'LENS' Lived Experience Narratives and Scenarios of Eating Disorders

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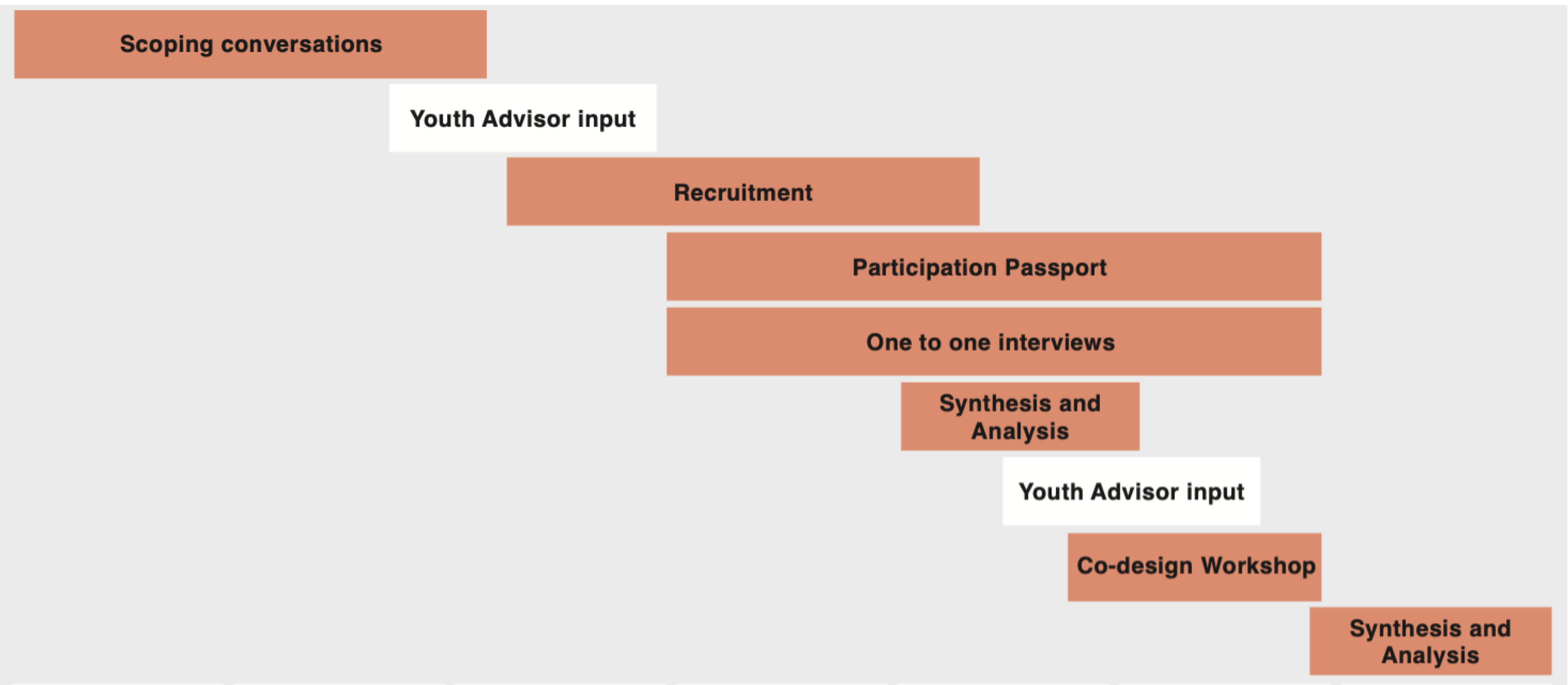
Background

- The LENS (Lived Experience Narratives and Scenarios of eating disorders) research project focused on understanding lived experiences of eating disorders of young people (16-25 years) from diverse, underrepresented and 'at risk' groups. This included young people from ethnically and culturally diverse groups; young people who are LGBTQ+; young people impacted by resource insecurity (e.g., poverty / cost of living); and young people living rurally.
- The aim was to co-create a range of stories from lived experience and develop an inclusive language for how we talk about and raise awareness of eating disorders.
- LENS is part of the lived experience workstream of the 'EDIFY' programme: Eating Disorders: Delineating illness and recovery trajectories to inform personalised prevention and early intervention in young people (EDIFY).
- Across the six workstreams of EDIFY, experiences of loneliness and hopefulness as part of the young people's journey, recovery, prevention and early intervention were identified as some of the key focus areas for further exploration when designing future forms of support for eating disorders.

