

LENS Lived Experience Narratives and Scenarios of Eating Disorders

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Background

LENS focuses on understanding lived experiences of young people (16-25 years) from diverse, underrepresented, and 'at risk' groups and co-designing ideas for future support and services. It is part of a wider programme 'EDIFY' focusing on transforming how eating disorders are perceived, prevented and treated (Hemmings et al., 2022).

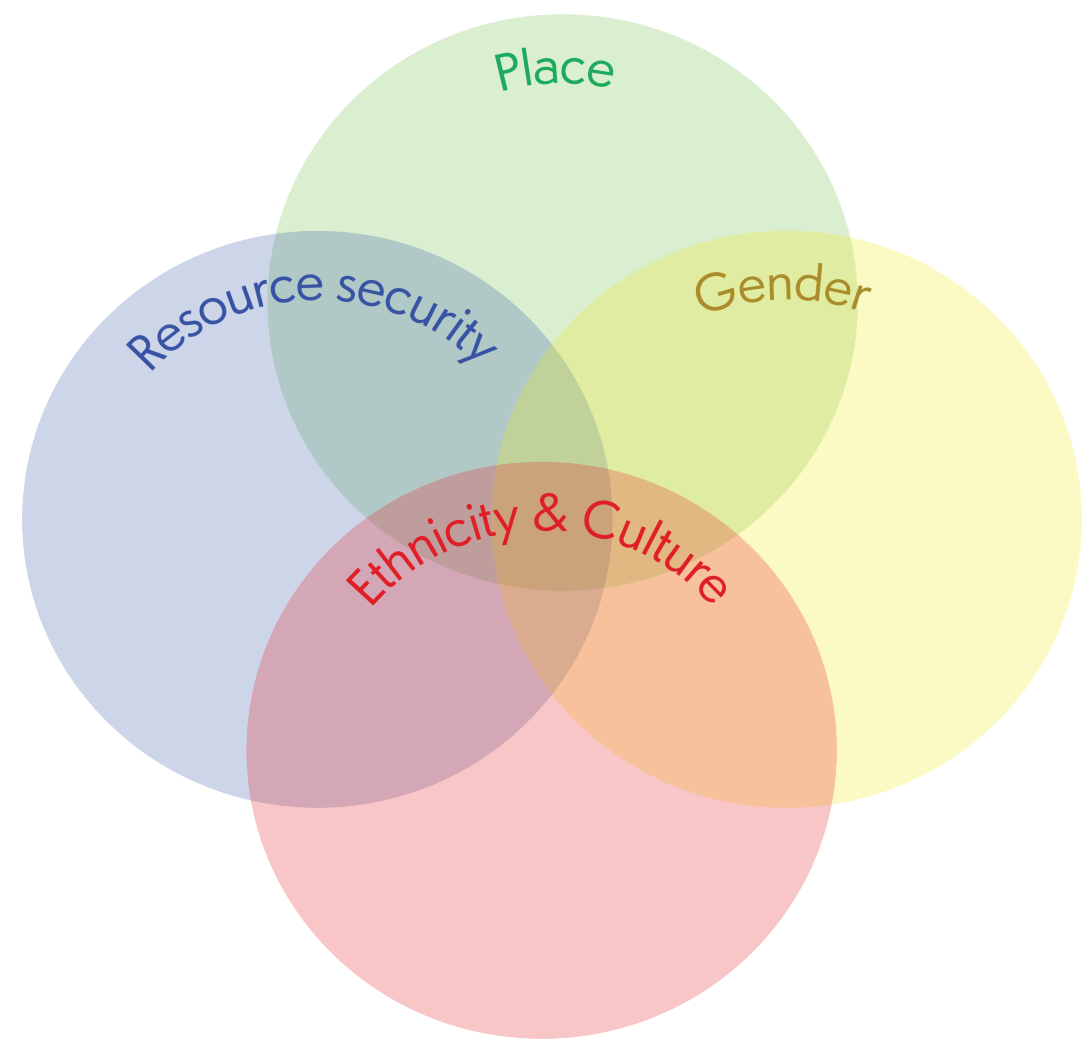


Figure 1. LENS focus areas

Methodology

Using a participatory design approach (Raman and French, 2022), young people with lived experiences participated in one to one interviews and a co-design workshop. Engagements used a visual metaphor of a 'kaleidoscope' to explore impacts of resource security, ethnicity and culture, place, and gender on young people's journeys of living with an eating disorder and understanding how and where these impacts might intersect (Stephens, Raman and French, 2024).

