



A Mixed Methods Exploration of  
Eating Disorders Self Help Groups  
in Relation to Social Value and Recovery

**APPENDICES**

Submitted to the University of Hertfordshire in partial fulfilment of the requirements for the award of the degree of Doctor of Philosophy.

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## Contents

Chapter Three Appendices.....	4
3.1 COREQ (COnsolidated criteria for REporting Qualitative research) Checklist .....	4
Chapter Four Appendices.....	15
Appendix 4.1: Annotated transcript (Jane) (Study 1) .....	15
Appendix 4.2: Example of reviewing of transcript themes together (Study 1) .....	20
Appendix 4.3: Confidentiality Agreement (Transcription Service) Study 1 .....	23
Appendix 4.4: Standard Risk Assessment Form (Study 1) .....	24
Appendix 4.5: Participant Information Sheet (Study 1) .....	25
Appendix 4.6: Participant Information Debrief Sheet (Study 1) .....	28
Appendix 4.7: Participant Pre-Interview Questionnaire (Study 1) .....	29
Appendix 4.8: Interview Questions (Study 1) .....	30
Appendix 4.9 Consent Form (Study 2) .....	31
Appendix 4.10: Harms, Hazards and Risks (Study 2).....	32
Appendix 4.11: Participant Information Sheet (Study 2) .....	35
Appendix 4.12: Participant Information Debrief Sheet (Study 2) .....	38
Appendix 4.13: Extracts from Qualtrics Questionnaire (Study 2) .....	38
Appendix 4.14: Consent Form for Studies Involving Human Participants (Study 3) .....	42
Appendix 4.15: Harms, Hazards and Risks: Assessment and Mitigation (Study 3).....	43
Appendix 4.16: Participant Information Sheet (Study 3) .....	46
Appendix 4.17: Participant Information Debrief Sheet (Study 3) .....	48
Appendix 4.18 Extracts from Qualtrics Questionnaire (Study 3).....	49
Appendix 4.19: Participant Information Sheet (Study 4) .....	54
Appendix 4.20: Consent Form (Study 4) .....	56
Appendix 4.21: interview schedule potential example questions (Study 4) .....	57
Appendix 4.22: Participant Debrief Sheet (Study 4) .....	57
Appendix 4.23: LMS Risk Assessment Form (Study 4) .....	59
Appendix 4.24: Participant Consent Form (Study 5).....	62
Appendix 4.25: EC5 Harms, hazards, and risks: assessment and mitigation (study 5) .....	63
Appendix 4.26: Qualtrics Questionnaire with Form with Participant Info Sheet (embedded within it) (Study 5) .....	64
4.27: Participant Debrief Sheet (Study 5) .....	72

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

4.28: Invitation email to participants (Study 5) .....	72
4.29: Consent from Co-facilitators of the Central London Group (S.....	72
4.29: Harms, Hazards and Risks: Assessment and Mitigation (Study 5) .....	74
4.30: Qualtrics Questionnaire with Form EC6 (Participant Info Sheet)- embedded within it (Study 5) .....	75
4.31: Participant Debrief Sheet (Study 5) .....	84
4.32: Invitation email to participants (Study 5) .....	84
4.33: Consent from Co-facilitators of the Central London Group (Study 5) .....	85
4.34: Ethics Approval Notifications .....	87
4.34a: Ethics Approval Notification for Study One .....	87
4.34b: Ethics Approval Notification for Study Two .....	88
4.34c: Ethics Approval Notification for Study Three .....	89
4.34d: Ethics Approval Notification for Study Four.....	90
4.34e: Ethics Approval Notification for Study Five.....	91
Chapter Five Appendices .....	92
Appendix 5.1: Researcher diary extract .....	92
Appendix 5.2 Participant Pre-Interview Questionnaire .....	93
Appendix 5.3: Example of stages of analysis (Jane).....	94
Appendix 5.4: Draft version superordinate and subordinate themes .....	97
Appendix 5.5 Coverage of themes for whole cohort.....	99
Chapter Six Appendices .....	100
Appendix 6.1: Full Survey Questions .....	100
Appendix 6.2: Detailed age breakdown.....	103
Appendix 6.3: Detailed Ethnic Breakdown .....	104
Appendix 6.4: Reasons for seeking group (extra qualitative comments) .....	104
Appendix 6.5: Reasons for delaying entry .....	105
Appendix 6.6: Total variance explained for 3-factor solution (group) .....	106
Appendix 6.7: Communalities Analysis (group .....	106
Appendix 6.8: Detailed descriptive statistics of generated factors (group).....	106
Appendix 6.9: Communalities Analysis (recovery) .....	107
Appendix 6.10: Detailed descriptive statistics of generated factors (recovery) .....	109
Appendix 6.11a: Prevalence survey WEMWBS detailed results.....	111

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

Appendix 6.11b: Statistics of WEMWBS question responses .....112

Appendix 6.12: Original classification table for step 0 (42 as cut point value) .....113

Appendix 6.13: Classification Table (42 as cut point value) .....113

Appendix 6.14: Variables not in the Equation (Steps 1 and 2 with 42 as cut point value) 114

Appendix 6.15: Variables not in the equation at Step 0 (51 as cut point value) .....114

Appendix 6.16: Classification Table Step 0 (51 as cut point value) .....115

Appendix 6.17: Classification table for the two steps (51 as cut point value) .....115

Appendix 6.18: Original Classification Table Step 0 (cut point value 35) .....115

Appendix 6.19: Variables not included in the equation (cut point value 35) .....116

Chapter Seven Appendices .....117

    Appendix 7.1: The 24 Recovery statements .....117

    Appendix 7.2: Would you consider attending an ED SHG (qualitative responses) .....118

Chapter Eight Appendices .....119

    Appendix 8.1: Confidentiality Agreement (Transcription) .....119

## Chapter Three Appendices

### 3.1 COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Paper 1: McNamara, N., & Parsons, H. (2016). 'Everyone here wants everyone else to get better': The role of social identity in eating disorder recovery. *British Journal of Social Psychology*, 55(4), 662–680. Scopus. <https://doi.org/10.1111/bjso.12161>**

Topic	Item No.	Guide Questions/Description	Reported on Page No (paper copy).
<b>Domain 1: Research team and reflexivity</b>			
<b>Personal characteristics</b>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group? Both authors. Inferred using the word 'we'.	9
Credentials	2	What were the researcher's credentials? PhD for at least one of authors. Unknown for second one.	1
Occupation	3	What was their occupation at the time of the study? Unclear one can assume that one works at university, and one worked for an ED charity.	1
Gender	4	Was the researcher male or female? Assumption made that both were female based on their names.	1
Experience and training	5	What experience or training did the researcher have? Not stated.	
<b>Relationship with participants</b>			
Relationship established	6	Was a relationship established prior to study commencement? Unclear, except that info was shared ahead and permission sought before each meeting was recorded.	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? Unclear except that 'study information was emailed to all registered group members and was posted on the participating organisation's website'	9
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? Nothing was overtly stated. It can be gleaned that as one of authors was linked to an ED charity that this led to an interest in the subject matter,	
<b>Domain 2: Study design</b>			
<b>Theoretical framework</b>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? A realist epistemological approach. Thematic analysis was used to code and analyse data.	9
<b>Participant selection</b>			
Sampling	10	How were participants selected? Through an advert on organisation's website. They were individuals who attended the group.	9
Method of approach	11	How were participants approached? Through an advert on organisation's website.	9

## A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)

Sample size	12	How many participants were in the study? 75 individuals across several groups. Average number that attended each session was 7.	9
Non-participation	13	How many people refused to participate or dropped out? Not specified. Permission was sought for recording, but no indication given that any objected to recording.	9
<b>Setting</b>			
Setting of data collection	14	Where was the data collected? Online transcripts.	9
Presence of non-participants	15	Was anyone else present besides the participants and researchers? The facilitator was there by dint of the fact that the session that were taking place were recorded.	9
Description of sample	16	What are the important characteristics of the sample? Unclear of demographic of transcripts but the registered members of the group were mainly female (95%) and over half were 25 years old. Type of ED: 'BED (32%) followed by BN (28%) and AN (20%). The remaining 20% identified as combination AN/BN'.	9
<b>Data collection</b>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested? N/A	
Repeat interviews	18	Were repeat interviews carried out? No.	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data? Yes. Meetings were recorded after permission had been sought.	9
Field notes	20	Were field notes made during and/or after the interview or focus group? N/A. There were no interviews, only the analysis of transcripts of recordings.	
Duration	21	What was the duration of the interviews or focus group? N/A	
Data saturation	22	Was data saturation discussed? Only that transcripts were read repeatedly.	10
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction? Not specified.	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data? Most likely at least 2.	
Description of the coding tree	25	Did authors provide a description of the coding tree? No.	
Derivation of themes	26	Were themes identified in advance or derived from the data? Derived out of the data. However, taken from a social recovery perspective.	10
Software	27	What software, if applicable, was used to manage the data? None specified.	
Participant checking	28	Did participants provide feedback on the findings? Not specified.	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? Participant name (pseudonyms) used to identify quotes.	11-22
Data and findings consistent	30	Was there consistency between the data presented and the findings? Not clear.	
Clarity of major themes	31	Were major themes clearly presented in the findings? Yes. Four themes were identified.	10, 11-22
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes? Cases that did not fit themes were alluded to briefly.	10

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

**Paper 2: Ronel, N., & Libman, G. (2003). Eating disorders and recovery: Lessons from overeaters anonymous. Clinical Social Work Journal, Vol. 31, No. 2, Summer 2003**

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group? Possibly the two authors. Not specified explicitly.	
Credentials	2	What were the researcher's credentials? One had a PhD	155
Occupation	3	What was their occupation at the time of the study? Not stated.	
Gender	4	Was the researcher male or female? Not stated.	
Experience and training	5	What experience or training did the researcher have? Not stated.	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement? The interviews had a prior relationship with the participants.	158
Participant knowledge of the interviewer	7	What did the participants know about the researcher? Not clear only that they were acquainted with them.	158
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? Nothing was overtly stated. One perhaps can infer that one or both may have been/or are members of OA.	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? Phenomenology. Used a qualitative- naturalistic approach.	157
<i>Participant selection</i>			
Sampling	10	How were participants selected? A snowball method was used.	
Method of approach	11	How were participants approached? The researchers had links with OA members and used that relationship to select participants.	158
Sample size	12	How many participants were in the study? 88 (80 women and 8 men).	158
Non-participation	13	How many people refused to participate or dropped out? None mentioned.	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? 'Most interviews were held in the participants' "territory"—after open OA meetings, at café's, in the respondents' homes, in parks'	158
Presence of non-participants	15	Was anyone else present besides the participants and researchers? None stated.	
Description of sample	16	What are the important characteristics of the sample? Israeli and mainly women (80 women and 8 men), aged 15 to 63. Some were newish members, and some were established members (months to several years). It was stated that they ranged in terms of ethnicity, religion, culture, social and economic background.	158
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? It would appear that the open ended interviews had 'flexible questions linked to the four specified life domains linked to worldview'.	157
Repeat interviews	18	Were repeat interviews carried out? Not stated.	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data? Data were recorded and transcribed in the participants' mother tongue.	157

## A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)

Field notes	20	Were field notes made during and/or after the interview or focus group? Not stated.	
Duration	21	What was the duration of the interviews or focus group? Not stated.	
Data saturation	22	Was data saturation discussed? No.	
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction. Not stated.	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data? Most likely the two authors (inferred).	
Description of the coding tree	25	Did authors provide a description of the coding tree? No.	
Derivation of themes	26	Were themes identified in advance or derived from the data? They derived out of the findings. However, they were linked to four life domains	157-8
Software	27	What software, if applicable, was used to manage the data? None stated.	
Participant checking	28	Did participants provide feedback on the findings? A draft version was presented to some OA members. It was not clear if those members were those that had been involved in the research. Some modifications were made considering their feedback.	158
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Quotations were used and different participants identified interview number e.g. interview no. 8.	
Data and findings consistent	30	Was there consistency between the data presented and the findings? Yes.	
Clarity of major themes	31	Were major themes clearly presented in the findings? Yes. Four themes were discussed and explored.	158-167
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes? None discussed.	

**3. Russell-Mayhew, S., Ranson, K. M. von, & Masson, P. C. (2010). How does overeaters anonymous help its members? A qualitative analysis. *European Eating Disorders Review*, 18(1), 33–42. <https://doi.org/10.1002/erv.966>**

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group? Two of the authors.	35
Credentials	2	What were the researcher's credentials? PhD (lead researcher).	
Occupation	3	What was their occupation at the time of the study? Two were registered psychologists and lead author had experience of facilitating groups for research.	35
Gender	4	Was the researcher male or female? Authors include male and female.	

## A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)

Experience and training	5	What experience or training did the researcher have? Lead author had experience of facilitating groups for research.	35
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement? Not specified.	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? Only information about the study. Not clear what the fliers said about the researchers.	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? Nothing was explicitly stated.	

### Domain 2: Study design

#### *Theoretical framework*

Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? Not explicitly mentioned.	
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#### *Participant selection*

Sampling	10	How were participants selected? They contacted lead researcher via email based on info that had been disseminated by OA regional trustees	35
Method of approach	11	How were participants approached? Not clear as the authors had to rely on regional trustees disseminating study details.	35
Sample size	12	How many participants were in the study? 19 women and 1 man	35
Non-participation	13	How many people refused to participate or dropped out? Not stated.	

#### *Setting*

Setting of data collection	14	Where was the data collected? Not clear where the focus groups took place.	
Presence of non-participants	15	Was anyone else present besides the participants and researchers? none	
Description of sample	16	What are the important characteristics of the sample? 19 women and 1 man. Average age was 53.6 years old. 95% were White/Caucasian.	35

#### *Data collection*

Interview guide	17	Were questions, prompts, guides provided by the authors? Semi structured focus group questions	35
Repeat interviews	18	Were repeat interviews carried out? No.	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data? Audio recorded and transcribed verbatim.	35
Field notes	20	Were field notes made during and/or after the interview or focus group? Not stated.	
Duration	21	What was the duration of the interviews or focus group? Two hours per group.	35
Data saturation	22	Was data saturation discussed? To a degree. It is implied as reference was made to coders looking across themes and comparing quotes.	35
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction. Not specified.	

### Domain 3: analysis and findings

#### *Data analysis*

Number of data coders	24	How many data coders coded the data? Three	34
Description of the coding tree	25	Did authors provide a description of the coding tree? None indicated.	
Derivation of themes	26	Were themes identified in advance or derived from the data?	

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

Software	27	What software, if applicable, was used to manage the data? None specified.	
Participant checking	28	Did participants provide feedback on the findings? Not specified.	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Individual quotations that were used were identified as FG 1,2 etc. or as participant or multiple participants.	36-39
Data and findings consistent	30	Was there consistency between the data presented and the findings? Yes.	
Clarity of major themes	31	Were major themes clearly presented in the findings? Yes	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes? A section on contradictions was briefly discussed.	39

**4. Stommel, W., & Meijman, F. J. (2011). The use of conversation analysis to study social accessibility of an online support group on eating disorders. *Global Health Promotion; Saint-Denis Cedex, 18(2)*, 18–26. <http://dx.doi.org.ezproxy.herts.ac.uk/10.1177/1757975911404764>**

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group? The two authors	
Credentials	2	What were the researcher's credentials? Not stated.	
Occupation	3	What was their occupation at the time of the study? Possibly university staff	18
Gender	4	Was the researcher male or female? Unsure.	
Experience and training	5	What experience or training did the researcher have? Not stated.	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement? A relationship with admin of group to gain access was present.	20
Participant knowledge of the interviewer	7	What did the participants know about the researcher? It seemed that they only knew about it if they had registered their details on the forum and the researchers wanted permission to use direct quotes.	20
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? None.	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? Discourse analysis with a basis in conversation analysis.	20
<i>Participant selection</i>			
Sampling	10	How were participants selected? They were not selected. An analysis of 21 threads from a forum were analysed.	20
Method of approach	11	How were participants approached? They were not initially approached only the admin of the forum.	20
Sample size	12	How many participants were in the study? Unclear.	
Non-participation	13	How many people refused to participate or dropped out? N/A	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? Gathered from an online forum.	

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

Presence of non-participants	15	Was anyone else present besides the participants and researchers? Technically no.	
Description of sample	16	What are the important characteristics of the sample? All were newcomers to the forum. It can be gleaned that one had AN and another BED.	22,23
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested? N/A	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many? N/A	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data? No.	
Field notes	20	Were field notes made during and/or after the interview or focus group? N/A	
Duration	21	What was the duration of the interviews or focus group? There were no interviews.	
Data saturation	22	Was data saturation discussed? No	
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction. No	

**Domain 3: analysis and findings**

*Data analysis*

Number of data coders	24	How many data coders coded the data? Probably two (the authors)	
Description of the coding tree	25	Did authors provide a description of the coding tree? No. They did describe the process of analysis. This informed the development of the themes.	20
Derivation of themes	26	Were themes identified in advance or derived from the data? Yes and no.	20
Software	27	What software, if applicable, was used to manage the data? Not specified.	
Participant checking	28	Did participants provide feedback on the findings? No.	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Quotes were used and identified by pseudonym names.	
Data and findings consistent	30	Was there consistency between the data presented and the findings? Yes	
Clarity of major themes	31	Were major themes clearly presented in the findings? Yes. The results and findings were subsumed into one subsection. They were presented as a series of analyses.	21-24
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes? No	

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

**5. Waller, A., Paganini, C., Andrews, K., & Hutton, V. (2020). The experience of adults recovering from an eating disorder in professionally-led support groups. *Qualitative Research Journal*, 21(2), 217–229. <https://doi.org/10.1108/QRJ-07-2020-0088>**

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group? All of them. The first author started the process off.	219
Credentials	2	What were the researcher's credentials? Not specified. All were linked with a university.	217
Occupation	3	What was their occupation at the time of the study? Mention is made that 'researcher works at eating disorder service'	220
Gender	4	Was the researcher male or female? All female	
Experience and training	5	What experience or training did the researcher have? Not specified.	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement? Only relationship was linked to fact that the researcher worked at the ED service where participants were recruited. Not clear how many of participants knew researcher.	220
Participant knowledge of the interviewer	7	What did the participants know about the researcher? The researcher worked at the ED service where participants were recruited.	220
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? As researcher worked at the service a reflexive journal was used and supervision at all stages	220/21
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? Thematic analysis	220
<i>Participant selection</i>			
Sampling	10	How were participants selected? Purposive sampling technique	219
Method of approach	11	How were participants approached? Their details were accessed from a database of an ED service. They were emailed details via the manager of the ED service. Participants opted to engage or not.	220
Sample size	12	How many participants were in the study? 18	219
Non-participation	13	How many people refused to participate or dropped out? None reported	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? Online survey which included opened questions.	219
Presence of non-participants	15	Was anyone else present besides the participants and researchers? No.	
Description of sample	16	What are the important characteristics of the sample? All were female. Had lived Ed between 2 and 30 years. 50% had attended more than 10 group sessions.	219
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested? Opened ended questions formed part of the online survey.	220

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

Repeat interviews	18	Were repeat interviews carried out? No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data? No
Field notes	20	Were field notes made during and/or after the interview or focus group? None
Duration	21	What was the duration of the interviews or focus group? N/A
Data saturation	22	Was data saturation discussed? No.
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction. N/A

**Domain 3: analysis and findings**

*Data analysis*

Number of data coders	24	How many data coders coded the data? Reference is made to authors so it would suggest that more than one person was involved.	219
Description of the coding tree	25	Did authors provide a description of the coding tree? No	
Derivation of themes	26	Were themes identified in advance or derived from the data? Derived from data using Thematic Analysis.	220
Software	27	What software, if applicable, was used to manage the data? Computer programme ATLAS	219
Participant checking	28	Did participants provide feedback on the findings? No.	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Yes. Participant quotations were used and identified by numbers.	221-223
Data and findings consistent	30	Was there consistency between the data presented and the findings? Yes.	
Clarity of major themes	31	Were major themes clearly presented in the findings? Yes.	221-223
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes? No.	

**6. Wasson, D. H., & Jackson, M. (2004). An Analysis of the Role of Overeaters Anonymous in Women’s Recovery from Bulimia Nervosa. *Eating Disorders*, 12(4), 337–356.**

<https://doi.org/10.1080/10640260490521442>

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group? It can be inferred that it was the two authors. Though reference is made to investigators- it’s not clear if the researchers were the investigators.	
Credentials	2	What were the researcher’s credentials? Not stated.	
Occupation	3	What was their occupation at the time of the study? Not stated. Can be inferred that they may have been employees of university.	
Gender	4	Was the researcher male or female? Female.	