Approach and methods

- The LENS project used a participatory design approach to work collaboratively with young people with eating disorders [1]. Figure 1 presents an overview of the approach. The focus was on designing ways to support genuine participation through making visible young people's lived experiences and co-designing ideas for future care and support from their perspectives, to shape eating disorder practice, policy and research.
- Across the wider EDIFY programme, young people with lived experience of eating disorders are involved as 'youth advisors' – who are experts by experience, working together with academics and practitioners to co-produce research and support knowledge mobilisation. Two youth advisors worked with LENS researchers throughout all stages of research design, co-design, analysis and synthesis, and development of outputs.
- 15 young people with lived experience from across the UK volunteered to take part in the participatory design activities, which involved one-to-one interviews using a visual mapping tool (online or in-person) and a co-design session (online).
- The LENS research focused on four priority areas which were informed by insights from the scoping conversations and review of existing literature. The priorities were: **ethnicity and culture, resource security, place, and gender**.
- The priority areas were framed as 'lenses' through which to explore with young people their views and lived experiences of eating disorders. The lenses helped to understand young people's intersectional experiences, where one or more lenses may overlap and impact each other.



Scoping conversations	Recruitment	Participation Passport	One to One Interview	Co-design Workshop	Synthesis and Analysis	Youth Advisor Input
Informed & validated our priority areas by drawing on the contextual expertise of people working in this area in Scotland.	Direct recruitment process was ongoing during the engagement period across social media, research networks and our programme partners, UK eating disorder charity, Beat.	Pre-engagement activity to support potential participants to share their perspectives on priority areas and how to best facilitate their taking part in the project.	15 one to one interviews capturing the unique journeys of young people to understand access to support, help seeking and the impact of the 'lenses' on eating disorders.	Young people with lived experience, researchers and LENS Youth Advisors designed ideas and recommendations for future experiences of accessing care and support.	Refined maps of the interviews were sense checked with participants and an overarching analysis was conducted, which informed the priorities for the co-design workshop.	Young people with lived experience in the EDIFY research team supported framing of the focus areas, language, design of interviews and workshop, and participated in co-designing ideas for future care.

Figure 1. Research approach.

Findings

- The findings present overarching themes and insights from across the lived experience interviews and co-design workshop. In addition a set of good practice principles for care and support and a series of concept ideas for quality care and support were also developed. Figure 2 presents the themes and subthemes recurring across young people's experiences of eating disorders.

THEMES AND SUBTHEMES

recurring across young people's experiences of eating disorders

Understanding eating disorders and challenging representations

- "Not assuming …": assumptions and negative perceptions
- Challenging perceptions through more diverse and relatable representations in media
- Empathetic awareness to support open conversations about eating disorders

Variation in experiences at the point of help seeking

- Missed opportunities for early intervention
- Experiences of first contact and diagnosis as a 'gateway' to accessing intervention
- Preparing for the journey ahead through clear communication and signposting

Tailored service access and treatment

- Flexible and appropriate support based on individual needs
- Cost of access and treatment (emotional and financial)
- Access to respectful and comfortable community environments for treatment & support

Key relationships and positive support networks to support the journey

- Friendships and peer support in life and services
- Enabling supportive family relationships to facilitate the journey
- Importance of community networks of support

Greater education and training tailored to context

- Training for all medical professionals - especially GPs
- Education and support for parents
- Education for schools and role of schools in education on eating disorders

Recovery as an open journey

- Recovery is not a linear process and it is multidimensional, complex and takes time
- Creating open mindsets for recovery
- Opening up life towards recovery

Figure 2. Themes and subthemes from LENS.

Concepts for excellent quality care and support

- Participants proposed ideas on ways to support excellent quality services and support for eating disorders, based on emerging ideas from the lived experience interviews and building and reflecting on each other's proposals in response to the co-design workshop prompts and questions.
- Concepts included:
    - Developing culturally accessible and inclusive materials;
    - Supporting services to tailor assessments to the unique and intersectional circumstances of each young person;
    - Co-creating care plans with young people to tailor support;
    - Making sure meal planning support is tailored to unique circumstances;
    - Ongoing review of training schemes to ensure they reflect the full diversity of people impacted by eating disorders;
    - Supporting peer networks led by young people with lived experience; and
    - Organising additional forms of support outside clinical services.

Conclusion

- Through engagement with young people with lived experience of eating disorders, the LENS research contributes insight to the emerging literature base relating to intersectional dimensions of ethnicity and culture, gender, resource security and place on the unique journeys of young people.
- The motivations of young people to engage in advocacy and research opportunities that inform future experiences for others should be built on to actively shape how young people can continue to be engaged in how recommended actions progress and influence subsequent changes in practice. The findings of the research reinforce the call for lived experience to be a core part of ongoing training, service design and delivery.

References

1. Raman, S., and French, T. (2022). Participatory design in sensitive contexts: A proposal for a conceptual framework. The Design Journal, 25(5), 752–767. https://doi.org/10.1080/14606925.2022.2088091