-star) in a short participant information film.
- Group members are writing blogs and podcasts for the website, and have co-presented with the research team at various national and international meetings.
- The PPI group co-designed an extensive and varied dissemination strategy (including illustrated journals, talking heads, short films, infographics, white board animations) to maximise public engagement.
- Group members are currently being trained to assist in participant interviews, to provide peer support and ensure person centred approach throughout the interview process.



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Thank you

Any questions?

L.Ells@leedsbeckett.ac.uk