## A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)

Experience and training	5	What experience or training did the researcher have? Not specified.	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement? Informants who were members of OA supported recruitment of participants.	342
Participant knowledge of the interviewer	7	What did the participants know about the researcher? Nothing was reported about this.	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? None specified.	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? Qualitative analysis. Inductive analysis of the data was involved.	343
<i>Participant selection</i>			
Sampling	10	How were participants selected? Their eligibility was checked in terms of meeting criteria for BN purging type and not having active symptoms for at least six months.	342
Method of approach	11	How were participants approached? The research was shared through a letter shared by informants within the OA organisation. Interested participants contacted investigators to check their eligibility to participate.	342
Sample size	12	How many participants were in the study? 26 women with BN.	342
Non-participation	13	How many people refused to participate or dropped out? None specified.	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? Four focus groups with 6 to 7 in each, and some interviews (6 participants).	342-3
Presence of non-participants	15	Was anyone else present besides the participants and researchers? Not specified.	
Description of sample	16	What are the important characteristics of the sample? Women with BN (purging type) and had no symptoms of BN for at least six months. Ages ranged 20 to 59. Other data around family life and length of attendance at OA was provided.	342
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Two broad questions were asked initially.	343
Repeat interviews	18	Were repeat interviews carried out? No repeat interviews but six people were interviewed in addition to the focus groups.	343
Audio/visual recording	19	Did the research use audio or visual recording to collect the data? Audiotaping which were transcribed.	343
Field notes	20	Were field notes made during and/or after the interview or focus group? Not specified.	
Duration	21	What was the duration of the interviews or focus group? 3-3.5 hours for the focus groups. Individual interviews were two hours each.	343
Data saturation	22	Was data saturation discussed? Yes.	343
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction? Not specified.	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data? Not clear, but two experts in ED field and with a background in qualitative research audited the data and debriefed the researchers.	343

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

Description of the coding tree	25	Did authors provide a description of the coding tree? None provided.	
Derivation of themes	26	Were themes identified in advance or derived from the data? Themes emerged out of the data.	343
Software	27	What software, if applicable, was used to manage the data? Not specified.	
Participant checking	28	Did participants provide feedback on the findings? No	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? Limited and individual quotes not identified by a name or number.	348-9
Data and findings consistent	30	Was there consistency between the data presented and the findings? Yes.	
Clarity of major themes	31	Were major themes clearly presented in the findings? Yes	344-
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes? No	

## Chapter Four Appendices

### Appendix 4.1: Annotated transcript (Jane) (Study 1)

This extract of Jane’s annotated transcript has some of the researcher’s initial thoughts, reflections and tentative themes were reviewed as part of a peer group IPA session led by one of the researcher’s supervisors. This peer review process elicited new ways of viewing the transcript. This was an important developmental process for the researcher as well as a quality assurance one. As a result of this the researcher reviewed the whole transcript.

Emerging themes	Extract Jane’s Transcript	Exploratory comments: Ideas, interpretative thoughts and reflections
<p>11) recovery versus recovered beliefs about recovery so I think recovery is it not been a significant part of life</p> <p>12) fake it till you make it:</p>	<p>Jane: I don’t know if anyone ever fully recovers from a mental illness if that’s what we’re going to call it, because it’s part of how your brain works. And I don’t mean that in a really sort of depressing way. But in a sense that it’s always something that I will be aware of, that doesn’t mean I’ll be aware of what I eat everyday hopefully. So I don’t know if you’ll ever... But then that’s not the same as recovery, that’s just part of you I think. So I think recovery is it not being a significant part of life, still a part but not prominent.</p> <p>Interviewer: And it doesn’t stop you doing things. You can carry on living your life. Is that what you’re aiming for?</p> <p>Jane: Yeah. I think that’s where I’m at as well. I’m still a bit of a sort of fake it till you make it stage.</p> <p>Interviewer: Fake it till you make it?</p>	<p>is this almost couched as a rhetorical type question to herself</p> <p>It is as if she seems unsure whether recovery is possible. She doesn’t use I but seems to initially talk in general terms she then uses I.</p> <p>She then comes up with her own definition. It is about a living with the ED in her life-not it being completely absent. It feels like she is accepted that is how it must be and that’s how life must be.</p>

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

<p>18a adrenaline-elated, important values-honesty truthful</p> <p>18b adrenaline because it just releases into your system</p> <p>19 people versus professional</p> <p>20 liberating</p> <p>21 finding the courage I can't believe I did that feeling reassured</p> <p>it would just resonate</p> <p>22 I think it's a lonely illness</p>	<p>Jane: That's what they always used to say. This lady always used to say this but it's sort of...even if you don't believe that what you're doing is</p> <p>Jane: I felt like I jumped out of a plane after I came out my first session. I felt so much adrenaline. I called my boyfriend and I was like, "I think that's the best thing I've ever done." I honestly felt elated because I was so nervous and it was so different to what I thought it was going to be and it is so different to speaking to a professional, to speaking to other... It's almost like having an in joke with everyone in the room. They can just relate to you no matter like, you know, we all have completely different experiences. But it was very liberating I think, my first group.</p> <p>Interviewer: I like that analogy of jumping out of a plane.</p> <p>Jane: Yeah, because it was so nerve-wracking before and that I had all of this adrenaline. And you know it's like after you do something that makes you scared, you feel great afterwards because it all just releases into your system. I just came out, I'm like, "Oh my god. I can't believe I did that."</p> <p>Interviewer: And from your own experience, what do you find helpful within the group, you know. Is it the topic style of the group, facilitation, others in the group?</p> <p>Jane: I think others because I don't really know. So for example at the beginning we do the recap of how everyone's been doing. I don't really like to go first because I don't know what I'm going to say, and I don't know how to articulate how I feel or maybe specific things that's happen that's really complex, I don't know how to make it understandable. But then someone else will say something and it will... it will just resonate and it will click. And that's really helpful, just to know that other people have similar thoughts and</p>	<p>fake it till you make it implies she is testing out recovery to see if she is succeeding. She got the phrase from her CBT therapist and has now adopted it as her own temporarily.</p> <p>felt like I jumped out of the plane speech- strong positive emotions evoked after the first session.</p> <p>The word adrenaline then and elated are action words like jumping into the unknown. Taking a risk.</p> <p>lots of positive analogies for example playing, having the in joke liberating</p> <p>she felt proud that she had conquered her anxiety. Strong emotional/bodily experience leading to exhilaration.</p> <p>ambivalence about getting better</p> <p>complexity equals difficulty finding the words.</p>
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**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

<p>23 inside the group things that resonate</p> <p>extra equal distance in own life no one notices you when you're ill</p> <p>24 what counts as being ill</p> <p>anxiety about telling people</p> <p>telling others about the problem</p>	<p>also... I don't know. I think that's just one of the biggest... It's just the reassurance that you're not... <b>I think it's a lonely illness.</b></p> <p>Interviewer: And can you think of things that people have said that have resonated?</p> <p>Jane: Probably. (Laughs) Let me think. <b>So something that I think that I talk about a lot and other people talk about is not wanting to get better, like being truthful about that.</b></p> <p>Interviewer: Well, being ambivalent about...</p> <p>Jane: Yeah. And just sort of being like, "Oh. It's the whole <b>fake it until you make it.</b>" Yeah. I want to get better but then the other part of me is like, "No you don't." So a lot of things when other people have talked about that has really stuck with me.</p> <p>Interviewer: It's given you permission to actually hold your hand up and actually "Sometimes I don't want to get better."</p> <p>Jane: Yeah, yeah. And there are other things but not for... I remember one girl saying that she felt like an extra in a film set and it's really stuck with me. <b>So it was just so beautiful and sad. But again, it's just a very good way of articulating that like she felt like an extra at a film set in her own life.</b> Yeah.</p> <p>Interviewer: Is that how you feel sometimes?</p> <p>Jane: Sometimes. I think not anymore. That's how I felt when I was looking for help because you feel like you're just there, <b>no one notices you and no one's noticed that you're not right, that's something not right with you. You felt like you're screaming and no one's, you know.</b></p> <p>Interviewer: Listening?</p>	<p><b>Don't know how to articulate-</b> represents the nature of ED as an illness. Professionals struggle too so it must be so much harder for the person with the eating disorder.</p> <p>The attendees in the group was the most important. The group helped to give a vocab to describe how she's feeling.</p> <p>Being amongst others who can relate. It is like Yalom idea of you've universality.</p> <p>Lessening isolation- links with her statement of the fact that the illness is a lonely illness. Self-recognition of her loneliness? It's relational.</p> <p><b>a space where there is no pressure to have to get better or to be able to say out loud. No need to pretend all life.</b></p> <p><b>Fake it until you make it. She used the analogy before.</b></p>
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**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

<p>Jane: Yeah, because they wouldn't notice. You can't expect people to notice all the time.</p> <p>Interviewer: Yeah. Because you seem to say that actually someone's visibly underweight, people recognise things are difficult. But for you because you weren't visibly thin, emaciated that people didn't understand how ill you were, how difficult things were.</p> <p>Jane: Yeah. That was a big problem. And I think it's still a problem that I have. I feel nervous to tell people.</p> <p>Interviewer: What would you tell people if you...</p> <p>Jane: If I wanted to tell them?</p> <p>Interviewer: Yeah.</p> <p>Jane: We don't really go into it much. I just say I've got an eating disorder, and they're like, "Oh." And I think people don't like to ask questions, so unless they're really close to you and that's the conversation that you're having. So for example when I told my current partner, it was like a sit down, "I need to tell you this. Ask as many questions as you want because you need to understand."</p> <p>But with my friends and flatmates, it's more of just situated in the conversation almost. So it's not as...</p> <p>Interviewer: It's like an aside rather than a...</p>	<p>Jane: Yeah, because they wouldn't notice. You can't expect people to notice all the time.</p> <p>Interviewer: Yeah. Because you seem to say that actually someone's visibly underweight, people recognise things are difficult. But for you because you weren't visibly thin, emaciated that people didn't understand how ill you were, how difficult things were.</p> <p>Jane: Yeah. That was a big problem. And I think it's still a problem that I have. I feel nervous to tell people.</p> <p>Interviewer: What would you tell people if you...</p> <p>Jane: If I wanted to tell them?</p> <p>Interviewer: Yeah.</p> <p>Jane: We don't really go into it much. I just say I've got an eating disorder, and they're like, "Oh." And I think people don't like to ask questions, so unless they're really close to you and that's the conversation that you're having. So for example when I told my current partner, it was like a sit down, "I need to tell you this. Ask as many questions as you want because you need to understand."</p> <p>But with my friends and flatmates, it's more of just situated in the conversation almost. So it's not as...</p> <p>Interviewer: It's like an aside rather than a...</p>	<p>feeling like an extra on the film set. She uses metaphors a lot for example it was just so beautiful and sad.</p> <p>She desperately wanted help but no one heard her cries. Echoes of feeling abandoned? A sense of abandonment?</p> <p>It is as if she screaming through her body why don't others notice why can't they see even if you're screaming?</p> <p>Gives a sense of being let down by people. Who is it she wanted to notice her?</p> <p>Being not thin enough in her mind makes it hard to be believed.</p> <p>Thin equals illness and being noticed</p> <p>is this link to shame the fear of not being believed</p> <p>reluctant to really tell others what her ED involves. Keeping them from the reality? Protecting them? Protecting herself? But this time she did it. It was different she came to the group and told.</p> <p>There is an air of desperation.</p>
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**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

<p>benefits of the group being understood and affirmation</p> <p>25 validating signs equal nodding</p> <p>26 valuable to be understood</p>	<p>Jane: Yeah, but it's not a proper...</p> <p>Interviewer: Mm-hmm. And when you've been in the group, have you experienced others within the group?</p> <p>Jane: <b>What do you mean how have I experienced them?</b></p> <p>Interviewer: Well, just thinking in terms of how you respond to what they say and how they respond to what you say.</p> <p>Jane: <b>Okay. I feel there's a lot of affirmation in the group. There's a lot of nodding. Not everyone will nod but lots of people go, "Yeah." And it's very validating. So that's something that I noticed, and I try and do when someone's talking, to try and... That again that's a problem that you have with everyone else is they can't understand and that's fine. So it's really valuable to go to a room full of people who do understand and to see that they understand.</b></p> <p>Interviewer: Yeah. <b>And you feel that people understand you when you're expressing yourself?</b></p> <p>Jane: Yeah. And when people sort of pitch in and say, "Oh yeah. And this or maybe do this" or "Does this happen to you as well?"</p> <p>Interviewer: And you find that quite helpful?</p> <p>Jane: Yeah, massively.</p> <p>Interviewer: And do you find that if you share anything with other people, give them suggestions that they respond to you?</p>	<p>She had difficulty articulating and trailing off in sentences. So many thoughts flooding in?</p> <p><b>She needed to ask me a clarifying question I wonder what that's about?</b></p> <p><b>She has been understood but also showing others she understands and this is very important for her. Reciprocity is a key value that she holds.</b></p> <p>.</p> <p>Description of how the group operated:</p> <ul style="list-style-type: none"> <li>-Checking out/checking in.</li> <li>- Mutual sharing and helping.</li> </ul> <p><b>There is an assumption that they all understand each other because they have a common illness.</b></p>
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**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

**Appendix 4.2: Example of reviewing of transcript themes together (Study 1)**

Superordinate Theme	Julie's themes			Lisa's themes		
	Subordinate Themes	Key words	page	Lisa subordinate themes		Page
Experiences in the SHG	(self)awareness and (self) insight	I don't think that I would have the self awareness and insight into myself	8	(self)awareness and (self) insight	I was really struggling and I needed to do something	8
		how people perceived you, what your relationships were with your family and friends	14		I think just coming to the group's kind of like a big step for me because I'm putting my needs first	11
		things we did talk about,.... It was less kind of ED focussed and more about the things we thought contributed to the beginning our ED	14		I don't use the group as well as I can because I end up talking about my family because it's easier to talk about that than what's going on for myself.	11
		ways of coping with comments that people make or things that people say to you	14			
				impact of group (actions)	I've managed to make a few changes just by going... because of like kind of advice or what has worked for the other people there	9
					I kind of like going to the group like it was kind of inadvertently kind of realised, yes, I do need more help than I'm getting	20
				relating to others in the group/reflecting on others in the group	I'm not as outspoken as some of the others but I think that's more a confidence thing but I'm hoping like in time it will come.	15
					one time I completely shut down because I don't know whether it was like the people I was with or what they were talking about	15

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

<b>Recovery as an ongoing process</b>	<b>I wouldn't say that I am 100% recovered</b>	I wouldn't say that I am 100% recovered... I still do have quite a lot of obsessive traits in terms of behaviours	9	<b>ED Voice</b>	like sometimes when I weighed myself and stuff the thoughts will come back but then I will—it was easier to kind of shut them up a bit?	5
		I think my mindset is still taking a bit of time to really shift into a healthy one	9		they [thoughts] weren't as predominant like I could eat without feeling guilty or having to exercise after I've eaten	6
		that voice is still there	9			
	<b>an anxiety about what I'm going to eat (p.10)</b>	where I would go without thinking necessarily about food	10	<b>relapse</b>	So, I managed to kind of sustain until I kind of like got to my target weight and then I kind of when I put on a bit more, I think with everything that was happening in my life at that time as well and dealing with the weight going above my kind of target even though it's still a healthy weight above it	6
		if I could get to a place where I'm not tracking my food	10			
		a big preoccupation with food	9			
	<b>deciding to recover (p. 6)</b>	going from a place where I didn't want to recover finding that part of myself that did and then realising	16	<b>freedom from...</b>	It was nice because like I could go out and have dinner and stuff with friends. I could be more social	7
					I do want to get back to that because I go on holidays a lot. I want to be able to enjoy the holiday where I am the an everything and not worry about food and just enjoy experiencing a new city	19
		I could see that there were so any great opportunities ahead of me and the one thing that was holding me back was my ED	6		I'm an active person but the reasons I'm doing it now are not for the reasons, so I'd like to be able to exercise or enjoy sports just because I like the	19

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

<b>Relationships/Views of others</b>	<b>parents</b>	initially thought in black and white terms a bit...she's unwell, but she's going to get 100% better if we get her treatment	17	<b>treatment</b>	it allowed me to kind of get back into like eating
		viewing recovery as something that's progressing... that has progressed the most the most in the last 3 years and is still getting better	18		I was still kind of recovering.... Getting towards my target weight
		there were moments where my dad... thought I was never going to get better. Mum's always been a bit more positive about it.	18		professionals gave me like a target weight to get to so I kind of thought well when I get there then everything will be fine
	<b>my GP was really dismissive'</b>	... basically just said you need to eat more	2	<b>recovery</b>	"you'll always gonna have something there. It's always gonna be there in the back of your head but you'll able to manage much better.
	<b>Treatment programmes</b>	treatment programme in E. There was a lot more compassion in the way that patients were treated	6	<b>the professionals</b>	they did say to me like right when you get to like a healthier weight the thoughts will like quieten down... but then they might pop up every now and again.
		I feel like the attention was paid more to getting me to a physically well place rather than taking steps to deal with the issues that were going on in my head.	19		

Appendix 4.3: Confidentiality Agreement (Transcription Service) Study 1



PhD in Psychology  
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:

Susan Dixon, PhD Psychology student  
And  
Dicate2us

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed: *Daryl LFLGH*

Name: *DARYL LFLGH*

Date: *16/4/18*



**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

**Appendix 4.4: Standard Risk Assessment Form (Study 1)**

Name of applicant: Susan Dixon

Date of assessment: 5th February 2018

Title of Study/Activity: Experiences of Eating Disorder Self Help Groups in relation to recovery

Activity Description					
1. IDENTIFY RISKS/HAZARDS	2. WHO COULD BE HARMED & HOW?		3. EVALUATE THE RISKS		4. ACTION NEEDED
<p><u>Activities/tasks and associated hazards</u> Describe the activities involved in the study and any associated risks/ hazards, both physical and <b>emotional</b>, resulting from the study. Consider the risks to participants/the research team/members of the public.</p> <p>In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.)</p>	<p><u>Who is at risk?</u> e.g. participants, investigators, other people at the location, the owner / manager / workers at the location etc.</p>	<p><u>How could they be harmed?</u> What sort of accident could occur, e.g. trips, slips, falls, lifting equipment etc., handling chemical substances, use of invasive procedures and correct disposal of equipment etc. <u>What type of injury is likely?</u> <b>Could the study cause discomfort or distress of a mental or emotional character to participants and/or investigators? What is the nature of any discomfort or distress of a mental or emotional character that you might anticipate?</b></p>	<p><u>Are there any precautions currently in place to prevent the hazard or minimise adverse effects?</u> Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc/</p>	<p><u>Are there any risks that are not controlled or not adequately controlled?</u></p>	<p><u>List the action that needs to be taken to reduce/manage the risks arising from your study</u> for example, provision of medical support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects NOTE: medical or other aftercare and/or support <b>must</b> be made available for participants and/or investigator(s) who require it where <b>invasive procedures</b> have been used in the study.</p>
<p>Interviewing participants about their Eating Disorder history and experiences.</p>	<p>Participants</p>	<p>The topic may cause you some distress and discomfort. It might also trigger some Eating Disorders Behaviours.</p>	<p>Participants can withdraw, take a break, stop or feel free to not answer any questions. They will gain an understanding of the areas that will be covered from the pre-interview questionnaire and information sheet. The researcher is experienced in working with people/clients with an ED. Participants will be signposted to support services and their own professional support.</p>	<p>none</p>	

<p>Signed by applicant: </p>	<p>Dated: 7/2/18</p>
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## **A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

### **Appendix 4.5: Participant Information Sheet (Study 1)**

#### **1 Title of study**

“Experiences of Eating Disorder Self Help Groups in relation to recovery”

#### **2 Introduction**

My name is Sue Dixon and I am currently a Part Time PhD student at the University of Hertfordshire. I am interested in researching the topic of eating disorders as I am a long established co facilitator of a Self Help Support Group in London that supports adults with an eating disorder which I have been involved with for over two decades. I am also a practising counsellor who specialises in eating disorders.

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision.

Please do take your time to decide whether you wish to take part. The University’s regulations governing the conduct of studies involving human participants can be accessed via this link:

<http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

#### **3 What is the purpose of this study?**

The purpose of the research is to investigate your experiences of attending a Self Help Support Group as part of your recovery from an eating disorder.

I will be asking you some questions about your eating disorder history and the type of support you had or have had; this information will be collected on a questionnaire which I will send out to you before embarking on the research.

In addition, I want to find out more about your motivations and expectations in attending the group. I am also curious to know how the group supplements the professional support you have or are receiving with a view to understanding if there is a role for self help groups in aiding recovery from an eating disorder.