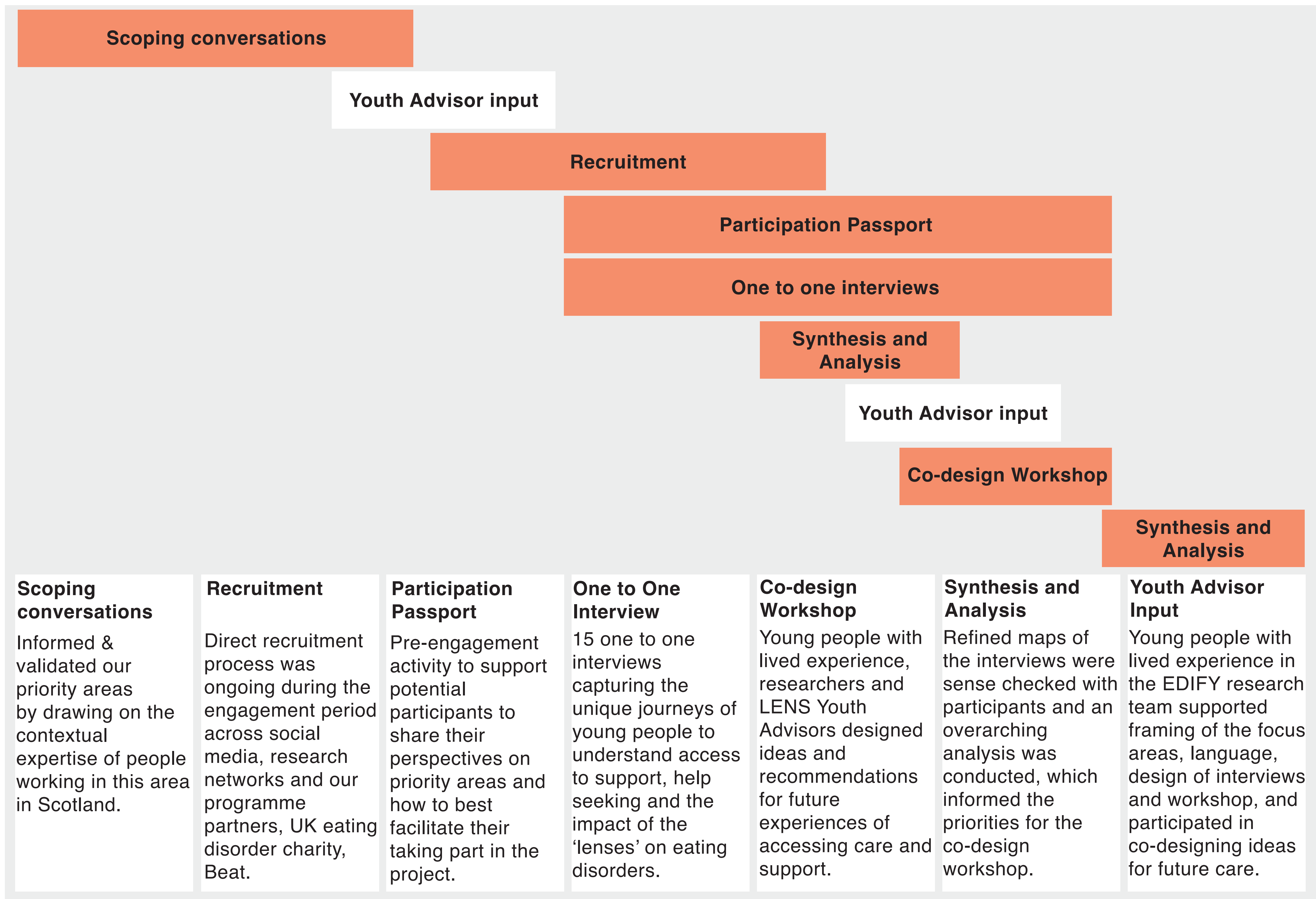


Figure 2. Research stages and activities

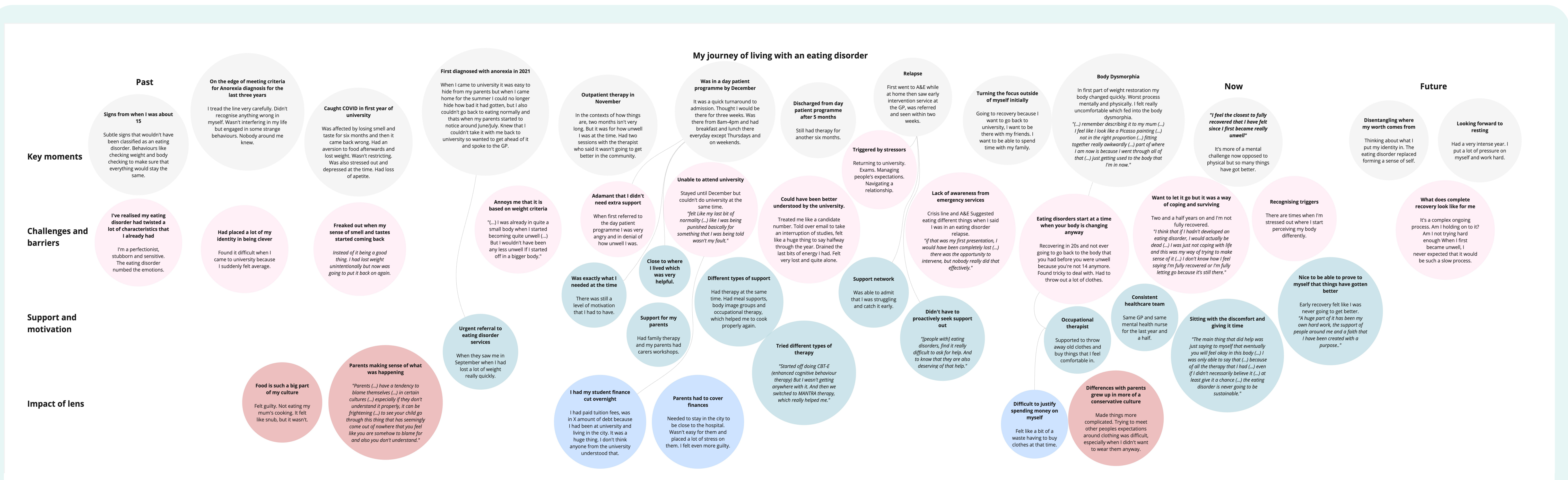


Figure 3. Example of a visual map

Findings

The visual journeys were synthesised into visual maps representing each young person's unique journey. These enabled a nuanced understanding of diversity in young people's experiences, and the impact of resource security, ethnicity and culture, place, and gender on accessing support.

The maps were analysed thematically to identify recurring themes and key principles for future support.

The emerging themes and principles reflect what matters to young people around future care and support. These will be further iterated based on outputs from the co-design workshop alongside synthesising key recommendations for future practice.

References

Hemmings, A. et al. (2023) 'EDIFY (Eating Disorders: Delineating Illness and Recovery Trajectories to Inform Personalised Prevention and Early Intervention in Young People): project outline', BJPsych Bulletin, 47(6), pp. 328-336. doi:10.1192/bjb.2022.83.

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

Stephens, F. Raman, S. and French, T. 2024. Designing Participation to Reframe Power in Collaborative Research with Young People with Lived Experience, In: Design4Health Conference 2024, 25-27 June 2024, Sheffield, UK. Available from: https://lab4living.org.uk/design4health/

LENS: INITIAL THEMES

Themes recurring across young people's journeys with eating disorders

Awareness and understanding	1
Understanding people's knowledge about eating disorders, including how to recognise and how to support others. This relates to clinicians, general population and young people with eating disorders.	
Training and education	2
Specific training guidelines for GPs, junior doctors, schools and carers of people with eating disorders.	
Seeking help	3
The influence of different care experiences and interactions young people have across different stages of their journey on their choice to seek support.	
Access	4
The ways that young people are able to seek and receive support, including enablers and barriers. This includes attending appointments, personalised care, how people find or are given information, digital inclusion and finances.	
Stigma and taboo	5
Perceptions and stereotypes around eating disorders in media and society that make young people feel misunderstood, unable to relate their own experiences or share with others.	
Networks	6
People coming together to connect and support each other in formal or informal ways. This can include peer support, charities, friends, carers and care teams.	
Recovering and recovery	7
Young people's personal and collective experiences and perceptions of recovering and recovery.	

Figure 4. Emerging themes from interviews

LENS: PRINCIPLES

Principles for future eating disorders care and support

Accessible support	regardless of diagnosis and removal of weight/BMI based criteria	Holistic support	focusing on the whole person and wider aspects of life
Care continuity and consistency	with care teams and options to access care when needed following discharge	Acceptance, compassion and empathy	across clinical services
Appropriate and comfortable environments	for care and support	Clear and engaging signposting	to support understanding of services
		Parity of support	across all types of eating disorders

Figure 5. Emerging principles for future support