

Co-producing eating disorder prevention research with South Asian experts-by-experience: preliminary findings

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BACKGROUND

People with lived-experience of eating disorders are crucial partners in co-designing and co-delivering research projects

It is especially important to involve those from marginalised groups in order to **advance mental health equalities** and access to services (Lewis and Foye, 2021).

This is due to the sampling bias which is often present in research pertaining to eating disorder interventions – including preventive body image interventions.

With the current policy landscape pointing to a commitment to these types of interventions, it is crucial to ensure that they are culturally relevant and inclusive, and that those with lived-experience are shaping the research agenda

AIMS

- a Patient and Public Involvement (PPI) engagement session will take place in order to involve experts-by-experience (ExE) in the research process.
- Lived-experience insights will be obtained from experts-by-experience to ensure cultural sensitivity in the language and approach used

METHOD

- 1 online session as well as individual video calls with those who could not attend took place.
- The sessions included South Asian women and girls with lived-experience of body image difficulties and disordered eating
- The session(s) explored the lived-experience perspective and highlight the nuances of experiencing body image distress and consequent research considerations in this culture
- These perspectives were utilised when reviewing research plans and materials such as focus group topic guides, participant information sheets and recruitment information

FINDINGS

Following the engagement sessions, certain modifications were proposed to the research process, participant materials and language used. For example:

- Due to the stigma surrounding body image/disordered eating in South Asian communities, ExE should share their experiences at the start of the focus group
- A co-facilitator of a similar ethnic background should conduct the focus groups

Original language	Adapted language
“Focus groups”	“Group discussions”
“Body dissatisfaction”	“Body image”
“British South Asian”	“South Asian”
“Treatment”	“Sessions”
“EL-CEDS-CYP”	“CAMHS”

CONCLUSION

- By involving ExE into the co-design of the research process, the approach to research will in turn become more culturally sensitive and appropriate
- Crucially, this process involved people from the community that was intended to be researched, which can contribute towards the advancement of mental health equalities in a group where misunderstandings about body image and eating disorders are commonplace

REFERENCES

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The Health Foundation, 2019.