In case any part of the interview process has raised difficult issues for you, you can access additional support via the Samaritans on 0845 7 90 90 90 or BEAT (Helpline 0808 801 0677 <https://www.beateatingdisorders.org.uk/>) or you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend

**Please keep this part of the sheet for reference.**

#### **4 Do I have to take part?**



## **A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

Troop and Dr Saskia Neville) will have access to the data. It may be necessary to use verbatim quotes to illustrate themes and ideas when writing up my thesis and presenting my work. Please be assured that they will be anonymised and disguised so that you are not easily identifiable.

### **11 Audio-visual material**

I will record our interview. After that I will transcribe it. Once I have finished transcribing our interview, I will save the file using your pseudonym name. The audio version of the interview will then be deleted from all devices.

### **12 What will happen to the data collected within this study?**

12.1 The data collected will be stored electronically, in a password-protected environment, for 5 years beyond the completion of my PhD, after which time it will be destroyed under secure conditions;

12.2 The data collected will be stored in hard copy by me in a locked filing cabinet until the end of my PhD and publication of the material, after which time it will be destroyed under secure conditions.

12.3 The data will be anonymised prior to storage.

### **13 Will the data be required for use in further studies?**

No.

14 **Who has reviewed this study?**The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority.

The UH protocol number is <enter>

### **15 Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email: Sue Dixon [s.dixon4@hert.ac.uk](mailto:s.dixon4@hert.ac.uk) or [REDACTED]

You can also contact one of my supervisors: Dr Nick Troop ([n.a.troop@herts.ac.uk](mailto:n.a.troop@herts.ac.uk)) or Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk))

**Although I hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:**

Secretary and Registrar  
University of Hertfordshire  
College Lane  
Hatfield  
Herts  
AL10 9AB

**Thank you very much for reading this information and giving consideration to participating in this study.**

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

**Appendix 4.6: Participant Information Debrief Sheet (Study 1)**

**Title of study: “Experiences of eating disorder Self Help Groups in relation to recovery”**

Thank you once again for taking the time to participate in this study.

If any part of the interview process has raised difficult issues for you, you can access additional support via the Samaritans on 0845 7 90 90 90 or BEAT (Helpline 0808 801 0677

<https://www.beateatingdisorders.org.uk/>) or you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

If there is anything you think of later that you would like to share with me then please do get in touch by phone or by email: Sue Dixon [s.dixon4@hert.ac.uk](mailto:s.dixon4@hert.ac.uk) or [REDACTED]. You can also contact one of my supervisors: Dr Nick Troop ([n.a.troop@herts.ac.uk](mailto:n.a.troop@herts.ac.uk)) or Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk))

Finally, I want to reiterate that your personal details will be kept confidential and all data will be anonymised.

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

**Appendix 4.7: Participant Pre-Interview Questionnaire (Study 1)**

<b>About You</b>	
<b>First Name</b>	<b>Family Name (use initial if you prefer)</b>
<b>Age</b>	<b>Gender</b>
<b>Employment</b>	<b>Civil status (e.g. single, married, in a long term relationship etc.)</b>
<b>Eating Disorders Diagnostic History</b>	
Please use this space to say a little about when your eating problems started (continue on another sheet if you wish to)	
<b>Eating Disorders Diagnosis/Diagnoses</b>	
<b>Diagnosis</b>	<b>Date and by whom (e.g. GP, psychiatrist, Psychologist)</b>
<b>Treatment History</b>	
Use this space to talk about any treatment you have received such as medication, hospital, in/out patient, dietician etc. (continue on another sheet if you wish to)	
<b>Information about the Self Help Group that you are attending</b>	
Use this space to tell me about the Self Help Group that you are attending such as how long you have been attending, the frequency of meetings, how often you attend etc. ((continue on another sheet if you wish to)	
<b>Other Information relating to your Eating Disorder History that you wish to share</b>	

Thank you for taking the time to complete this initial questionnaire. Please return this email to [s.dixon4@herts.ac.uk](mailto:s.dixon4@herts.ac.uk) I will then be in touch very soon to agree a date for your interview.

**What is the best way to contact you?**

Sue Dixon, PhD Psychology Student, University of Hertfordshire

**A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)**

**Appendix 4.8: Interview Questions (Study 1)**

I am interested in finding out two key things: your personal experiences/views of recovery and your experiences of attending an Eating Disorders Self Help Support Group

**1. What has your relationship with recovery from an Eating disorder been like for you?**

*Prompt: What would recovery look/feel like for you / How will you know if you have recovered?*

**2. What motivations did you have when you started attending the group?**

*Prompt: what were your hopes and expectations?*

**3. How does the group help you in your everyday life?**

*Prompt: Your eating, your emotions, your relationships*

**4. From your own experience, what do you find helpful within the group**

*Prompt: The topics, the style of the group, the facilitator(s), others in the group*

**5. What have you found challenging within the group?**

*Prompt: The topics, the style of the group, the facilitator, others in the group*

**6. How have you experienced others within the group?**

*Prompt: Listening to their experiences, their responses to what you might say? Your responses to what they might say to you*

**7. Having been in the group, what does recovery now mean to you?**

*Prompt: Has it changed over time e.g. from when you first started attending?*

**8. How do you think those around you view your recovery and what it might look like?**

*Prompts: professional help, friend, family etc*

**9. What do you make of their view(s)? For example,**

**a) is it the same/different to your own?**

**b) Is it helpful or unhelpful for you in your recovery?**

Appendix 4.9 Consent Form (Study 2)

**This info will go on the online questionnaire before the participant commences the survey**

By completing this questionnaire, you are giving your consent and freely agree to take part in the study entitled: **“Eating Disorder Self Help Groups and what matter in recovery”**

UH Protocol number: **xxxx**

I confirm that I have read the Participant Information Sheet giving particulars of the study, including its aim and design, the names and contact details of key people and, as appropriate, the risks and potential benefits. I am also aware of how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on the questionnaire will be stored and for how long.

I know that I may withdraw from the study at any time.

I understand that my participation in this study may reveal findings that could indicate that I may require medical advice.

[Tick box to confirm consent]

## A Mixed Methods Exploration of Eating Disorders Self Help Groups in Relation to Social Value and Recovery (APPENDICES)

### Appendix 4.10: Harms, Hazards and Risks (Study 2)

#### ASSESSMENT AND MITIGATION

Name of applicant: Susan Dixon

Date of assessment: 27th June 2020 02 July 2020 Title of

Study/Activity: "Eating Disorders Self Help Groups and what matters in recovery"

Activity Description					
1. IDENTIFY RISKS/HAZARDS	2. WHO COULD BE HARMED & HOW?		3. EVALUATE THE RISKS		4. ACTION NEEDED
<p><u>Activities/tasks and associated hazards</u> Describe the activities involved in the study and any associated risks/ hazards, both physical and <b>emotional</b>, resulting from the study. Consider the risks to participants/the research team/members of the public.</p> <p>In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.)</p>	<p><u>Who is at risk?</u> e.g. <b>participants</b>, investigators, other people at the location, the owner / manager / workers at the location etc.</p>	<p><u>How could they be harmed?</u> What sort of accident could occur, eg trips, slips, falls, lifting equipment etc, handling chemical substances, use of invasive procedures and correct disposal of equipment etc. What type of injury is likely? <b>Could the study cause discomfort or distress of a mental or emotional character to participants and/or investigators? What is the nature of any discomfort or distress of a mental or emotional character that you might anticipate?</b></p>	<p><u>Are there any precautions currently in place to prevent the hazard or minimise adverse effects?</u> Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc/</p>	<p><u>Are there any risks that are not controlled or not adequately controlled?</u></p>	<p><u>List the action that needs to be taken to reduce/manage the risks arising from your study</u> for example, provision of medical support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects NOTE: medical or other aftercare and/or support <b>must</b> be made available for participants and/or investigator(s) who require it.</p>
<p>Questionnaire asking about their Eating Disorder history and experiences.</p>	<p>Participants</p>	<p>The topic may cause you some distress and discomfort.</p>	<p>Participants are informed of the nature of questions in the Information Sheet and of the possible feelings some people may experience. Participants can stop the questionnaire at any point. The questionnaire does not have to be completed in one go. Participants will be signposted to support services and their own professional support at the end of the questionnaire</p>	<p>None</p>	<p>No action needed beyond the precautions and information provided that are already indicated in Section 3.</p>

Signed by applicant: Susan Dixon

Dated:  
02/07/2020

Ref No	
Date	
Review Date	
<b>OFFICE USE ONLY</b>	

**Life and Medical Sciences Risk Assessment**

*The completion of this is an integral part of the preparation for your work, it is not just a form to be completed, but is designed to alert you to potential hazards so you can identify the measures you will need to put into place to control them. You will need a copy on you when you carry out your work*

General Information			
Name	Sue Dixon	Email address	s.dixon4@herts.ac.uk
Contact number	07957641449		
Supervisor name (if student)	Nick Troop	Supervisor's e-mail address (if student)	n.a.troop@herts.ac.uk
Supervisor's contact number	07757559084		
Activity			
Title of activity		Completion of a computer based questionnaire and analysis of data for a study on "Eating Disorders Self Help Groups and what matters in recovery"	
Brief description of activity		Completion of an online questionnaire/s in the respondent's (or participant's) own location. Recruiting up to 500 participants, also online, and including the analysis of data. Questionnaire content (not including demographics) not sensitive and all data are anonymous.	
Location of activity		College Lane, de Havilland campus (described as such for the purposes of this type of study where the analysis of data takes place here).	
Who will be taking part in this activity		UH Undergraduate and postgraduate students and staff. Members of the general public. Volunteers and employees of public and private organisations in their work capacity.	
Types of Hazards likely to be encountered			
<input checked="" type="checkbox"/> Computers and other display screen	<input type="checkbox"/> Falling objects	<input type="checkbox"/> Farm machinery	<input type="checkbox"/> Fire
<input type="checkbox"/> Cuts	<input type="checkbox"/> Falls from heights	<input type="checkbox"/> Manual handling	<input type="checkbox"/> Hot or cold extremes
<input type="checkbox"/> Repetitive handling	<input type="checkbox"/> Severe weather	<input type="checkbox"/> Slips/trips/falls	<input checked="" type="checkbox"/> Stress

<input type="checkbox"/> Travel		<input type="checkbox"/> Vehicles		<input type="checkbox"/> Aggressive response, physical or verbal		<input type="checkbox"/> Workshop machinery	
Other hazards not listed above				None			
<b>Risk Control Measures</b>							
<p>List the activities in the order in which they occur, indicating your perception of the risks associated with each one and the probability of occurrence, together with the relevant safety measures. Describe the activities involved.</p> <p>Consider the risks to participants, research team, security, maintenance, members of the public – is there anyone else who could be harmed? In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.</p>							
Identify hazards	Who could be harmed?	How could they be harmed?	Control Measures – what precautions are currently in place?	What is the residual level of risk after the control measures have been put into place?	Are there any risks that are not controlled or not adequately controlled?	Is more action needed to reduce/manage the risk? for example, provision of support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects	
	e.g. participants, research team, security, maintenance, members of the public, other people at the location, the owner / manager / workers at the location etc.		Are there standard operating procedures or rules for the premises. Are there any other local codes of practice/local rules which you are following, eg Local Rules for the SHE labs? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc	Low Medium or High			
Use of computers	Researcher and participants	Eye strain and upper limb disorder	LMS Health and Safety Code of Practice	Low	No	No	
Stress	Participant	Unpleasant feelings/memories	LMS Health and Safety Code of Practice	Low	No	Information on sources of support are provided both before and after completing the online questionnaire.	
List any other documents relevant to this application			Local Code of Practice and Local Rules applicable: BPS Code of Ethics & Conduct (2009) BPS Code of Human Research Ethics (2014) LMS Health and Safety Policy				

Signatures					
Assessor name	Susan Dixon	Assessor signature	Susan Dixon	Date	20/10/20
Supervisor, if Assessor is a student	Nicholas Troop	Supervisor signature			26/10/20
Local Health and Safety Advisor Lab Manager	John Bain	Local Health and Safety Advisor/ Lab Manager signature			27/10/2020

## Appendix 4.11: Participant Information Sheet (Study 2)

1 **Title of study**

“Eating Disorders Self Help Groups and what matters in recovery”

2 **Introduction**

My name is Sue Dixon and I am currently a Part Time PhD student in her 3<sup>rd</sup> year at the University of Hertfordshire. I am interested in researching the topic of eating disorders (ED) as I am a long- established facilitator of a Self Help Support Group (SHG) that supports adults with an eating disorder that I have been involved with for over two decades. I am also a practising MBACP (accredited) counsellor/psychotherapist who has a special interest in eating disorders.

I have already completed a detailed study with people who have attended a face-to-face Self Help Group for people with eating disorders. Some of their words and experiences have informed the content of this study. I want to see if their experiences are the same for a larger number of the population who have attended a Self Help Group for their eating disorder.

You are being invited to take part in an online questionnaire. Before you decide whether to do so, it is important that you understand what the questionnaire is about. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask me anything that is not clear. The University’s regulations governing the conduct of studies involving human participants can be accessed via this link: <http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

**What is the purpose of this study?**

The main purpose of the research is to find out about your experiences of attending a Self Help Group as part of your recovery from an eating disorder. You will be taken through a series of questions that cover a range of topics. Some are information type questions; some require you to rate your level of agreement with statements; and some explore your experiences of recovery. There is also space for you to write additional comments.

Although it is not the intention of this study to cause any distress, given the nature of the questions and topic area, it may lead to uncomfortable feelings in some people. Please only complete the study if you feel comfortable doing so. In case any part of the survey raises difficult issues for you, you can access additional support via the Samaritans (116 123 or [jo@samaritans.org.uk](mailto:jo@samaritans.org.uk)) OR BEAT (0808 801 0677 <https://www.beateatingdisorders.org.uk/>) OR you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

**Do I have to take part?**

It is completely up to you whether you decide to complete the questionnaire. Please read the information carefully before starting. You will be asked to give consent by ticking the relevant boxes before you are able to proceed fully with the questionnaire.

You are free to withdraw at any stage of the questionnaire.

**Are there any age or other restrictions that may prevent me from participating?**

Yes. You must be over 18 and have attended an Eating Disorders Self Help Group.

**How long will the questionnaire take?**

If you decide to complete the questionnaire it should take around 15 minutes on average.

**What are the possible disadvantages, risks or side effects of taking part?**

The topic matter of the questionnaire may cause you some distress and make you feel uncomfortable. It might also trigger some experiences related to your ED. You do not have to complete the questionnaire all in one go.

**What are the possible benefits of taking part?**

From experience I have found that people want to have an opportunity to share aspects of their own story, their journeys of recovery, and what support they have found helpful. This information can help others in addition to educating professionals about the range of non-professional support, such as Self Help Groups that many sufferers access and engage with.

**How will my taking part in this study be kept confidential?**

You are not required to give your name. The data that are collected from the questionnaire are anonymised.

**What will happen to the data collected within this study?**

The data collected will be stored electronically in a password-protected file. All data will be anonymous and there will be no way of identifying participants from the information given.

**Will the data be required for use in further studies?**

There is a possibility of publication resulting from this study and therefore a need to adhere to the principles of open science and policies of journals. There may be a requirement to make data available for re-analysis, however data will be anonymous and there will be no means of identifying you.

**Who has reviewed this study?**

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee ECDA with Delegated Authority. The UH protocol number is **xxxxxxx**

**Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email: Sue Dixon [s.dixon4@hert.ac.uk](mailto:s.dixon4@hert.ac.uk) or **[REDACTED]**

You can also contact one of my supervisors:

Dr Nick Troop ([n.a.troop@herts.ac.uk](mailto:n.a.troop@herts.ac.uk)) or Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk))

**Although I hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:**

Secretary and Registrar  
University of Hertfordshire  
College Lane  
Hatfield Herts AL10 9AB

**Thank you very much for reading this information and giving consideration to participating in this study.**

#### Appendix 4.12: Participant Information Debrief Sheet (Study 2)

##### **Title of study: “Eating Disorders Self Help Groups and what matters in recovery”**

Thank you once again for taking the time to participate in this study.

If any part of the survey has raised difficult issues for you, you can access additional support via the Samaritans (116 123 or [jo@samaritans.org.uk](mailto:jo@samaritans.org.uk)) OR BEAT (0808 801 0677 <https://www.beateatingdisorders.org.uk/>) OR you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

If there is anything you think of later that you would like to share with me then please do get in touch by email: Sue Dixon ([s.dixon4@hert.ac.uk](mailto:s.dixon4@hert.ac.uk)). You can also contact one of my supervisors: Dr Nick Troop ([n.a.troop@herts.ac.uk](mailto:n.a.troop@herts.ac.uk)) or Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk))

Finally, I want to reiterate that your personal details will be kept confidential and all data will be anonymised.

Sue

#### Appendix 4.13: Extracts from Qualtrics Questionnaire (Study 2)

##### *Eating Disorders Self Help Groups and What Matters in Recovery*

Note: This is not the full questionnaire. In each section extracts of choices have been provided.

##### *Consent and eligibility to complete study*

- (i) I have read the participant information sheet
- (ii) I understand by clicking this box I give consent for you to use my information and the data from this study for research purposes
- (iii) I am over 18

---

Q1.1 **Age**

Q1.2 *What is your gender?*

---

**Q1.3 What is your ethnic group? Please tick the one that applies.**

Ethnic group choices taken from the Office of National Statistics definitions

*Q2.1 How did you find out about the Eating Disorders Self Help Group?*

Please tick all that apply.

Internet search someone showed me

I was told by a professional such as a nurse, doctor, therapist etc. was told by friends or family or partner

I was told by someone at work Other

*Q2.2 Why did you look for the group? Please tick all that apply.*

My treatment ended

There was a long wait for treatment I was put on a waiting list

I was waiting for treatment after an assessment I was getting panicky about my ED

Other

*Q3.1 When you found out about the ED self help group what did you do?*

Please choose the one that best describes your experience.

Example of some of the choices

I attended the next scheduled group straightaway when I got the details

I delayed my entry to the group because I was worried about my body size I delayed my entry to the group because I was feeling anxious

*Q3.2 How long did you delay your entry to the group?*

---

**Q4.1 When you attended your first session at the group how did it make you feel?**

**Please tick all that apply.**

***Example of the choices***

I had a feeling of adrenaline

I felt like I had jumped out of a plane I felt proud of myself

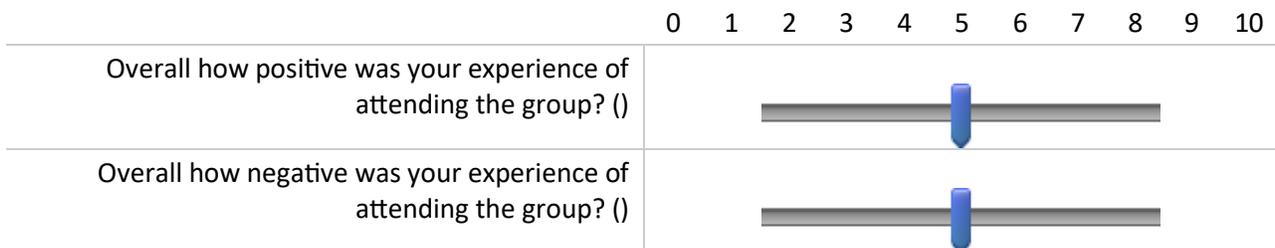
Q4.2 When you are in the group what happens?

	Agree (27)	neutral (28)	disagree (29)
I learn things about myself (1)	?	?	?
I feel that I don't always use the group as well as I want to (2)	?	?	?
I find it hard to talk about myself (3)	?	?	?
I find myself talking about my family (4)	?	?	?
I find it an encouraging space (5)	?	?	?

Q4.3 Please use this space to say more about the ED group that you attend, ensuring you respect confidentiality. For example: how is it run; and how many people usually attend; number of facilitators and their roles etc.

Q4.4 Please rate your overall experience of attending an ED self help group. The sliding scale is 0 to 10.

You need to move the slider.



Q5.1

Please rate the following statements about being in recovery. When I was or am in recovery...

If you have not been in recovery, then please go straight to the next question.

	agree (73)	neutral (74)	disagree (75)
It felt good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I could eat without feeling guilty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I could eat without having to exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't purge any more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I still think about what I have eaten, and what I can eat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q6 Please rate the following statements in relation to being a member of an Eating Disorders Self Help Group

[adapted from the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.]

	None of the time (20)	Rarely (21)	Some of the time (22)	Often (23)	All of the time (24)
I've been feeling optimistic about the future (6)	<input type="checkbox"/>				
I've had energy to spare (17)	<input type="checkbox"/>				
I've been feeling close to other people (14)	<input type="checkbox"/>				
I've been feeling confident (19)	<input type="checkbox"/>				

*Q5.2 People or things that support or have supported my recovery journey so far.*

Please tick all that apply.

Example of choices

The ED Self Help  
Group ED Self Help  
Book

Therapist e.g. Counsellor, Psychologist, Psychotherapist  
My friends

ED Charity e.g. BEAT, ABC etc

*Q7 Please use this space to tell me anything else that has not been covered in the survey.*

*Q8 Thank you for taking part in this survey. I appreciate the time you have taken to do so. Attached is a debrief sheet that you might wish to draw on if the survey has raised issues for you. [debrief sheet .pdf](#)*

#### Appendix 4.14: Consent Form for Studies Involving Human Participants (Study 3)

**This info will go on the online questionnaire before the participant commences the survey**

By completing this questionnaire, you are giving your consent and freely agree to take part in the study entitled:  
Adults with an ED who have never attended a Self Help Group and what matters in recovery  
UH Protocol number: xxxx

I confirm that I have read the Participant Information Sheet giving particulars of the study, including its aim and design, the names and contact details of key people and, as appropriate, the risks and potential benefits. I am also aware of how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on the questionnaire will be stored and for how long.

I know that I may withdraw from the study at any time.

I understand that my participation in this study may reveal findings that could indicate that I may require medical advice.

[Tick box to confirm consent]

## Appendix 4.15: Harms, Hazards and Risks: Assessment and Mitigation (Study 3)

Name of applicant: Susan Dixon

Date of assessment: 12/12/21

Title of Study/Activity: Adults with an ED who have never attended a Self Help Group and what matters in recovery

Activity Description					
5. IDENTIFY RISKS/HAZARDS	6. WHO COULD BE HARMED & HOW?		7. EVALUATE THE RISKS		8. ACTION NEEDED
<p><u>Activities/tasks and associated hazards</u> Describe the activities involved in the study and any associated risks/ hazards, both physical and <b>emotional</b> resulting from the study. Consider the risks to participants/the research team/members of the public.</p> <p>In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.)</p>	<p><u>Who is at risk?</u> e.g. <b>participants</b>, investigators, other people at the location, the owner / manager / workers at the location etc.</p>	<p><u>How could they be harmed?</u> What sort of accident could occur, eg trips, slips, falls, lifting equipment etc, handling chemical substances, use of invasive procedures and correct disposal of equipment etc. What type of injury is likely? <b>Could the study cause discomfort or distress of a mental or emotional character to participants and/or investigators? What is the nature of any discomfort or distress of a mental or emotional character that you might anticipate?</b></p>	<p><u>Are there any precautions currently in place to prevent the hazard or minimise adverse effects?</u> Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc/</p>	<p><u>Are there any risks that are not controlled or not adequately controlled?</u></p>	<p><u>List the action that needs to be taken to reduce/manage the risks arising from your study</u> for example, provision of medical support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects NOTE: medical or other aftercare and/or support <b>must</b> be made available for participants and/or investigator(s) who require it.</p>
<p>Questionnaire asking facilitators (who are the participants) about ED SHG they run</p>	<p>Participants</p>	<p>Talking about their ED history and what matters in recovery may cause you some distress and discomfort</p>	<p>Participants are informed of the nature of questions in the Information Sheet and of the possible feelings some people may experience. Participants can stop the questionnaire at any point. The questionnaire does not have to be completed in one go. Participants will be signposted to support services and their own professional support at the end of the questionnaire</p>	<p>None</p>	<p>No action needed beyond the precautions and information provided that are already indicated in Section 3.</p>

Signed by applicant: Susan Dixon

Dated  
29/11/21

General Information						
Name	Sue Dixon	Email address	Sd17acw@herts.ac.uk			
Contact number	07957 641 449					
Supervisor name (if student)	Dr Saskia Keville	Supervisor's e-mail address (if student)	s.keville@herts.ac.uk			
Supervisor's contact number						
Activity						
Title of activity	<p>Completion of a computer-based questionnaire and analysis of data for a study on There are 17 questions (most require you to tick which answer applies and there some which are require you to reflect briefly).            1-10 are demographic, consent questions and ED history            11-12 are about the types of support you have accessed            13 and 14 are about recovery            15 and 16 are about ED Self Help Groups            17 is for closing thoughts</p>					
Brief description of activity	<p>Completion of an online questionnaire in the respondent's (participant's) own location. Recruiting up to 200 participants also online and including analysis. Questionnaire content (not including demographics)</p>					
Location of activity	<p>College Lane, de Havilland Campus (described as such for the purposes of this type of study where the analysis of data takes place here)</p>					
Who will be taking part in this activity	<p>UH postgraduate students and staff. Members of the public who fit the brief as not having attended an ED SHG. The Research Team</p>					
Types of Hazards likely to be encountered						
<input type="checkbox"/> Computers and other display screen	<input type="checkbox"/> Falling objects	<input type="checkbox"/> Farm machinery			<input type="checkbox"/> Fire	
<input type="checkbox"/> Cuts	<input type="checkbox"/> Falls from heights	<input type="checkbox"/> Manual handling			<input type="checkbox"/> Hot or cold extremes	
<input type="checkbox"/> Repetitive handling	<input type="checkbox"/> Severe weather	<input type="checkbox"/> Slips/trips/falls			<input type="checkbox"/> Stress	
<input type="checkbox"/> Travel	<input type="checkbox"/> Vehicles	<input type="checkbox"/> Aggressive response, physical or verbal			<input type="checkbox"/> Workshop machinery	
Risk Control Measures						
<p>List the activities in the order in which they occur, indicating your perception of the risks associated with each one and the probability of occurrence, together with the relevant safety measures. Describe the activities involved.            Consider the risks to participants, research team, security, maintenance, members of the public – is there anyone else who could be harmed?            In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.</p>						
<b>Identify hazards</b>	<b>Who could be harmed?</b> <i>e.g. participants, research team, security, maintenance, members of the public, other people at the location, the owner / manager / workers at the location etc.</i>	<b>How could they be harmed?</b>	<b>Control Measures – what precautions are currently in place?</b> <i>Are there standard operating procedures or rules for the premises. Are there any other local codes of practice/local rules which you are following, eg Local Rules for the SHE</i>	<b>What is the residual level of risk after the control measures have been put into place?</b> <i>Low Medium or High</i>	<b>Are there any risks that are not controlled or not adequately controlled?</b>	<b>Is more action needed to reduce/manage the risk?</b> <i>for example, provision of support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects</i>

			<i>labs? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc</i>			
Use of computers	Researcher and participants	Eye strain and upper limb disorder	<i>LMS Health and Safety Policy</i>	Low	No	No
Stress	Participant	Unpleasant feelings and/or memories	<i>LMS Health and Safety Policy</i>	Low	No	Information on sources of support are provided before and after completing the online questionnaire
List any other documents relevant to this application		<i>Include Standard Operating Procedures, local rules and so on.          BPS Code of Ethics and Conduct (2009)          BPS Code of Human Research Ethics (2014)          LMS Health and Safety Policy</i>				
<b>Signatures</b>						
Assessor name	Susan Dixon	Assessor signature	<i>Susan Dixon</i>	Date	12/12/2021	
Supervisor, if Assessor is a student	Dr Saskia Keville	Supervisor signature	<i>SK</i>		20/01/22	
Local Health and Safety Advisor Lab Manager	Jon Gillard	Local Health and Safety Advisor/ Lab Manager signature	<i>J.G.</i>		21/01/2022	

Ref No	
Date	
Review Date	
	<b>OFFICE USE ONLY</b>

**Life and Medical Sciences Risk Assessment**

*The completion of this is an integral part of the preparation for your work, it is not just a form to be completed, but is designed to alert you to potential hazards so you can identify the measures you will need to put into place to control them. You will need a copy on you when you carry out your work*

## Appendix 4.16: Participant Information Sheet (Study 3)

### 1. Title of study

Adults with an ED who have never attended a Self Help Group and what matters in recovery

### 2. Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

<https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs>

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

### 3. What is the purpose of this study?

My name is Sue Dixon; I am a long-established co facilitator and Group Contact of an Eating Disorders (ED) Self Help Support Group (SHG) in London that supports adults with an ED that I have been linked with for 25 years. I am also a practising MBACP (accredited) counsellor/psychotherapist who has a special interest in ED. As part of my ongoing research and professional development within my field I am currently studying part time as a PhD student at the University of Hertfordshire. I am interested in researching the topic of EDs.

Within my studies portfolio I have been involved with interviewing a selection of people who had attended an ED SHG to establish how they experienced such groups, and how it supported their recovery. The subsequent study, which is still operational concerns identifying from a larger sample of people what their experience of ED SHGs are.

To develop my research to the next stage to gain a perspective from the voice of the people who have never experienced attending an ED SHG and why. I am looking for participants to engage in an online questionnaire.

### 4. Do I have to take part?

It is completely up to you whether you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

### 5. Are there any age or other restrictions that may prevent me from participating?

Yes. You must be over 18 and be someone who has or had an ED who has never attended an ED SHG.

### 6. How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for *10-15 minutes*.

### 7. What will happen to me if I take part?

Initially you will be asked to give consent by ticking the relevant boxes, confirming you are over 18 and have been involved in facilitating an ED SHG before you are able to proceed fully with the questionnaire. You will then be taken through a series of questions that cover a range of topics.

There are **17 questions** (most require you to tick which answer applies and there some which are require you to reflect briefly).

There are questions:

- concerning demographics, consent and ED history.
- about the types of support you have accessed and recovery
- exploring why you have not attended ED Self Help Groups.

There is space for you to add any additional comments.

**8. What are the possible disadvantages, risks or side effects of taking part?**

There is a possibility that aspects of the questionnaire may cause some distress and discomfort by triggering experiences related to lived ED (past or present).

**9 What are the possible benefits of taking part?**

There will be an opportunity to add to a national picture about what informal support people with an ED access or would benefit from.

**How will my taking part in this study be kept confidential?**

You are not required to give your name. The data that are collected from the questionnaire are anonymised.

**10 What will happen to the data collected within this study?**

The data will be anonymised prior to storage.

**11 Will the data be required for use in further studies?**

- The data collected may be re-used or subjected to further analysis as part of a future ethically-approved study; the data to be re-used will be anonymised.
- The results of the study and/or the data collected (in anonymised form) may be deposited in an open access repository.

**12 Who has reviewed this study?**

This study has been reviewed by The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is **xxxxxx**

**13. Factors that might put others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

**14. Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email: Sue Dixon [sd17acw@herts.ac.uk](mailto:sd17acw@herts.ac.uk) or [REDACTED]  
You can also contact my supervisor Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)).

**Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:**

Secretary and Registrar  
University of Hertfordshire  
College Lane  
Hatfield  
Herts  
A10 9AB

## Appendix 4.17: Participant Information Debrief Sheet (Study 3)

**Title of study: Adults with an ED who have never attended a Self Help Group and what matters in recovery**

Thank you once again for taking the time to participate in this study.

If any part of the survey has raised difficult issues for you, you can access additional support via the Samaritans (116 123 or [jo@samaritans.org.uk](mailto:jo@samaritans.org.uk)) OR BEAT (0808 801 0677 <https://www.beateatingdisorders.org.uk/>) OR you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

If there is anything you think of later that you would like to share with me then please do get in touch by email: Sue Dixon ([sd17acw@herts.ac.uk](mailto:sd17acw@herts.ac.uk)). You can also contact my supervisor: Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)).

Finally, I want to reiterate that your personal details will be kept confidential, and all data will be anonymised.

Sue

## Appendix 4.18 Extracts from Qualtrics Questionnaire (Study 3)

### Adults with an ED who have never attended a Self Help Group and what matters in recovery

#### Q1 SUMMARY

Thank you very much for taking time to engage with this research. By completing this questionnaire, you are giving your consent and freely agree to take part in the study entitled: 'Adults with an ED who have never attended a Self Help Group and what matters in recovery'

UH Protocol number: xxxx

There are **17 questions** (most require you to tick which answer applies and there some which are require you to reflect briefly).

There are questions:  
concerning demographics,  
consent and ED history.  
about the types of support you have accessed and recovery  
exploring why you have not attended ED Self Help Groups.

There is space for you to add any additional comments.

The average time to complete this survey is about 10 minutes. Thank you for your participation.

[Participant information sheet not attended ed shg](#)

#### Q2 Participant information sheet

I confirm that I have read the Participant Information Sheet giving particulars of the study, including its aim and design, the names and contact details of key people and, as appropriate, the risks and potential benefits. I am also aware of how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on the questionnaire will be stored and for how long. (18)

#### Q3 Right to withdraw

I know that I may withdraw from the study at any time. (1)

#### Q4 Awareness of the possible impact of taking part in this study

I understand that my participation in this study may reveal findings that could indicate that I may

require medical advice. (1)

Q5 Confirmation of meeting age requirement

yes I am over 18 (1)

No I am not over 18 (4)

Q6 Confirmation that I am someone who has never attended a Self Help Group for adults with an Eating Disorder.

yes (1)

No (4)

Q7 Age

Q8 What is your gender?

Q9 What is your ethnic group? Please tick the one that applies.

Q10 What type of ED and/or related problems have you had or have? Please tick all that apply.

Anorexia (purging type) (1)

Anorexia (restrictive type) (3)

Bulimia (5)

Binge Eating Disorder (6)

Emotional regulation (13)

Perfectionism (14)

Q11 Where do you access informal support (please tick all that apply)

Instagram (1)

Facebook (2)

Self Help Books (5)

ED Charity e.g. Beat, ABC (Please specify) (7)

Family e.g. parent(s), Carer(s), sibling(s) etc. (10)

Partner e.g. husband, wife etc. (11)

Employer (12)

Q12 What professional support have you had or are having? Please tick all that apply.

GP (1)

Counsellor (2)

Psychotherapist (3)

Psychologist (4)

ED inpatient treatment. Please say a little more if you wish to below. (9)

---

ED outpatient treatment. Please say a little more if you wish to below. (11)

---

I am on a waiting list for specialist ED treatment. How long have you been waiting? Please say a little more below (12)

**Q 13 Please rate the following statements about being in recovery. When I am in recovery/when I was in recovery**

	agree (73)	neutral (74)	disagree (75)	N/A (76)
I feel/felt excited (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It feels/felt good (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
it feels/felt like coming back to life again (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can/could eat without having to exercise (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
it is/was nice being able to eat without having to worry (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can/could see that my ED was holding me back (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am not 100% recovered; I still have a lot of obsessive traits (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do purge/I did purge (18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I still think about what I can eat/ I thought about what I had eaten or could eat (19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do record calories/ I did record calories (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do record my weight/did record my weight (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q14 Please use this space to share any further thoughts about recovery

Q15 Why have you never attended an ED Self Help Group?

- I have never heard of them (1)
- I was worried that there would not be anyone there like me (2)
- I am worried that I would be the biggest person there (3)
- I am worried that I would be too thin to attend (4)

I am worried that I am not sick enough to attend (5)

I am not sure what happens there (6)

I do not know where to find them (7)

Q16 Would you consider attending an ED Self Help Group if you had sufficient information? Please use this space to share your thoughts.

Q17 Thank you for participating. I am very grateful. Attached is a debrief sheet should you need further support as a result of participating. Please use this space to share anything that you feel has not been covered in the survey.

[Debrief sheet not attended an ed shg](#)

## Appendix 4.19: Participant Information Sheet (Study 4)

### 1 Title of study

What matters in recovery: Exploring facilitators' perspectives of eating disorders self-help groups

### 2 Introduction

As part of my PhD qualification (doctoral thesis), I am conducting a piece of research with a team of interviewers at the University of Hertfordshire, finding out more about people who have facilitated an Eating Disorders (ED) Self Help Group (SHG). I am looking for facilitators of ED SHGs to participate in this study through completing interviews. This research is important to help us understand the types of groups that exist and who runs them. I am a long-established voluntary co facilitator and Group Contact of an ED SHG that supports adults with an ED that I have been linked with for 25 years.

Thank you very much for taking time to engage with this research.

#### **Please take time to read the Participant Information before you continue with this survey.**

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link: <https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs> (after accessing this website, scroll down to Letter S where you will find the regulation).

### 3. *Do I have to take part?*

It is completely up to you whether you decide to take part in this study. If you do decide to take part, you will be given this information sheet and asked to read and sign a consent form. Agreeing to join the study does not mean that you must complete it. You are free to withdraw at any stage.

### 4. *Are there any age or other restrictions that may prevent me from participating?*

Yes. You must be over 18 and be facilitating/or have facilitated an ED SHG.

### 5. *How long will my part in the study take?*

If you decide to take part in this study, the interviews will last around 45-60 minutes. These interviews can take place via an online platform such as zoom, or if you prefer, face to face, in a confidential environment.

### 6. *What will happen if I take part?*

Initially you will be asked to give consent by reading this information, confirming you are over 18 and have been involved in facilitating an ED SHG before you are able to proceed with the interview. We will supply a consent form, which you need to sign and send back electronically, or email us confirming your consent for the interview to proceed. We will then organise an interview where you will then be taken through a series of questions that cover a range of topics about your experiences of facilitating a self help group, and experiences of eating disorders. The interviews will be semi structured allowing you to elaborate and tell your story in your own words. You will then be

given a debrief form informing you again of the purpose of the study and any contact details you may need.

**7. What are the possible disadvantages, risks or side effects of taking part?**

Due to the nature of the interview, you may find some of your responses may be emotionally upsetting. For example, if relevant, there is a possibility that aspects of the interview may cause some distress and discomfort by triggering experiences related to lived ED experience (past or present). However, care has been taken to reduce this as much as possible. If, however, you do feel your participation has impacted your wellbeing, the participant debrief form is designed to help guide you towards additional support or advice. This will be given at the end of the interview.

**8. What are the possible benefits of taking part?**

There will be an opportunity to add to our understanding of ED SHGs and give voice to the work of facilitators, providing recognition for this.

**9. How will my taking part in this study be kept confidential?**

Only basic contact and demographic data will be kept for the purpose of the study. This will include your contact details, and length of time you have been a SHG facilitator. Any data will be kept in a password protected document. After the study has been completed, reports written and/or the student published, personal data will be deleted. Recordings of the interviews will be taken using for example, Zoom, interviews will be downloaded and saved the same day the interview has taken place and will be filed with simply a participant number e.g. 'Participant A' within a password protected document. Once transcribed, the interview recordings will be deleted to ensure anonymity. Verbal consent for the interview occurs by continuing into the interview, however, a copy of the consent form will be provided which can be signed and returned electronically or consent confirmed in an email. Your consent will be stored in a password protected document and will also be deleted following the write up of the study. Only the interview or principal researcher and the supervisory team will have access to any of these documents listed above.

**10. Audio-visual material**

This study will involve the use of an audio-visual recording. Your participation in this study will be recorded using a screen-recording tool, to allow for the later transcription of your data. You can choose to have the camera on or off during the interview and only an audio recording will be made. These recordings will be held on a password-protected device, and will only be accessible to the interviewer, principal researcher and the supervisor. The recordings will be saved under a pseudonym, and therefore your personal information will not be associated with them. Following the transcription of your data, the recording will be deleted.

**11. What will happen to the data collected within this study?**

Interviews will be downloaded and saved the same day as the interview has taken place and will be titled with a participant number/letter or pseudonym. They will then be transcribed and analysed by the research team. The original recordings will be deleted after being transcribed and the study completed. Once analysis is complete maintaining your anonymity it will be presented in a research report and may be presented or published.

**12. Will the data be required for use in further studies?**

The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymised. You may also be contacted about future relevant studies.

**13. Who can I contact if I have any questions?** If you would like further information or would like to discuss any details personally, please get in touch with the principal researcher by email: Sue Dixon [s.j.dixon@herts.ac.uk](mailto:s.j.dixon@herts.ac.uk) or you can also contact my supervisor Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)).

**14. Who has reviewed this study?**

This study has been reviewed by The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority, Ethical Protocol Number: xxxxxxx

#### 15. Factors that might put others at risk

Please note that if, during the study, any medical conditions, or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

**Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:**

Secretary and Registrar  
University of Hertfordshire  
College Lane  
Hatfield  
Herts  
AL10 9AB

**Thank you very much for reading this information and giving consideration to taking part in this study.**

#### [Appendix 4.20: Consent Form \(Study 4\)](#)

By completing this questionnaire, you are giving your consent and freely agree to take part in the study entitled:  
What matters in recovery: *Exploring facilitators' perspectives of eating disorders self-help groups*

UH Protocol number: xxxx

I confirm that I have read the Participant Information giving particulars of the study, including its aim and design, the names and contact details of key people and, as appropriate, the risks and potential benefits. I am also aware of how the information collected will be stored and for how long, plans for publication, and plans for follow-up studies that might involve use of the data or further approaches to participants. I have also been informed of how my personal information on the questionnaire will be stored and for how long.

I know that I may withdraw from the study at any time.

I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

I understand I will be given a debrief sheet following the interview, which will include information on who to contact if I need further support.

I understand that by proceeding into the interview, I am offering my verbal consent for the interview to progress.

Signature of participant.....Date.....

Signature of (principal) investigator.....Date.....

Name of (principal) investigator **xxx**

.....

#### Appendix 4.21: interview schedule potential example questions (Study 4)

1. Can you tell me about your experience of facilitating an eating disorder self help group?
2. Can you describe the reasons why you facilitate this group?
3. What are the helpful and difficult aspects for you about facilitating a group? (prompts: training and professional knowledge; resonance with personal experience; logistics)
4. What eating issues do members of the group talk about and explore in your group?
5. What other issues do members of the group talk about and how do you manage these?
6. What has your experience been around managing emotional experiences within group members? (prompts: sadness, anger, anxiety)
7. What has your experience been around managing conflict and arguments between group members? (prompts: specific examples)
8. What are your best tips around providing support for members around their eating or other issues?
9. What has been your own personal experience of eating disorders over your life?
10. What impacts does facilitating a group have on your own life?
11. How did you find facilitating the group during the experience of lockdown during the COVID-19 pandemic? (prompts: online v face to face; attendance; )

#### Appendix 4.22: Participant Debrief Sheet (Study 4)

**Title of study:** What matters in recovery: *Exploring facilitators' perspectives of eating disorders self-help groups*

Thank you once again for taking the time to participate in this study. We hope this data can build an evidence base for the work of SHG and the valuable role of facilitators in supporting people with an ED in their recovery.

If any part of the survey has raised difficult issues for you, you can access additional support via the Samaritans (116 123 or [jo@samaritans.org.uk](mailto:jo@samaritans.org.uk)) OR BEAT (0808 801 0677 <https://www.beateatingdisorders.org.uk/>) OR you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

If there is anything you think of later that you would like to share with me then please do get in touch by email: Sue Dixon ([sd17acw@herts.ac.uk](mailto:sd17acw@herts.ac.uk)). You can also contact my supervisor: Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk))  
Finally, I want to reiterate that your personal details will be kept confidential, and all data will be anonymised.

## Appendix 4.23: LMS Risk Assessment Form (Study 4)

### SCHOOL OF LIFE AND MEDICAL SCIENCES

Ref No	
Date	
Review Date	
	<b>OFFICE USE ONLY</b>

#### Risk Assessment

*The completion of this is an integral part of the preparation for your work, it is not just a form to be completed, but is designed to alert you to potential hazards so you can identify the measures you will need to put into place to control them. You will need a copy on you when you carry out your work*

General Information			
Name	Sue Dixon	Email address	<a href="mailto:S.j.dixon@herts.ac.uk">S.j.dixon@herts.ac.uk</a>
Contact number	07957 641 449		
Supervisor name (if student)	Dr Saskia Keville	Supervisor's e-mail address (if student)	<a href="mailto:s.keville@herts.ac.uk">s.keville@herts.ac.uk</a>
Supervisor's contact number	x4232		
Activity			
Title of activity		Exploring facilitators' perspectives of eating disorders self-help groups and what matters in recovery	
Brief description of activity		<p><i>The proposed study will use interviews to explore facilitators experiences of eating disorder self help groups - the study will recruit 6-8 participants and will consist of a semi-structured interview taking place via an online video-calling platform, such as Zoom or Skype, or over the telephone, there is a small likelihood they may also take place face to face if this is the participants preference; if this is the case, they will occur in a private location (e.g. at the participants home). Loan Working guidelines will be implemented with the Research Team made aware of appointment times and location, and informed when the interview is completed and the interviewer has left the premises.</i></p>	

Location of activity		This is an online study that will take place via zoom; participants will be able to choose a private location, e.g. their home. <b>There is a small possibility interviews may be face to face where lone working guidelines will be followed (see above)</b>				
Who will be taking part in this activity		<i>UH postgraduate students and staff. Members of the public (volunteers and professionals) who fit the brief as being a facilitator of an ED SHG. Sue Dixon is the primary researcher; Nick Troop, Keith Sullivan and Saskia Keville are supervisors. Students on the MSc Research in Clinical Psychology will be interviewers under the guidance of Saskia Keville.</i>				
<b>Types of Hazards likely to be encountered</b>						
<input type="checkbox"/> Computers and other display screen	<input type="checkbox"/> Falling objects	<input type="checkbox"/> Farm machinery		<input type="checkbox"/> Fire		
<input type="checkbox"/> Cuts	<input type="checkbox"/> Falls from heights	<input type="checkbox"/> Manual handling		<input type="checkbox"/> Hot or cold extremes		
<input type="checkbox"/> Repetitive handling	<input type="checkbox"/> Severe weather	<input type="checkbox"/> Slips/trips/falls		<input type="checkbox"/> Stress		
<input type="checkbox"/> Travel	<input type="checkbox"/> Vehicles	<input type="checkbox"/> Aggressive response, physical or verbal		<input type="checkbox"/> Workshop machinery		
<b>Risk Control Measures</b>						
<p><i>List the activities in the order in which they occur, indicating your perception of the risks associated with each one and the probability of occurrence, together with the relevant safety measures.</i></p> <p><i>Describe the activities involved.</i></p> <p><i>Consider the risks to participants, research team, security, maintenance, members of the public – is there anyone else who could be harmed?</i></p> <p><i>In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.</i></p>						
<b>Identify hazards</b>	<b>Who could be harmed?</b> <i>e.g. participants, research team, security, maintenance, members of the public, other people at the location, the owner / manager / workers at the location etc.</i>	<b>How could they be harmed?</b>	<b>Control Measures – what precautions are currently in place?</b> <i>Are there standard operating procedures or rules for the premises. Are there any other local codes of practice/local rules which you are following, eg Local Rules for the SHE labs? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc</i>	<b>What is the residual level of risk after the control measures have been put into place?</b> <i>Low Medium or High</i>	<b>Are there any risks that are not controlled or not adequately controlled ?</b>	<b>Is more action needed to reduce/manage the risk?</b> <i>for example, provision of support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects</i>
Stress	Participants	Stress from use of computers.	Demographic questionnaire will be used, and participants reminded of the right to	Medium		Support information

		Stress resulting from talking about their experiences of facilitating and ED SHG	withdraw at any time. LMS Health and Safety Code of Practice will be followed. Signposting to additional support Information provided in the EC1 and Debrief sheets.  <a href="#">UH Stress Management Guidance</a>			Supervisor's contact details – who is a clinical psychologist
Computers and other display screens	Investigators and participants	Eye strain from screen use. Upper Limb disorder from use of computers.	LMS Health and Safety Code of Practice  <a href="#">UH DSE Guidelines</a>	Low	No	Information on sources of support are provided before and after completing the interviews
Risk of COVID -19 if face to face interviews occur	Investigator and participants	Contracting or passing on covid19	<b>Latest Update (19 October 2022):</b> Although face-to-face research can now go ahead, please note that in line with <a href="#">University guidance on COVID-19</a> – applications involving face-to-face contact should still be accompanied by a risk assessment showing how Covid-19 risks to the researcher and participants will be managed (Form EC5 or a school specific risk assessment form).	Medium	No	Use of face masks and hand gel
List any other documents relevant to this application			<p><i>Include Standard Operating Procedures, local rules and so on.</i></p> <p><i>BPS Code of Ethics and Conduct (2009)</i></p> <p><i>BPS Code of Human Research Ethics (2014)</i></p> <p><i>LMS Health and Safety Policy</i></p>			
<b>Signatures</b>						
Assessor name	Susan Dixon	Assessor signature	<i>Susan Dixon</i>	Date	19/10/2022	
Supervisor, if Assessor is a student	Dr Saskia Keville	Supervisor signature			19/10/2022	
Local Health and Safety Advisor Lab Manager	Jon Gillard	Local Health and Safety Advisor/ Lab Manager signature			28/10/2022	

## Appendix 4.24: Participant Consent Form (Study 5)

Q2

Participant information sheet

I confirm that I have read the Participant Information giving particulars of the study, including its aim and design, the names and contact details of key people and, as appropriate, the risks and potential benefits. I am also aware of how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on the questionnaire will be stored and for how long.

Q3 Right to withdraw

I know that I may withdraw from the study at any time.

Q4 Awareness of the possible impact of taking part in this study

I understand that my participation in this study may reveal findings that could indicate that I may require medical advice.

Q5 Confirmation of meeting age requirement

Yes, I am over 18

No I am not over 18

If they tick no I am not over 18 an error message will appear saying that they are not eligible to participate.

## Appendix 4.25: EC5 Harms, hazards, and risks: assessment and mitigation (study 5)

Name of applicant: Susan Dixon

Date of assessment: 15/04/2024

Title of Study/Activity: Evaluating the impact of the Central London Eating Disorders Self Help Group for Adults and what matters in recovery.

Activity Description		Completion of an online survey.			
1. IDENTIFY RISKS/HAZARDS	2. WHO COULD BE HARMED & HOW?	3. EVALUATE THE RISKS		4. ACTION NEEDED	
<p><u>Activities/tasks and associated hazards</u> Describe the activities involved in the study and any associated risks/ hazards, both physical and emotional, resulting from the study. Consider the risks to participants/the research team/members of the public.</p> <p>In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.)</p>	<p><u>Who is at risk?</u> e.g. participants, investigators, other people at the location, the owner / manager / workers at the location etc.</p>	<p><u>How could they be harmed?</u> What sort of accident could occur, eg trips, slips, falls, lifting equipment etc, handling chemical substances, use of invasive procedures and correct disposal of equipment etc. What type of injury is likely? Could the study cause discomfort or distress of a mental or emotional character to participants and/or investigators? What is the nature of any discomfort or distress of a mental or emotional character that you might anticipate?</p>	<p><u>Are there any precautions currently in place to prevent the hazard or minimise adverse effects?</u> Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc/</p>	<p><u>Are there any risks that are not controlled or not adequately controlled?</u></p>	<p><u>List the action that needs to be taken to reduce/manage the risks arising from your study</u> for example, provision of medical support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects NOTE: medical or other aftercare and/or support <b>must</b> be made available for participants and/or investigator(s) who require it.</p>
Use of computers	Participants and investigator	Eye strain and upper limb disorder	n/a	no	none
Stress	Participants	Unpleasant feelings and/or memories	n/a	no	Information on sources of support is provided before and after completing the online survey.
Signed by applicant: <i>Susan Dixon</i>				Dated: 15/04/24	

## Appendix 4.26: Qualtrics Questionnaire with Form with Participant Info Sheet (embedded within it) (Study 5)

### Q1 SUMMARY

I am conducting a piece of research finding out more about your experience of the Central London Group and your experiences of recovery. The research is important to better understand the value that Eating Disorder (ED) Self Help Groups bring, and how they can support the recovery of those who attend. It is an anonymous online questionnaire which should take no longer than 10 to 15 minutes to complete.

Thank you very much for taking time to engage with this research. By completing this online survey, you are giving your consent and freely agree to take part in the study entitled: Evaluating the impact of the Central London Eating Disorders Self Help Group for Adults and what matters in recovery. Please take time to read the Participant Information before you continue with this survey. You are being invited to take part in a study.

Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:<https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs> (after accessing this website, scroll down to Letter S where you will find the regulation)

### **Do I have to take part?**

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

### **Are there any age or other restrictions that may prevent me from participating?**

You must be over the age of 18 and be someone who has or is attending the Central London Eating Disorders Self Help Group.

### **What will happen if I take part?**

Initially you will be asked to give consent by reading this information, confirming you are over 18. You will be asked if you attend the Central London Self Help Group, or have done so in the past. You will then be taken through a series of questions that cover a range of topics.

There are 20 questions (most require you to tick which answer applies and there are some which require you to reflect briefly).

1-9: demographic and consent questions

10-11: your ED history and access to professional support

12-16: Your experiences of the Central London Group

17-19 Wellbeing and Recovery

20 Opportunities for any further reflection

There is a debrief sheet.

The average time to complete this survey is about 10 to 15 minutes.

### **What are the possible disadvantages, risks or side effects of taking part?**

If relevant, there is a possibility that aspects of the questionnaire may cause some distress and discomfort by triggering experiences related to lived ED experience (past or present).

### **What are the possible benefits of taking part?**

There will be an opportunity to add to a national picture about Eating Disorder Self Help Groups and the value they bring for people with an ED in their recovery journeys.

### **How will my taking part in this study be kept confidential?**

You are not required to give your name. The data collected from the survey are anonymised, and information aggregated.

### **Will the data be required for use in further studies?**

The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymised. The results of the study and/or the data collected (in anonymised and aggregated form) may be deposited in an open access repository.

**Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me by email: Sue Dixon s.j.dixon@herts.ac.uk or you can also contact my supervisor Dr Saskia Keville (s.keville@herts.ac.uk).

**Who has reviewed this study?**

This study has been reviewed by The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority, Ethical **Protocol Number: xxxxxx**

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address: Secretary and Registrar, University of Hertfordshire, College Lane, Hatfield, Herts AL10 9AB

Q2 Participant information sheet

I confirm that I have read the Participant Information giving particulars of the study, including its aim and design, the names and contact details of key people and, as appropriate, the risks and potential benefits. I am also aware of how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on the questionnaire will be stored and for how long. (18)

Q3 Right to withdraw

I know that I may withdraw from the study at any time. (1)

Q4 Awareness of the possible impact of taking part in this study

I understand that my participation in this study may reveal findings that could indicate that I may require medical advice. (1)

Q5 Confirmation of meeting age requirement

Yes, I am over 18 (5)

No, I am over 18 (1)

Q6 Please confirm

I am someone who has attended or is attending the Central London Self Help Group for adults (1)

Q7 Age

18 to 24 (21)

25 to 34 (22)

35 to 44 (23)

45 to 54 (24)

over 55 (25)

**Q8 What is your gender?**

- Male (1)
- Female (2)
- I would prefer to describe my gender myself. Please state in the box below if you wish to do so. (3)
- prefer not to say (4)

**Q9 What is your ethnic group? Please select from the dropdown menu.**

▼ White English/Welsh/Scottish/Northern Irish/British (1) ... Prefer not to say (26)

**Q10 What type of ED have you had or currently have? Please tick all that apply.**

- Anorexia (purging type) (1)
- Anorexia (restrictive type) (3)
- Anorexia (long term) (4)
- Bulimia (5)
- Binge Eating Disorder (6)
- Obesity (7)
- Osfed/Ufed (8)
- No formal diagnosis (9)
- Other (please specify) (18)
- Prefer not to say (19)

**Q11 What professional support have you had or are currently having for your ED? Please tick all that apply.**

- GP (1)
- Specialist ED therapy. Please say a little more below. (6)
- non ED therapy (2)
- Dietician (7)
- ED inpatient treatment. Please say a little more if you wish to below. (9)
- ED outpatient treatment. Please say a little more if you wish to below. (11)
- I am on a waiting list for specialist ED treatment. How long have you been waiting? Please say a little

more below (12)

Other. Please say a little more. (4)

Q12 Approximately how long ago did you first start attending the Central London Group

▼ less than 6 months (1) ... other (please say more) (5)

Q13 Which of the following have you taken part in? Please tick the one that applies.  
text.

In person face to face group (1)

online ZOOM (2)

both in person and online (3)

Q14 Please think back to when you first started attending the Group. Why did you decide to start attending the group. Please tick all that apply.

A professional such as a nurse, doctor, therapist etc. suggested it. (1)

My friends/family or partner suggested it. (2)

My treatment ended and I decided that I needed more support (3)

There was a long wait for treatment and I needed more support (4)

I was put on a waiting list (5)

I was waiting for treatment after an assessment (6)

I was getting panicky about my ED (7)

Things are/were spiralling out of control (8)

I was using my food more to deal with my emotions (9)

I was told that I was not ill enough by a specialist ED service to receive help (10)

I had attended other support groups and found them useful (11)

I was thinking about starting my recovery (12)

I was ready to start recovery (13)

Other. Please use the box below to say more. (14)

---

Q15 Please rate the following statements.

	Strongly agree (30)	Agree (31)	Neither agree nor disagree (33)	Disagree (34)	Strongly Disagree (35)	Does not apply (36)
I felt excited at starting the process of attending the group. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The group sometimes raises uncomfortable feelings for me when I am there. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I sometimes feel impacted by what others share in the group. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The group creates opportunities for me to learn from others. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have become more open to talking and sharing with others in the Group. (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have become more self aware as a result of participating the group. (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
As a result of participating in the Group I feel more self motivated. (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel less isolated since attending the Group. (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participation in the Group has led to me seeking professional support. (24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Participation in the Group has helped alongside my professional help. (25)

Q16 Is there anything else you would like to tell us about your experiences of the Group (such as any good experiences or any improvements)?

Q17 Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each **over the last 2 weeks**.

[questions taken from the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.]

	none of the time (1)	rarely (2)	some of the time (3)	often (4)	all of the time (5)
I've been feeling optimistic about the future (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling useful (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling relaxed (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been dealing with problems well (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been thinking clearly (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling close to other people (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been able to make up my own mind about things (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q18 Below are some statements about feelings and thoughts. **How would you have answered these questions BEFORE you started attending the group?** Please tick the box that best describes your experience.

[questions taken from the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.]

	none of the time (1)	rarely (2)	some of the time (3)	often (4)	all of the time (5)
I've been feeling optimistic about the future (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling useful (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling relaxed (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been dealing with problems well (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been thinking clearly (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling close to other people (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been able to make up my own mind about things (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q19 Please rate the following statements.

	Strongly agree (30)	Agree (31)	Neither agree nor disagree (33)	Disagree (34)	Strongly Disagree (35)	Does not apply (36)
The Group creates/ has created opportunities for self reflection on my own recovery progress (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participation in the Group has helped me/ helped me recognise that I need/needed support with my recovery. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Since attending the group, I have felt hopeful and optimistic about my recovery (3)

I have started/started to engage more actively in my recovery as a result of participating in the Group. (4)

The Group creates/ has created a space for me to learn strategies for how to manage recovery relapses. (20)

Seeing other people at different stages of recovery has helped me with my own recovery. (29)

The group has helped me to stay on track with my recovery once I was discharged from an ED service or specialist. (21)

Q20 Please feel free to use this space to add any further comments about how the Group helps / has helped you with your recovery.

End of Survey

Thank you for taking the time to complete this survey. I appreciate this.

Below is a debrief sheet which contains information about sources of support you can draw on if the survey has raised any uncomfortable feelings.

Thank you

Sue Dixon

s.j.dixon@herts.ac.uk

University of Hertfordshire

debrief sheet central london study april 2024 .docx

#### 4.27: Participant Debrief Sheet (Study 5)

**Title of study:** Evaluating the impact of the Central London Eating Disorders Self Help Group for Adults and what matters in recovery.

Thank you once again for taking the time to participate in this study.

If any part of the survey has raised difficult issues for you, you can access additional support via the Samaritans (116 123 or [jo@samaritans.org.uk](mailto:jo@samaritans.org.uk)) OR BEAT (0808 801 0677 <https://www.beateatingdisorders.org.uk/>) OR you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

If there is anything you think of later that you would like to share with me then please do get in touch by email: Sue Dixon ([s.j.dixon@herts.ac.uk](mailto:s.j.dixon@herts.ac.uk)). You can also contact my supervisor: or Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)).

Finally, I want to reiterate that your personal details will be kept confidential, and all data will be anonymised.

Sue

#### 4.28: Invitation email to participants (Study 5)

Dear All

I am currently partway through my PhD qualification (doctoral thesis) at the University of Hertfordshire. As part of my studies. I am conducting a piece of research finding out more about your experience of the Central London Group and your experiences of recovery.

The research is important to better understand the value that Eating Disorder Self Help Groups bring, and how they can support the recovery of those who attend. It is an anonymous online questionnaire which should take no longer than 10 to 15 minutes to complete.

The link below will take you to an online platform which provides fuller details about the research.

**Insert anonymous link to survey.**

Thank you very much for taking the time to read this email.

Best wishes  
Sue Dixon

*This study is approved by the University of Hertfordshire Health, Science, Engineering & Technology ECDA. Ethical Protocol Number: xxxxxxxx*

#### 4.29: Consent from Co-facilitators of the Central London Group (S

**From** [REDACTED] <[REDACTED]>

**Sent:** Friday, April 26, 2024 4:34 PM

**To:** Susan Dixon [Student-LMS] <[s.j.dixon@herts.ac.uk](mailto:s.j.dixon@herts.ac.uk)>

**Subject:** Re: permission to send out a questionnaire to members of the Central London Group

Hello Sue,

Thanks for your email requesting permission to contact group members. I do not have any problems whatsoever for you to go ahead with this process and I want to take this opportunity to wish you all the best with carrying out this valuable study you are trying to complete.

Best wishes,

██████████  
Sent from my iPhone

On 26 Apr 2024, at 15:02, Susan Dixon [Student-LMS] [s.j.dixon@herts.ac.uk](mailto:s.j.dixon@herts.ac.uk) wrote:

Dear All

I am writing to you as my fellow co facilitators of the Central London Group.

As you know I am doing my PhD. I am seeking your permission to contact group members about a study I am carrying out. I have included the email that I wish to you use.

*Dear All*

*I am currently partway through my PhD qualification (doctoral thesis) at the University of Hertfordshire. As part of my studies. I am conducting a piece of research finding out more about your experience of the Central London Group and your experiences of recovery.*

*The research is important to better understand the value that Eating Disorder Self Help Groups bring, and how they can support the recovery of those who attend. It is an anonymous online questionnaire which should take no longer than 10 to 15 minutes to complete.*

*The link below will take you to an online platform which provides fuller details about the research.*  
[Insert anonymous link to survey.](#)

*Thank you very much for taking the time to read this email.*

*Best wishes*  
*Sue Dixon*

*This study is approved by the University of Hertfordshire Health, Science, Engineering & Technology ECDA. Ethical Protocol Number: [xxxxxxx](#)*

Please let me know if you are happy for me to do so by return email. I need to provide evidence of your agreement with my ethics application.

Best  
Sue

## 4.29: Harms, Hazards and Risks: Assessment and Mitigation (Study 5)

Name of applicant: Susan Dixon

Date of assessment: 15/04/2024

Title of Study/Activity: Evaluating the impact of the Central London Eating Disorders Self Help Group for Adults and what matters in recovery.

Activity Description	Completion of an online survey.				
5. IDENTIFY RISKS/HAZARDS	6. WHO COULD BE HARMED & HOW?		7. EVALUATE THE RISKS		8. ACTION NEEDED
<p><u>Activities/tasks and associated hazards</u> Describe the activities involved in the study and any associated risks/ hazards, both physical and emotional, resulting from the study. Consider the risks to participants/the research team/members of the public.</p> <p>In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.)</p>	<p><u>Who is at risk?</u> e.g. participants, investigators, other people at the location, the owner / manager / workers at the location etc.</p>	<p><u>How could they be harmed?</u> What sort of accident could occur, eg trips, slips, falls, lifting equipment etc, handling chemical substances, use of invasive procedures and correct disposal of equipment etc. What type of injury is likely? Could the study cause discomfort or distress of a mental or emotional character to participants and/or investigators? What is the nature of any discomfort or distress of a mental or emotional character that you might anticipate?</p>	<p><u>Are there any precautions currently in place to prevent the hazard or minimise adverse effects?</u> Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc/</p>	<p><u>Are there any risks that are not controlled or not adequately controlled?</u></p>	<p><u>List the action that needs to be taken to reduce/manage the risks arising from your study</u> for example, provision of medical support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects NOTE: medical or other aftercare and/or support <b>must</b> be made available for participants and/or investigator(s) who require it.</p>
Use of computers	Participants and investigator	Eye strain and upper limb disorder	n/a	no	none
Stress	Participants	Unpleasant feelings and/or memories	n/a	no	Information on sources of support is provided before and after completing the online survey.

Signed by applicant: <i>Susan Dixon</i>	Dated: 15/04/24
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## 4.30: Qualtrics Questionnaire with Form EC6 (Participant Info Sheet)- embedded within it (Study 5)

### Q1 SUMMARY

I am conducting a piece of research finding out more about your experience of the Central London Group and your experiences of recovery. The research is important to better understand the value that Eating Disorder (ED) Self Help Groups bring, and how they can support the recovery of those who attend. It is an anonymous online questionnaire which should take no longer than 10 to 15 minutes to complete.

Thank you very much for taking time to engage with this research. By completing this online survey, you are giving your consent and freely agree to take part in the study entitled: Evaluating the impact of the Central London Eating Disorders Self Help Group for Adults and what matters in recovery. Please take time to read the Participant Information before you continue with this survey. You are being invited to take part in a study.

Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:<https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs> (after accessing this website, scroll down to Letter S where you will find the regulation)

### Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

### Are there any age or other restrictions that may prevent me from participating?

You must be over the age of 18 and be someone who has or is attending the Central London Eating Disorders Self Help Group.

### What will happen if I take part?

Initially you will be asked to give consent by reading this information, confirming you are over 18. You will be asked if you attend the Central London Self Help Group, or have done so in the past. You will then be taken through a series of questions that cover a range of topics.

There are 20 questions (most require you to tick which answer applies and there are some which require you to reflect briefly).

1-9: demographic and consent questions

10-11: your ED history and access to professional support

12-16: Your experiences of the Central London Group

17-19 Wellbeing and Recovery

20 Opportunities for any further reflection

There is a debrief sheet.

The average time to complete this survey is about 10 to 15 minutes.

### What are the possible disadvantages, risks or side effects of taking part?

If relevant, there is a possibility that aspects of the questionnaire may cause some distress and discomfort by triggering experiences related to lived ED experience (past or present).

### What are the possible benefits of taking part?

There will be an opportunity to add to a national picture about Eating Disorder Self Help Groups and the value they bring for people with an ED in their recovery journeys.

### How will my taking part in this study be kept confidential?

You are not required to give your name. The data collected from the survey are anonymised, and information aggregated.

### Will the data be required for use in further studies?

The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymised. The results of the study and/or the data collected (in anonymised and aggregated form) may be deposited in an open access repository.

### Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me by email: Sue Dixon s.j.dixon@herts.ac.uk or you can also contact my supervisor Dr Saskia Keville (s.keville@herts.ac.uk).

### Who has reviewed this study?

This study has been reviewed by The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority, Ethical **Protocol Number: xxxxxx**

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address: Secretary and Registrar, University of Hertfordshire, College Lane, Hatfield, Herts AL10 9AB

### Q2 Participant information sheet

I confirm that I have read the Participant Information giving particulars of the study, including its aim and design, the names and contact details of key people and, as appropriate, the risks and potential benefits. I am also aware of how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on the questionnaire will be stored and for how long. (18)

### Q3 Right to withdraw

I know that I may withdraw from the study at any time. (1)

### Q4 Awareness of the possible impact of taking part in this study

I understand that my participation in this study may reveal findings that could indicate that I may require medical advice. (1)

### Q5 Confirmation of meeting age requirement

Yes, I am over 18 (5)

No, I am over 18 (1)

### Q6 Please confirm

I am someone who has attended or is attending the Central London Self Help Group for adults (1)

**Q7 Age**

- 18 to 24 (21)
- 25 to 34 (22)
- 35 to 44 (23)
- 45 to 54 (24)
- over 55 (25)

**Q8 What is your gender?**

- Male (1)
- Female (2)
- I would prefer to describe my gender myself. Please state in the box below if you wish to do so. (3)
- prefer not to say (4)

**Q9 What is your ethnic group? Please select from the dropdown menu.**

▼ White English/Welsh/Scottish/Northern Irish/British (1) ... Prefer not to say (26)

**Q10 What type of ED have you had or currently have? Please tick all that apply.**

- Anorexia (purging type) (1)
- Anorexia (restrictive type) (3)
- Anorexia (long term) (4)
- Bulimia (5)
- Binge Eating Disorder (6)
- Obesity (7)
- Osfed/Ufed (8)
- No formal diagnosis (9)
- Other (please specify) (18)

Prefer not to say (19)

Q11 What professional support have you had or are currently having for your ED? Please tick all that apply.

GP (1)

Specialist ED therapy. Please say a little more below. (6)

non ED therapy (2)

Dietician (7)

ED inpatient treatment. Please say a little more if you wish to below. (9)

ED outpatient treatment. Please say a little more if you wish to below. (11)

I am on a waiting list for specialist ED treatment. How long have you been waiting? Please say a little more below (12)

Other. Please say a little more. (4)

Q12 Approximately how long ago did you first start attending the Central London Group

▼ less than 6 months (1) ... other (please say more) (5)

Q13 Which of the following have you taken part in? Please tick the one that applies.  
text.

In person face to face group (1)

online ZOOM (2)

both in person and online (3)

Q14 Please think back to when you first started attending the Group. Why did you decide to start attending the group.

Please tick all that apply.

- A professional such as a nurse, doctor, therapist etc. suggested it. (1)
- My friends/family or partner suggested it. (2)
- My treatment ended and I decided that I needed more support (3)
- There was a long wait for treatment and I needed more support (4)
- I was put on a waiting list (5)
- I was waiting for treatment after an assessment (6)
- I was getting panicky about my ED (7)
- Things are/were spiralling out of control (8)
- I was using my food more to deal with my emotions (9)
- I was told that I was not ill enough by a specialist ED service to receive help (10)
- I had attended other support groups and found them useful (11)
- I was thinking about starting my recovery (12)
- I was ready to start recovery (13)
- Other. Please use the box below to say more. (14)

Q15 Please rate the following statements.

	Strongly agree (30)	Agree (31)	Neither agree nor disagree (33)	Disagree (34)	Strongly Disagree (35)	Does not apply (36)
I felt excited at starting the process of attending the group. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The group sometimes raises uncomfortable feelings for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

when I am there. (2)						
I sometimes feel impacted by what others share in the group. (3)	<input type="radio"/>					
The group creates opportunities for me to learn from others. (4)	<input type="radio"/>					
I have become more open to talking and sharing with others in the Group. (20)	<input type="radio"/>					
I have become more self aware as a result of participating the group. (21)	<input type="radio"/>					
As a result of participating in the Group I feel more self motivated. (22)	<input type="radio"/>					
I feel less isolated since attending the Group. (23)	<input type="radio"/>					
Participation in the Group has led to me seeking professional support. (24)	<input type="radio"/>					
Participation in the Group has helped alongside my professional help. (25)	<input type="radio"/>					

Q16 Is there anything else you would like to tell us about your experiences of the Group (such as any good experiences or any improvements)?

Q17 Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each **over the last 2 weeks**.

[questions taken from the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.]

	none of the time (1)	rarely (2)	some of the time (3)	often (4)	all of the time (5)
I've been feeling optimistic about the future (4)	<input type="radio"/>				
I've been feeling useful (5)	<input type="radio"/>				
I've been feeling relaxed (6)	<input type="radio"/>				
I've been dealing with problems well (7)	<input type="radio"/>				
I've been thinking clearly (8)	<input type="radio"/>				
I've been feeling close to other people (9)	<input type="radio"/>				
I've been able to make up my own mind about things (10)	<input type="radio"/>				

Q18 Below are some statements about feelings and thoughts. **How would you have answered these questions BEFORE you started attending the group?** Please tick the box that best describes your experience.

[questions taken from the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.]

	none of the time (1)	rarely (2)	some of the time (3)	often (4)	all of the time (5)
I've been feeling optimistic about the future (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling useful (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling relaxed (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been dealing with problems well (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been thinking clearly (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling close to other people (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been able to make up my own mind about things (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q19 Please rate the following statements.

	Strongly agree (30)	Agree (31)	Neither agree nor disagree (33)	Disagree (34)	Strongly Disagree (35)	Does not apply (36)
The Group creates/ has created opportunities for self reflection on my own recovery progress (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participation in the Group has helped me/ helped me recognise that I need/needed support with my recovery. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Since attending the group, I have felt hopeful and optimistic about my recovery (3)

I have started/started to engage more actively in my recovery as a result of participating in the Group. (4)

The Group creates/ has created a space for me to learn strategies for how to manage recovery relapses. (20)

Seeing other people at different stages of recovery has helped me with my own recovery. (29)

The group has helped me to stay on track with my recovery once I was discharged from an ED service or specialist. (21)

Q20 Please feel free to use this space to add any further comments about how the Group helps / has helped you with your recovery.

End of Survey

Thank you for taking the time to complete this survey. I appreciate this.

Below is a debrief sheet which contains information about sources of support you can draw on if the survey has raised any uncomfortable feelings.

Thank you

Sue Dixon

s.j.dixon@herts.ac.uk

University of Hertfordshire

debrief sheet central london study april 2024 .docx

#### 4.31: Participant Debrief Sheet (Study 5)

**Title of study:** Evaluating the impact of the Central London Eating Disorders Self Help Group for Adults and what matters in recovery.

Thank you once again for taking the time to participate in this study.

If any part of the survey has raised difficult issues for you, you can access additional support via the Samaritans (116 123 or [jo@samaritans.org.uk](mailto:jo@samaritans.org.uk)) OR BEAT (0808 801 0677

<https://www.beateatingdisorders.org.uk/>) OR you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

If there is anything you think of later that you would like to share with me then please do get in touch by email: Sue Dixon ([s.j.dixon@herts.ac.uk](mailto:s.j.dixon@herts.ac.uk)). You can also contact my supervisor: or Dr Saskia Keville ([s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)).

Finally, I want to reiterate that your personal details will be kept confidential, and all data will be anonymised.

Sue

#### 4.32: Invitation email to participants (Study 5)

Dear All

I am currently partway through my PhD qualification (doctoral thesis) at the University of Hertfordshire. As part of my studies. I am conducting a piece of research finding out more about your experience of the Central London Group and your experiences of recovery.

The research is important to better understand the value that Eating Disorder Self Help Groups bring, and how they can support the recovery of those who attend. It is an anonymous online questionnaire which should take no longer than 10 to 15 minutes to complete.

The link below will take you to an online platform which provides fuller details about the research.

**Insert anonymous link to survey.**

Thank you very much for taking the time to read this email.

Best wishes

Sue Dixon

*This study is approved by the University of Hertfordshire Health, Science, Engineering & Technology ECDA.  
Ethical Protocol Number: xxxxxxxx*

#### 4.33: Consent from Co-facilitators of the Central London Group (Study 5)

From [redacted] <[redacted]>

Sent: Friday, April 26, 2024 4:34 PM

To: Susan Dixon [Student-LMS] <[s.j.dixon@herts.ac.uk](mailto:s.j.dixon@herts.ac.uk)>

Subject: Re: permission to send out a questionnaire to members of the Central London Group

Hello Sue,

Thanks for your email requesting permission to contact group members. I do not have any problems whatsoever for you to go ahead with this process and I want to take this opportunity to wish you all the best with carrying out this valuable study you are trying to complete.

Best wishes,

[redacted]

Sent from my iPhone

On 26 Apr 2024, at 15:02, Susan Dixon [Student-LMS] <[s.j.dixon@herts.ac.uk](mailto:s.j.dixon@herts.ac.uk)> wrote:

Dear All

I am writing to you as my fellow co facilitators of the Central London Group.

As you know I am doing my PhD. I am seeking your permission to contact group members about a study I am carrying out. I have included the email that I wish to you use.

*Dear All*

*I am currently partway through my PhD qualification (doctoral thesis) at the University of Hertfordshire. As part of my studies. I am conducting a piece of research finding out more about your experience of the Central London Group and your experiences of recovery.*

*The research is important to better understand the value that Eating Disorder Self Help Groups bring, and how they can support the recovery of those who attend. It is an anonymous online questionnaire which should take no longer than 10 to 15 minutes to complete.*

*The link below will take you to an online platform which provides fuller details about the research.*

*[Insert anonymous link to survey.](#)*

*Thank you very much for taking the time to read this email.*

*Best wishes*

*Sue Dixon*

*This study is approved by the University of Hertfordshire Health, Science, Engineering & Technology ECDA. Ethical Protocol Number: xxxxxxxx*

Please let me know if you are happy for me to do so by return email. I need to provide evidence of your agreement with my ethics application.

Best

Sue

## 4.34: Ethics Approval Notifications

### 4.34a: Ethics Approval Notification for Study One



**HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA**

#### **ETHICS APPROVAL NOTIFICATION**

**TO** Susan Dixon  
**CC** Dr Saskia Keville  
**FROM** Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair  
**DATE** 06/03/2018

---

Protocol number: **LMS/PGR/UH/03244**

Title of study: Experiences of Eating Disorder Self Help Groups in relation to recovery

Your application for ethics approval has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

This approval is valid:

From: 06/03/2018

To: 28/02/2019

**Additional workers:**

**Dr Nick Troop (733049)**



HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

**ETHICS APPROVAL NOTIFICATION**

TO Susan Dixon  
CC Dr Nicholas Troop  
FROM Mrs Rosemary Godbold, Health, Science, Engineering and Technology ECDA  
DATE 17/11/2020

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Protocol number: LMR/PGR/UH/04306

Title of study: Eating Disorders Self Help Groups and what matters in recovery

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Saskia Keville (co-supervisor)

**General conditions of approval:**

Ethics approval has been granted subject to the standard conditions below:

**Permissions:** Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications:** Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures:** If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission:** Students must include this Approval Notification with their submission.

**Validity:**

This approval is valid:

From: 17/11/2020

To: 31/12/2021



HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

**ETHICS APPROVAL NOTIFICATION**

TO Susan Dixon  
CC Saskia Keville  
FROM Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair  
DATE 01/04/2022

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Protocol number: LMS/PGR/UH/04873  
Title of study: What matters in recovery: Adults with an Eating Disorder who have never attended a Self Help Group

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

**General conditions of approval:**

Ethics approval has been granted subject to the standard conditions below:

**Permissions:** Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications:** Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures:** If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission:** Students must include this Approval Notification with their submission.

**Validity:**

This approval is valid:

From: 01/04/2022

To: 31/12/2022

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#### 4.34d: Ethics Approval Notification for Study Four



HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

### ETHICS APPROVAL NOTIFICATION

TO Susan Dixon  
CC Dr Saskia Keville  
FROM Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair  
DATE 08/11/2022

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Protocol number: LMS/PGR/UH/05154

Title of study: What matters in recovery: Exploring facilitators' perspectives of eating disorders self-help groups

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:



#### General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

**Permissions:** Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications:** Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures:** If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission:** Students must include this Approval Notification with their submission.

#### Validity:

This approval is valid:

From: 08/11/2022

To: 30/09/2023

## 4.34e: Ethics Approval Notification for Study Five

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HEALTH, SCIENCE, ENGINEERING AND  
TECHNOLOGY ECDA

### ETHICS APPROVAL NOTIFICATION

**TO** Susan Dixon  
**CC** Dr Saskia Keville  
**FROM** Dr Rosemary Godbold, Health,  
Science, Engineering and Technology  
ECDA Vice-Chair  
**DATE** 03/05/2024

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Protocol number: **LMS/PGR/UH/05633**

Title of study: Evaluating the impact of the Central  
London Eating Disorders Self Help  
Group for Adults and what matters in  
recovery.

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

**Dr Keith Sullivan (k.sullivan3@herts.ac.uk)**  
**Dr Nick Troop (n.a.troop@herts.ac.uk) – no longer works at UH but is still being involved as third supervisor**

#### **General conditions of approval:**

Ethics approval has been granted subject to the standard conditions below:

**Permissions:** Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications:** Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures:** If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission:** Students must include this Approval Notification with their submission.

#### **Validity:**

This approval is valid:

From: 03/05/2024

To: 31/10/2024

#### **Please note:**

## Chapter Five Appendices

### Appendix 5.1: Researcher diary extract

Reflective diary 12 July 2018

Going through the data and the transcripts I am realising how I went sometimes into counsellor/psychotherapist mode and as a result, there are places where I make interpretations and the participants saying yes. So, I missed out on their rich words which is really frustrating for me. There is a sense of my goodness, I've got so much rich data and what am I going to do with it, despite my earlier lament about not having enough data due to me over interpreting.

As I did the interview, I realised that some of the questions were not suitable especially the one asking them to reflect on whether their thoughts about recovery had changed having been in the group when it is far more complex than that and it is not so linear.

Having looked at all the data I wonder if I have enough information about what happens inside the group. I remember I found it hard to get them to tell me what happens inside the group. I was waiting to hear about things that were discussed and how it was organised but what I got were personal reflections of what it brought up for them. Thank goodness for semi structured interviews and for allowing them to go off into that angle. I would have missed out on a lot of the interpersonal stuff.

I do think what's interesting with some of them is that I am surprised by my emotional responses- now that could be the psychotherapist side of me. For example, there's one place where I got so angry with Maria's parents for how dare they be so cruel and how could family say something like that. I got a real sense of how it might've felt for her and the more I read and reread the data listening to it and hearing her voice. I could feel that sadness within what she was saying. We were separated by a screen as her interview was via skype but I could still feel the sadness, but I felt I could not comfort her. But now I wonder if there was part of her that wanted me to witness her story and affirm it.

I felt really energised by Jane when she talked about, oh my god, I did it and how excited she felt about going to the group because it made me realise how as a group contact and facilitator of group you don't get that opportunity to hear that. It could be that they don't want to tell everyone else in the group as new members. They are so focussed on being new and trying to fit in? But they have given me some food for thought about how much I miss.

There's a lot of sadness evoked in me hearing some of the participants' experiences of recovery of having been recovered and going out of recovery then coming back and there's this push-pull where they are written they are in recovery, and they enjoy it. They see that life is happening and then there's this counter opposite where they go back and relapse. For some reason that isn't enough to keep them in recovery. It made me think if I'm confused then the participants were confused too possibly. I was especially struck by Daisy's interview data. She was one of the earlier ones, so this had a huge and impact on me.

I wonder if the people who were in the group that I facilitated held back on some of their responses? When I compare for example what others said about the facilitators who didn't belong to my group, I noticed that the people from my group very rarely mentioned the facilitator. Now this could be out of assumed shared knowledge or not wanting to offend or not wanting to say positive things to my face. It brings into question the whole role of the impact of the researcher on the participants. Having said that I strongly believe that because of my relationship with some the participants they were more open perhaps than they would have been with a researcher not known to them.

## Appendix 5.2 Participant Pre-Interview Questionnaire

About You	
First Name	Family Name (use initial if you prefer)
Age	Gender
Employment	Civil status (e.g. single, married, in a long term relationship etc.)
Eating Disorders Diagnostic History	
Please use this space to say a little about when your eating problems started (continue on another sheet if you wish to)	
Eating Disorders Diagnosis/Diagnoses	
Diagnosis	Date and by whom (e.g. GP, psychiatrist, Psychologist)
Treatment History	
Use this space to talk about any treatment you have received such as medication, hospital, in/out patient, dietician etc. (continue on another sheet if you wish to)	

Information about the Self Help Group that you are attending
Use this space to tell me about the Self Help Group that you are attending such as how long you have been attending, the frequency of meetings, how often you attend etc. ((continue on another sheet if you wish to)
Other Information relating to your Eating Disorder History that you wish to share

Thank you for taking the time to complete this initial questionnaire. Please return this email to [s.dixon4@herts.ac.uk](mailto:s.dixon4@herts.ac.uk) I will then be in touch very soon to agree a date for your interview.

**What is the best way to contact you?**

Sue Dixon, PhD Psychology Student, University of Hertfordshire

### Appendix 5.3: Example of stages of analysis (Jane)

#### 'Jane'

Below is a description of how the researcher employed steps 4, 5, and 6 of the steps outlined by Smith et al. (2009) above. This is demonstrated through the emergence of the themes of the first participant 'Jane'. The process of developing the superordinate and subordinate themes was laborious but very necessary. 'Jane' started the process that ultimately led to the final superordinate and subordinate themes. An extract of Jane's annotated transcript (eight pages) which had some of the researcher's initial thoughts, reflections and tentative themes were reviewed as part of a peer group IPA session led by one of the researcher's supervisors. This peer review process elicited new ways of viewing the transcript. This was an important developmental process for the researcher as well as a quality assurance one. As a result of this the researcher reviewed the whole transcript.

Once the analysis of the transcript had been completed possible themes were written onto strips of paper. These strips of paper were spread out all over the researcher's office floor and then grouped into tentative headings and stuck onto sheets of paper. This process was repeated for each transcript.

Jane's analysis generated 53 strands. The researcher engaged in an iterative process of reviewing and re-reviewing how the 53 strands could be grouped and what these groupings could be called. There were four iterations.

The first iteration had eight superordinate themes (see Table ii)

Table ii: First Iteration

Label	Superordinate themes
1	The supportive partner
2	Relapsing
3	Being validated
4	Am I ill enough to get help?
5	The impact of social media.
6	Others roadblocking.
7	Notion of Recovery
8	What it is and what it is no.

The second iteration involved a reflection process where the strips of paper were moved around again. This was due to the belief that it was important at this stage that at least one of the headings needed to have the term 'group' in the title. Some of the other headings were re-named which resulted in seven superordinate headings (see Table iii).

The third iteration represented the penultimate stage of analysing Jane's transcript before moving onto the other participants' transcript. At this stage relapsing and recovery were linked together to form one theme with a new name called '*recovery benefits*'. The social media and roadblocking themes were combined under the roadblocking heading and is shown in Table iv.

Table iii: Second Iteration

Label	Superordinate themes
1	The supportive partner
2	Relapsing
3	The SHG as a place for validation
4	Am I ill enough to get help?
5	The impact of social media
6	Others roadblocking
7	What recovery is and what recovery is not- Recovery beliefs.

Table iv: Third iteration

Superordinate Themes and Subordinate Themes (Jane)	Key words
1. <b>The supportive partner</b> Being lucky (p.12) Recognizing things are slipping	Maybe you should go back (p. 17). "You need to listen to yourself" (p. 17) "I'm very lucky"
2. <b>Recovery benefits</b>	
Recovery is (defining what recovery is/is not)	Not normal thoughts (p. 1) "being really healthy" (p. 18) really conscious (p. 18) never worrying (p. 16) not questioning "fake it till you make it" (p. 6)
Relapsing (feelings & triggers)	Black cloud (p. 16) I can do anything (p. 16) Recognizing different voices in head (p. 20) Lonely illness (p. 5)
Ebb and flow of recovery	Acknowledging the thoughts (p. 4)
3. <b>The SHG as a place for validation</b> <ul style="list-style-type: none"> <li>● Signs of validation (p. 10)</li> <li>● Me compared to everyone else (p. 5)</li> <li>● Being understood</li> <li>● Emotional response</li> </ul>	"I can't believe I did that" (p. 8) "It was very liberating" (p. 8) "You're me" (p. 11) Yeah, that's valid (p. 14) I had all of this adrenaline (p. 8)
4. <b>Am I ill enough to get help?</b> <ul style="list-style-type: none"> <li>● What counts as being ill?</li> <li>● Telling others (parents or professional)</li> </ul> (being believed)	Oh my god, I don't deserve to be here (p. 4). I had to tell someone (p. 2) I'm not bad enough (p. 21) Not deserving of help (p. 3)
5. <b>Others roadblocking</b> <ul style="list-style-type: none"> <li>● People versus professional (p. 8)</li> <li>● Asking for help (p. 7)</li> <li>● Social Media (+ve/-ve) (p. 19)</li> </ul>	"Desperate for anything" (p. 21) I didn't even love (p. 4) Damaging (p. 3)
Thought: Could themes 1 and 5 be linked together?	

The fourth iteration demonstrates the last stage of the iterative process which ended with four superordinate and ten subordinate themes. Two of the original superordinate themes were reworked and two stayed the same. This final iteration was captured electronically onto an excel spreadsheet to form a grid (see Table v).

Table v: Fourth Iteration

Superordinate Theme	Subordinate Themes	Key words	page	
Roadblocking and Signposting	the signposting supportive partner	you should go back	17	experiences outside the group
		listen to yourself	17	
		lucky	12	
	the professionals	desperate for anything	21	
		I didn't even look	7	
social media	damaging	3		
Recovery Beliefs	Defining what recovery is and is not	not normal thoughts	1	
		being really healthy	18	
		really conscious	18	
		not disliking myself	15	
		never worrying	16	
	Relapsing (feelings and triggers)	black cloud	16	
		I can't do anything	16	
		recognising different voices in head	20	
	ebb & flow of recovery	fake it till you make it	6	
		me compared to everyone else	5	
	acknowledging the thoughts	4		
The Self Help Group as a place for Validation (Universality)	validating signs	yeah that's valid	10	experiences inside the group
		you're me	11	
		nodding	10	
		room full of people who understand	10	
		in that mindset	10	
		different suggestions and experiences	12	
	emotional reactions (attending and others in groups)	adrenaline	8	
		releases into your system	8	
		liberating	8	
		I can't believe I did that	8	
		comfortable, varied & encouraging	22	
		annoyed	21	
really scared	7			
Am I ill enough to get help?	perceptions	I don't deserve to be here	7	experiences internally
		not deserving of help	3	
	telling others about the Eating Disorders DOES THIS OVERLAP WITH FIRST ONE	I had to tell someone	21	
		I'm not bad enough	21	
		it sort of like bursting out of me	2	
		you need to understand	9	

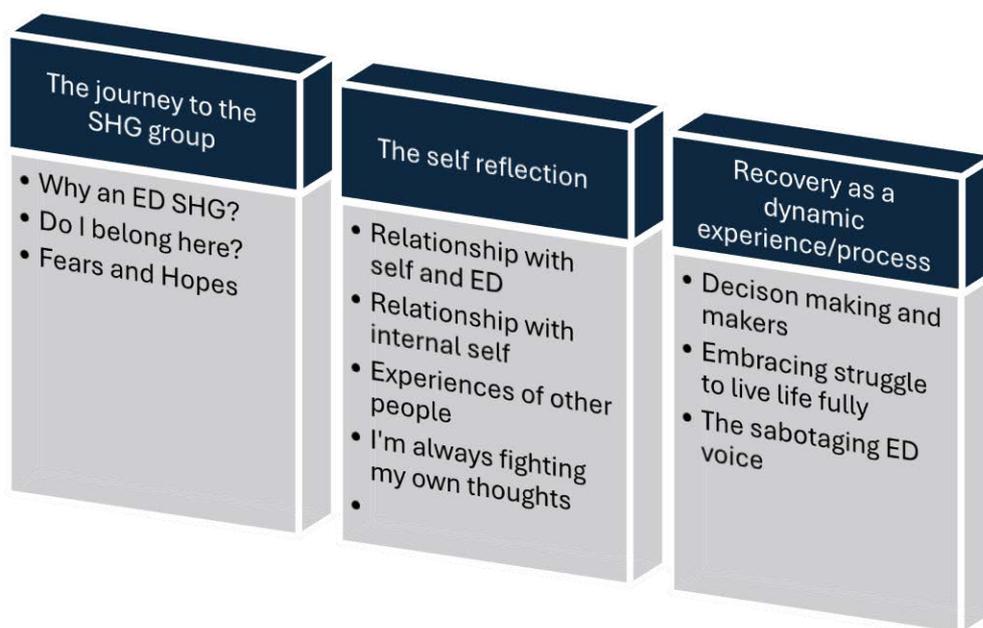
## Appendix 5.4: Draft version superordinate and subordinate themes

### Superordinate and Subordinate Themes Draft Version 7.12.2018

Their lived experiences have been clustered together into superordinate themes. These superordinate themes tell a story of what happens in an ED SHG, who attends, why they attend and what happens there not just in terms of its activities but the impact of being in the group had on them. What emerged from the analysis of these interviews is that the ED SHGs have created an opportunity and space for the participants to reflect within themselves but also reflect in the presence of others.

The themes which reflect common experience happens internally for the participants.

Want to capture the essence of the participants' experiences outside the group, inside the group and experiences internally.



#### **SUPER THEME 1: The Journey leading to attending an ED SHG group**

This theme is about what led them to attend the group. What pre experiences led up to this.

Maria- an outlet for me to start recovering and not recovering

- Why an ED SHG?
- Do I belong here?
- Fears and Hopes

A last resort

Needing help- being angry with the professional help received and it not helping (Jane)

Having had professional help

### **SUPER THEME 2: The proximity of relationships**

This is about the nature of how the participants are in touch with their internal sense of agency with respect to their ED. How do they engage with others close to them or those involved in their treatment (past or present)? So the roles that others play involve one that is directing and one that is controlling them or are they absent in their recovery?

- Relationship with self and ED
- Relationship with internal self
- Experiences of other people
- I'm always fighting my own thoughts

### **SUPER THEME 3: Recovery as a dynamic process**

The first sub theme, that of decision makers overlaps with theme 2 insomuch as how are the decisions about recovery made and who influences such decisions.? Are the decision makers facilitators and enablers of recovery?

Some expressed dreams and hopes about recovery- rebirth and resurrection

Being able to live with the struggle with the aim of wanting to life live fully-often expressed as a wish or a hope

- Decision making and makers
- Embracing struggle to live life fully
- The sabotaging ED voice

## Appendix 5.5 Coverage of themes for whole cohort

Superordinate themes	Subordinate Themes	Names								
		Daisy	Jane	Sally	Maria	Alison	Jackson	Emma	Julie	Lisa
The journey leading to attendance at an ED SHG	I looked it up and found the group		x		x		x	x		x
	Fears and hopes: I've never been in a place like this before	x	x	x	x	x	x	x	x	x
	Uplifting being in the group: like I jumped out of a plane	x	x	x	x	x	x	x	x	x
The Proximity of relationships	Self-exploration as a way/means to discover		x	x	x		x	x	x	x
	Helpful and unhelpful aspects of relationships with others	x	x	x	x	x	x	x	x	x
Recovery as a dynamic experience and process	Recovery reflections	x	x	x	x		x		x	x
	ED Voice as saboteur	x	x	x	x	x		x	x	x
	Moments of freedom	x	x	x	x	x	x	x	x	x

## Chapter Six Appendices

### Appendix 6.1: Full Survey Questions

Eating Disorders Self Help Groups and What Matters in Recovery

**Q1.1 Age**

**Q1.2 What is your gender?**

**Q1.3 What is your ethnic group?**

**Q2.1 How did you find out about the Eating Disorders Self Help Group?**

Please tick all that apply.

Internet search

someone showed me

I was told by a professional such as a nurse, doctor, therapist etc.

I was told by friends or family or partner

I was told by someone at work

Other

**Q2.2 Why did you look for the group? Please tick all that apply.**

My treatment ended

there was a long wait for treatment

I was put on a waiting list

I was waiting for treatment after an assessment

I was getting panicky about my ED

Things were spiralling out of control

I was using my food more to deal with my emotions

I was told that I was not ill enough by a specialist ED service to receive help

Other

**Q3.1 When you found out about the ED Self Help Group what did you do?**

Please choose the one that best describes your experience.

I attended the next scheduled group straightaway when I got the details

I delayed my entry to the group because I was worried about my body size

I delayed my entry to the group because I was feeling anxious

I delayed my entry to the group because I was worried about what would happen

I delayed my entry to the group because I was worried about who would be there

I delayed my entry to the group because I was feeling scared

Use this box to add any further comments if you wish to do so

**Q3.2 How long did you delay your entry to the group?**

Not applicable

Tell us how long

**Q4.1 When you attended your first session at the group how did it make you feel?**

Please tick all that apply.

- I had a feeling of adrenaline
- I felt like I had jumped out of a plane
- I felt proud of myself
- I felt less alone
- I felt liberated
- I felt uplifted
- I wanted to keep attending
- I felt reassured
- I felt that the group is the most helpful thing I've ever done
- I felt out of place
- I felt pressurised by other attendees or the facilitators
- I didn't feel welcome
- I felt disappointed; it was not what I expected
- There was no one there that looked like me
- Please use this space to say more if you would like to do so

**Q4.2 When you are in the group what happens?**

**(Likert scale agree, neutral, disagree)**

- I learn things about myself
- I feel that I don't always use the group as well as I want to
- I find it hard to talk about myself
- I find myself talking about my family
- I find it an encouraging space
- I can talk about anything I want to
- I leave the group feeling motivated
- I feel a commitment to action
- I can recognise a lot of my own traits in other people
- I am able to tell myself I'm doing well
- I have found out how to access treatment
- I have learnt about what help I am entitled to
- I have sought professional help as a result of attending the group

**Q4.3 Please use this space to say more about the ED group that you attend, ensuring you respect confidentiality.** For example: the type of group (e.g., face to face or online) how it is run; how many people usually attend; number of facilitators and their roles etc.

**Q4.4 Please rate your overall experience of attending an ED Self Help Group. The sliding scale is 0 to 10.**

0 1 2 3 4 5 6 7 8 9 10

Considering only the positive things about attending the group (and ignoring the negative things), how positive are those things? ()	
Considering only the negative things about attending the group (and ignoring the positive things), how negative are those things? ()	

### Q5.1

**Please rate the following statements about being in recovery. When I am in recovery/when I was in recovery** (If you have not been in recovery, please go straight to the next question.)

(Likert scale: disagree, neutral, agree)

I feel/felt excited

It feels/felt good

it feels/felt like coming back to life again

I feel/ felt emotional at times

I recognise/recognised how life is/was quite dull when I have/ had my ED

I can/could eat without feeling guilty

I can/could eat without having to exercise

it is/was nice being able to eat without having to worry

I find/found it hard to sustain my recovery at my target weight

I am/was sick of being ill and restricting

I can/could see there were many opportunities ahead of me

I can/could see that my ED was holding me back

I still have/had wobbles

I believe/believed that recovery is/was an ongoing thing and I will/would always need to work hard towards that

I am not 100% recovered; I still have a lot of obsessive traits

It is/was easy for me to fall back into restrictive habits

I don't/didn't really know what it is/was to be fully recovered

I do purge/I did purge

I still think about what I can eat/ I thought about what I had eaten or could eat

I do record calories/ I did record calories

I do record my weight/did record my weight

I am/was scared to weigh myself because I am/was worried I will/would not like the number

I do count numbers/did count numbers

I have/ had ups and downs during my recovery

### Q5.2 **People or things that support or have supported your recovery journey so far.**

(Please tick all that apply)

The ED Self Help Group

ED Self Help Book

ED Self Help Manual/Workbook

Online Support Group

Recovery App

Recovery Coach

Recovery Blog

Therapist e.g., Counsellor, Psychologist, Psychotherapist

Psychiatrist  
 GP  
 Dietician or nutritionist  
 My partner or family  
 My friends  
 ED Charity e.g., BEAT, ABC etc.

**Q6 Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each over the last 2 weeks**

[questions taken from the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.]

(Likert scale: None of the time, Rarely, Some of the time, Often, All of the time)

- I've been feeling optimistic about the future
- I've been feeling useful
- I've been feeling relaxed
- I've been feeling interested in other people
- I've had energy to spare
- I've been dealing with problems well
- I've been thinking clearly
- I've been feeling good about myself
- I've been feeling close to other people
- I've been feeling confident
- I've been able to make up my own mind about things
- I've been feeling loved
- I've been interested in new things
- I've been feeling cheerful

**Please use this space to tell me anything else that has not been covered.**

#### Appendix 6.2: Detailed age breakdown

Age	Frequency	Percent %
18	2	2
19	3	3
20	4	4
21	1	1
22	8	8
23	2	2
24	6	6
25	14	13
26	8	8
27	9	9
28	2	2
29	2	2
30	4	4
31	5	5
32	4	4
33	3	3
34	2	2

35	2	2
36	2	2
38	2	2
39	1	1
40	3	3
41	2	2
42	1	1
43	1	1
44	2	2
45	1	1
46	2	2
50	1	1
51	1	1
52	1	1
54	1	1
57	1	1
61	1	1
71	1	1
72	1	1
Total	106	100.0

### Appendix 6.3: Detailed Ethnic Breakdown

	Frequency	Percent %
White English/Welsh/Scottish/Northern Irish/British	72	68
White Irish	3	3
Any other White background, please describe	17	16
Mixed/Multiple ethnic groups: White and Black Caribbean	1	1
Mixed/Multiple ethnic groups: White and Black African	1	1
Mixed/Multiple ethnic groups: White and Asian	2	2
Mixed/Multiple ethnic groups: Any other Mixed/Multiple ethnic background, please describe	2	2
Asian/Asian British: Indian	1	1
Asian/Asian British: Pakistani	2	2
Black/ African/Caribbean/Black British: Caribbean	2	2
Other ethnic group: Any other ethnic group, please describe	2	2
Prefer not to say	1	1
Total	106	

### Appendix 6.4: Reasons for seeking group (extra qualitative comments)

1. I wanted extra support
2. I was discharged from inpatient treatment and wanted to try and maintain recovery in the community, whilst receiving a stepped down approach to specialist ED community treatment.
3. I was discharged from inpatient/day patient, but community support was v limited.
4. I knew that I couldn't manage my eating myself and I hated putting on weight.
5. A friend told me about the group
6. My friend knew of my food and body image issues and recommended the SHG to me - she benefited a lot from the organisation and I thought I would too.
7. I was told about it from professionals as an additional support to treatment
8. I was put in the group as part of my recovery
9. Wanting to try all options.

10. I was in treatment but wanted to speak to other people in the same situation.
11. I had no other means of access to a group
12. I needed to talk and the phonelines weren't cutting it.
13. My treatment had the ED group as part of the treatment, and I wanted to stay in touch with my friends in a healthy way.
14. I was in treatment but wanted to speak to other people in the same situation.
15. I had no other means of access to a group.
16. I needed to talk and the phonelines weren't cutting it. -My treatment had the ED group as part of the treatment and I wanted to stay in touch with my friends in a healthy way.
17. Attending the group was part of my treatment plan; though I organised going to such meetings myself.
18. I was feeling lonely and isolated due to the ED.
19. My therapist does not specialize in ED or BDD.
20. I needed extra support while being in outpatient treatment, there was not therapy available for ED and the psychiatrist was useless
21. There were no other forms of support in my area
22. After 7 years of hiding the problem I decided to tell my parents & start getting help but I didn't know where to turn.
23. Couldn't see another way forward.

#### Appendix 6.5: Reasons for delaying entry

1. I was worried I wasn't sick enough to attend and everyone would think I was a fraud.
2. This was over 25 years ago so I am having difficulty recalling all details.
3. I delayed contact because I was still trying to come to terms with having an eating disorder, despite inpatient treatment I thought I had things more under control, but I didn't!!!! So I put off going to a support group for a while. I also didn't know anyone else going to the support group to start with, so it felt very scary not knowing be what to expect or how to behave (what would the rules of the group be etc).
4. I delayed my entry because it clashed with my (admittedly very excessive) exercise programme.
5. I had attended many self help organisations in the past and had never experienced a solution for my addictive eating. Going to Addictive Eaters Anonymous felt daunting and I was scared. I am so grateful that I went and have kept attending. It has changed my life
6. I was hoping I wouldn't need the group, and I was concerned that someone from work might recognize me going into the meeting.
7. My bingeing and purging was out of control and the anxiety of attending got me stuck at home with the behaviours
8. Took best 6 months for me to physically attend a group meeting from first becoming aware of a self-help group. I felt scared & wanted to do it by myself. Admitting I couldn't do it alone, was in extreme suffering and asking for help by going to a self-help group was a key step.
9. And then covid came and then I attended online because it is less scary
10. I haven't been to a group yet.
11. I delayed going as wanted to get over it myself and didn't mind my current state at that time
12. I put off self-referral for about 6 months because a) I was maybe a bit in denial b) I thought it was too busy and didn't have enough time c) the pandemic started
13. I was worried I wasn't sick enough to attend and everyone would think I was a fraud.
14. This was over 25 years ago so I am having difficulty recalling all details.

15. I delayed contact because I was still trying to come to terms with having an eating disorder, despite inpatient treatment I thought I had things more under control, but I didn't!!!! So I put off going to a support group for a while. I also didn't know anyone else going to the support group to start with, so it felt very scary not knowing be what to expect or how to behave (what would the rules of the group be etc).

#### Appendix 6.6: Total variance explained for 3-factor solution (group)

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	4.095	31.497	31.497	4.095	31.497	31.497
2	2.004	15.417	46.914	2.004	15.417	46.914
3	1.214	9.339	56.253	1.214	9.339	56.253

#### Appendix 6.7: Communalities Analysis (group)

Factors	Extraction
1. I learn things about myself	.576
2. I feel that I don't always use the group as well as I want to	.721
3. I find it hard to talk about myself	.679
4. I find myself talking about my family	.708
5. I find it an encouraging space	.638
6. I can talk about anything I want to	.467
7. I leave the group feeling motivated	.620
8. I feel a commitment to action	.719
9. I can recognise a lot of my own traits in other people	.651
10. I am able to tell myself I'm doing well	.497
11. I have found out how to access treatment	.762
12. I have learnt about what help I am entitled to	.753
13. I have sought professional help as a result of attending the group	.618

#### Appendix 6.8: Detailed descriptive statistics of generated factors (group)

		Statistic	Std. Error	
Motivation/ intrapersonal	Mean	-.5711	.05425	
	95% Confidence Interval for Mean	Lower Bound	-.6791	
		Upper Bound	-.4630	
	5% Trimmed Mean	-.6129		
	Median	-.6000		
	Variance	.224		
	Std. Deviation	.47295		
	Minimum	-1.00		
	Maximum	1.00		
	Range	2.00		
	Interquartile Range	.60		
	Skewness	1.171	.276	
	Kurtosis	.862	.545	
Help seeking	Mean	.1886	.07183	

	95% Confidence Interval for Mean	Lower Bound	.0455		
		Upper Bound	.3317		
	5% Trimmed Mean			.2096	
	Median			.3333	
	Variance			.392	
	Std. Deviation			.62618	
	Minimum			-1.00	
	Maximum			1.00	
	Range			2.00	
	Interquartile Range			1.00	
	Skewness			-.273	.276
	Kurtosis			-.925	.545
	Personal difficulties inside the group	Mean		.0044	.07453
95% Confidence Interval for Mean		Lower Bound	-.1441		
		Upper Bound	.1529		
5% Trimmed Mean			.0049		
Median			.0000		
Variance			.422		
Std. Deviation			.64977		
Minimum			-1.00		
Maximum			1.00		
Range			2.00		
Interquartile Range			1.33		
Skewness			.025	.276	
Kurtosis			-1.255	.545	
Talking	Mean		-.0395	.07301	
	95% Confidence Interval for Mean	Lower Bound	-.1849		
		Upper Bound	.1060		
	5% Trimmed Mean			-.0439	
	Median			.0000	
	Variance			.405	
	Std. Deviation			.63647	
	Minimum			-1.00	
	Maximum			1.00	
	Range			2.00	
	Interquartile Range			1.00	
	Skewness			.152	.276
	Kurtosis			-.986	.545

#### Appendix 6.9: Communalities Analysis (recovery)

Factors	Extraction
1. I feel/felt excited	.729
2. It feels/felt good	.842
3. it feels/felt like coming back to life again	.734
4. I feel/ felt emotional at times	.671
5. I recognise/recognised how life is/was quite dull when I have/ had my ED	.649
6. I can/could eat without feeling guilty	.817
7. I can/could eat without having to exercise	.642
8. It is/was nice being able to eat without having to worry	.759
9. I find/found it hard to sustain my recovery at my target weight	.814
10. I am/was sick of being ill and restricting	.607
11. I can/could see there were many opportunities ahead of me	.576
12. I can/could see that my ED was holding me back	.630
13. I still have/had wobbles	.649

14. I believe/believed that recovery is/was an ongoing thing and	.535
15. I am not 100% recovered; I still have a lot of obsessive traits	.725
16. It is/was easy for me to fall back into restrictive habits	.693
17. I don't/didn't really know what it is/was to be fully recovered	.669
18. I do purge/I did purge	.589
19. I still think about what I can eat/ I thought about what I had eaten or could eat	.841
20. I do record calories/ I did record calories	.783
21. I do record my weight/did record my weight	.590
22. I am/was scared to weigh myself because I am/was worried I will/would not like the number	.693
23. I do count numbers/did count numbers	.762
24. I have/ had ups and downs during my recovery	.602

Appendix 6.10: Detailed descriptive statistics of generated factors (recovery)

Impact on self	Mean		-0.3184	.06714	
	95% Confidence Interval for Mean	Lower Bound	-0.4522		
		Upper Bound	-0.1847		
	5% Trimmed Mean		-0.3485		
	Median		-0.4000		
	Variance		.343		
	Std. Deviation		.58531		
	Minimum		-1.00		
	Maximum		1.00		
	Range		2.00		
	Interquartile Range		1.00		
	Skewness		.473	.276	
Kurtosis		-0.808	.545		
Self recognition	Mean		-0.6875	.04639	
	95% Confidence Interval for Mean	Lower Bound	-0.7799		
		Upper Bound	-0.5951		
	5% Trimmed Mean		-0.7332		
	Median		-0.7500		
	Variance		.164		
	Std. Deviation		.40440		
	Minimum		-1.00		
	Maximum		.75		
	Range		1.75		
	Interquartile Range		.50		
	Skewness		1.542	.276	
Kurtosis		2.037	.545		
struggles	Mean		-0.6816	.05794	
	95% Confidence Interval for Mean	Lower Bound	-0.7970		
		Upper Bound	-0.5662		
	5% Trimmed Mean		-0.7439		
	Median		-1.0000		
	Variance		.255		
	Std. Deviation		.50510		
	Minimum		-1.00		
	Maximum		1.00		
	Range		2.00		
	Interquartile Range		.40		
	Skewness		1.776	.276	
Kurtosis		2.236	.545		
Freedom to eat	Mean		-0.1743	.06689	
	95% Confidence Interval for Mean	Lower Bound	-0.3076		
		Upper Bound	-0.0411		
	5% Trimmed Mean		-0.1806		
	Median		.0000		
	Variance		.340		
	Std. Deviation		.58312		
	Minimum		-1.00		
	Maximum		1.00		
	Range		2.00		
	Interquartile Range		1.00		
	Skewness		-0.144	.276	
Kurtosis		-1.219	.545		
	Mean		-0.1754	.08200	

Weight and Calories	95% Confidence Interval for Mean	Lower Bound	-0.3388			
		Upper Bound	-0.0121			
	5% Trimmed Mean			-0.1949		
	Median			-0.3333		
	Variance			.511		
	Std. Deviation			.71487		
	Minimum			-1.00		
	Maximum			1.00		
	Range			2.00		
	Interquartile Range			1.33		
	Skewness			.358	.276	
	Kurtosis			-1.088	.545	
Behaviours	Mean			-0.2237	.06714	
	95% Confidence Interval for Mean	Lower Bound		-0.3574		
		Upper Bound		-0.0899		
	5% Trimmed Mean			-0.2485		
	Median			.0000		
	Variance			.343		
	Std. Deviation			.58535		
	Minimum			-1.00		
	Maximum			1.00		
	Range			2.00		
	Interquartile Range			.50		
	Skewness			.382	.276	
Kurtosis			-0.266	.545		
Sustaining recovery	Mean			-0.4211	.06886	
	95% Confidence Interval for Mean	Lower Bound		-0.5582		
		Upper Bound		-0.2839		
	5% Trimmed Mean			-0.4678		
	Median			-0.5000		
	Variance			.360		
	Std. Deviation			.60029		
	Minimum			-1.00		
	Maximum			1.00		
	Range			2.00		
	Interquartile Range			1.00		
	Skewness			.779	.276	
Kurtosis			-0.318	.545		

Appendix 6.11a: Prevalence survey WEMWBS detailed results

<b>WEMWBS Score</b>	<b>No: of participants</b>	<b>Percentage</b>	<b>Cumulative Percent</b>
21.00	2	2.6	2.6
24.00	1	1.3	3.9
25.00	1	1.3	5.3
26.00	1	1.3	6.6
28.00	2	2.6	9.2
29.00	1	1.3	10.5
30.00	3	3.9	14.5
31.00	3	3.9	18.4
32.00	2	2.6	21.1
34.00	2	2.6	23.7
35.00	5	6.6	30.3
36.00	1	1.3	31.6
37.00	3	3.9	35.5
38.00	3	3.9	39.5
39.00	4	5.3	44.7
40.00	3	3.9	48.7
41.00	2	2.6	51.3
42.00	3	3.9	55.3
43.00	3	3.9	59.2
44.00	3	3.9	63.2
45.00	1	1.3	64.5
46.00	1	1.3	65.8
47.00	3	3.9	69.7
48.00	1	1.3	71.1
49.00	2	2.6	73.7
50.00	1	1.3	75.0
51.00	2	2.6	77.6
52.00	2	2.6	80.3
53.00	4	5.3	85.5
54.00	2	2.6	88.2
55.00	4	5.3	93.4
56.00	1	1.3	94.7
60.00	1	1.3	96.1
61.00	1	1.3	97.4
67.00	1	1.3	98.7
70.00	1	1.3	100.0
Total	76	100.0	

Appendix 6.11b: Statistics of WEMWBS question responses

	I've been feeling optimistic about the future	I've been feeling useful	I've been feeling relaxed	I've been feeling interested in other people	I've had energy to spare	I've been dealing with problems well	I've been thinking clearly	I've been feeling good about myself	I've been feeling close to other people	I've been feeling confident	I've been able to make up my own mind about things	I've been feeling loved	I've been interested in new things	I've been feeling cheerful
Mean	3.08	3.14	2.67	3.39	2.72	3.01	3.08	2.55	3.09	2.61	3.16	3.37	3.12	2.92
Median	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00
Std. Deviation	.977	.948	.944	.881	1.078	.887	.963	1.100	.969	1.059	.801	.950	1.006	1.017
Skewness	-.338	-.104	.320	-.392	.053	-.144	-.253	.110	.083	.165	.024	-.329	-.243	-.073
Std. Error of Skewness	.276	.276	.276	.276	.276	.276	.276	.276	.276	.276	.276	.276	.276	.276
Kurtosis	-.002	-.258	.093	.255	-.452	-.338	-.088	-.867	-.672	-.484	.042	-.289	-.317	-.348
Std. Error of Kurtosis	.545	.545	.545	.545	.545	.545	.545	.545	.545	.545	.545	.545	.545	.545

Appendix 6.12: Original classification table for step 0 (42 as cut point value)

		Observed	Predicted		Percentage Correct
			Wellbeing 42	1.00	
Step 0	Wellbeing 42	.00	38	0	100.0
		1.00	33	0	.0
	Overall Percentage				53.5

Appendix 6.13: Classification Table (42 as cut point value)

		Observed	Predicted		Percentage Correct
			Wellbeing cut point 42	1.00	
Step 1	Wellbeing 42	.00	27	12	69.2
		1.00	7	30	81.1
	Overall Percentage				75.0
Step 2	Wellbeing 42	.00	30	9	76.9
		1.00	8	29	78.4
	Overall Percentage				77.6

Appendix 6.14: Variables not in the Equation (Steps 1 and 2 with 42 as cut point value)

			Score	df	Sig.
Step 1	Variables	Motivation/intrapersonal	3.984	1	.046
		Help seeking	.268	1	.605
		Personal difficulties inside the group	12.630	1	0.000380
		Talking	1.294	1	.255
		Self recognition	2.633	1	.105
		Struggles	1.292	1	.256
		Freedom to eat	.964	1	.326
		Weight and calories behaviours	.494	1	.482
			.182	1	.670
		Sustaining recovery	4.750	1	.029
		Ethnic group	.801	1	.371
		Age	.214	1	.643
Overall Statistics			17.714	12	.125
Step 2	Variables	Motivation/intrapersonal	.340	1	.560
		Help seeking	.498	1	.480
		Talking	.041	1	.840
		Self recognition	.529	1	.467
		Struggles	.709	1	.400
		Freedom to eat	.389	1	.533
		Weight and calories	.063	1	.801
		Behaviours	.107	1	.743
		Sustaining recovery	2.882	1	.090
		Ethnic group	.659	1	.417
		Age	.242	1	.623
		Overall Statistics			6.165

Appendix 6.15: Variables not in the equation at Step 0 (51 as cut point value)

			Score	df	Sig.
Step 0	Variables	Age	3.097	1	.078
		Ethnic grp	.422	1	.516
		Motivation/Intrapersonal	4.960	1	.026
		Help seeking	2.782	1	.095
		Personal difficulties inside the group	9.686	1	.002
		Talking	.538	1	.463
		Impact on self	8.905	1	.003
		Self recognition	1.428	1	.232
		struggles	9.216	1	.002
		Freedom to eat	6.765	1	.009
		Weight and calories	8.179	1	.004
		Behaviours	.324	1	.569
		Sustaining recovery	8.338	1	.004
Overall Statistics			22.398	13	.049

Appendix 6.16: Classification Table Step 0 (51 as cut point value)

		Predicted			
		Wellbeing 51		Percentage Correct	
Observed		.00	1.00		
Step 0	Wellbeing 51	.00	57	0	100.0
		1.00	19	0	.0
	Overall Percentage				

The constant is included in the model. The cut value is .500

Appendix 6.17: Classification table for the two steps (51 as cut point value)

		Predicted			
		Wellbeing 51		Percentage Correct	
Observed		.00	1.00		
Model 1	Wellbeing 51	.00	53	4	93.0
		1.00	13	6	31.6
	Overall Percentage				
Model 2	Wellbeing 51	.00	55	2	96.5
		1.00	13	6	31.6
	Overall Percentage				

a. The cut value is .500

Appendix 6.18: Original Classification Table Step 0 (cut point value 35)

		Predicted			
		Wellbeing 35		Percentage Correct	
Observed		.00	1.00		
Step 0	Wellbeing 35	.00	0	18	.0
		1.00	0	58	100.0
	Overall Percentage				

The Constant is included in the model. The cut value is .500.

Appendix 6.19: Variables not included in the equation (cut point value 35)

			Score	df	Sig.
Step 0	Variables	Motivation/intrapersonal	1.713	1	.191
		Help seeking	.485	1	.486
		Personal difficulties inside the group	3.935	1	.047
		Talking	.092	1	.762
		Impact on self	9.186	1	.002
		Self recognition	.176	1	.675
		struggles	4.469	1	.035
		Freedom to eat	8.174	1	.004
		Weight and calories	3.866	1	.049
		Behaviours	.227	1	.634
		Sustaining recovery	.755	1	.385
		Age	4.355	1	.037
		Ethnicity	.095	1	.758
Overall Statistics			14.041	13	.371
Six of the variables (highlighted in green) not in the equation are significant: Personal difficulties inside the group; Impact on self; Struggles; Freedom to eat; Weight and calories; and Age.					
			Score	df	Sig.
Step 1	Variables	Motivation/intrapersonal	.001	1	.975
		Help seeking	.070	1	.791
		Personal difficulties inside the group	.852	1	.356
		Talking	.043	1	.836
		Self recognition	.005	1	.944
		Struggles	2.877	1	.090
		Freedom to eat	2.416	1	.120
		Weight and calories	.667	1	.414
		Behaviours	.197	1	.657
		Sustaining recovery	.122	1	.727
		Age	2.666	1	.102
		ethnicity	.021	1	.886
Overall Statistics			7.014	12	.857
There are two covariates which are borderline significant: 'Struggles' (0.090) and Age (0.102).					

## Chapter Seven Appendices

### Appendix 7.1: The 24 Recovery statements

1. I feel/felt excited
2. It feels/felt good
3. it feels/felt like coming back to life again
4. I feel/ felt emotional at times
5. I recognise/recognised how life is/was quite dull when I have/ had my ED
6. I can/could eat without feeling guilty
7. I can/could eat without having to exercise
8. It is/was nice being able to eat without having to worry
9. I find/found it hard to sustain my recovery at my target weight
10. I am/was sick of being ill and restricting
11. I can/could see there were many opportunities ahead of me
12. I can/could see that my ED was holding me back
13. I still have/had wobbles
14. I believe/believed that recovery is/was an ongoing thing and
15. I am not 100% recovered; I still have a lot of obsessive traits
16. It is/was easy for me to fall back into restrictive habits
17. I don't/didn't really know what it is/was to be fully recovered
18. I do purge/I did purge
19. I still think about what I can eat/ I thought about what I had eaten or could eat
20. I do record calories/ I did record calories
21. I do record my weight/did record my weight
22. I am/was scared to weigh myself because I am/was worried I will/would not like the number
23. I do count numbers/did count numbers
24. I have/ had ups and downs during my recovery

## Appendix 7.2: Would you consider attending an ED SHG (qualitative responses)

	Reasons
Yes	<ul style="list-style-type: none"> <li>-I would attend a group that supported ED in autism only.</li> <li>-I've recently been using twitter a lot for support / hearing other people's stories. I think attending a support group would be helpful way to connect and engage with people who have had similar experiences.</li> <li>-It plays a major role in my life. It can be very reflective of events I want to be in control/ strong enough, to do the right thing and have a better life.</li> <li>-To gain support and to feel less alone. There's a lot of emphasis on the younger generation having EDs but not so much adults. I wouldn't feel comfortable in a group with lots of teenagers.</li> <li>-I would feel less anxious about it</li> <li>-If the right information is given it might encourage me to go along.</li> <li>-I feel the group environment can be really supportive</li> <li>-I have just finished 12 weeks of talking therapy for my ED, I feel like while the closing of the sessions was managed well, I could still use a support system for when I have wobbles with my ED</li> <li>-Might be beneficial but would also be concerned about the factors listed in the previous section.</li> <li>-Good way to connect with support and people who understand, constant support.</li> <li>-maybe, if autistic friendly.</li> </ul>
No	<ul style="list-style-type: none"> <li>-I feel embarrassed and ashamed as a man.</li> <li>-As eating disorders are very competitive illnesses, for me a self-help group would possibly turn into a competition of who was the sickest, and if others were worse than me I would strive to be the sickest rather than getting better</li> <li>-I don't believe it would help me, I'd just try to be 'better at it' than everyone there</li> <li>-I find talking to people about problems (of any sort) a bit weird to be honest</li> <li>At the moment I'm not interested in having support, and I wouldn't be interested specifically in having support from a group setting</li> <li>-Fully recovered now</li> <li>-I need to lose weight first</li> <li>-See previous answer (previous answer: Full recovery is encouraged too much and being in partial recovery and being perfectly fine with being there is looked down on/discouraged)</li> <li>-same as previous, I think I am past the point where it would be most beneficial for me. I am coping with recovery on my own now.</li> <li>-I believe the roots of my issues to be more likely to be resolved by other types of therapy.</li> <li>-I don't think I would find it useful.</li> </ul>
I would rather not say	n/a

## Chapter Eight Appendices

### Appendix 8.1: Confidentiality Agreement (Transcription)

University of  
Hertfordshire 

PhD in Psychology  
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

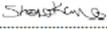
This non-disclosure agreement is in reference to the following parties:

Susan Dixon, PhD Psychology student  
And  
**RANDSTAD**

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed:  ..... (on behalf of RANDSTAD)

Name: Sharon Kane

Date: 27/05/2023

