


**Thesis submitted in partial fulfilment of the degree of Doctor of Clinical Psychology (DClinPsych)**

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## Word Count by Component

Systematic Review of the Literature.....6, 516

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Executive summary of TDRP.....983

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# Abstracts

**SRL**

Chronic abdominal-pelvic pain (CAPP) is debilitating and associated with distress, functional disability and reduced quality of life. CAPP is additionally associated with delays in diagnosis and treatment. Current NICE guidelines recommend cognitive behavioural therapy (CBT), pharmacology and more recently acceptance and commitment therapy (ACT) as interventions for chronic pain conditions broadly. Mindfulness-based approaches (MBA) have also been posited as useful, though have not yet been recommended. Despite the impact of CAPP on individuals and current interest in ACT and MBA in treating chronic pain generally, there has been no synthesis of the research supporting these interventions for CAPP. This systematic review of the literature aims to provide an overview of the current research into ACT and MBA for CAPP in both males and females.

**SIP**

Dementia is a neurodegenerative disease characterised by cognitive decline. Alzheimer's disease (a dementia subtype) affects around 88% of people with Down's Syndrome (DS) by the age of 65. In the general population, dementia is identified by comparing an individual's scores on neuropsychological assessments against age- and education- matched controls. This is not possible for people with DS due to the large variability in cognitive abilities between age- matched individuals. The United Kingdom (UK) Government has recommended baseline cognitive testing of individuals with DS at the age of 30, to provide a comparison score for later identification of dementia. Buckinghamshire Community Learning Disability Health Team (Buckinghamshire CLDHT) wished to understand potential impact of introducing a baseline assessment as part of their dementia pathway through identifying: what approach other local services are using, potential impact on staffing requirements, the number of individuals in Buckinghamshire who would be eligible for baseline assessments, an audit of the current dementia pathway used by the service, and staff thoughts on introducing baseline assessments in this population. Recommendations from this project concern allocation of responsibility for assessments across team members, and staff training.

**TDRP**

Overweight/obesity is associated with both physical and psychological correlates. Though psychological intervention is mentioned in guidelines, the nature of psychological support for this group is undefined. As such, a better understanding of the psychological underpinning and maintaining factors of overweight/obesity is timely. This study explores applicability of Cooper, Todd & Wells (2008) cognitive model, originally designed for use in disordered eating, in overweight/obesity. The role of adverse childhood experiences (ACEs), negative self-beliefs (NSB), and self-compassion in body mass index (BMI) is explored in an online sample of 222 adult females,

grouped by normal weight (BMI 18.5-24.9) and overweight/obese (BMI >25). Results indicate significantly lower mood and greater self-loathing in the overweight/obese group. There was no difference in self-compassion between the groups. No predictive relationship between ACEs or NSB and BMI was identified, nor any mediating effect of NSB or moderating effect of self-compassion on these relationships. Findings partially support the application of this cognitive model in a general population sample of overweight/obese and indicate the importance of mood. Self-loathing may be a relevant NSB in overweight/obese populations. Considering the likely heterogeneity of overweight/obese populations is important in future work.

# A systematic review of Acceptance and Commitment therapy and mindfulness-based approaches for chronic abdominal pain conditions

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**Proposed journal:** Cognitive Behaviour Therapy. This journal publishes studies within clinical health psychology that explore the application of cognitive and behavioural psychology to these fields. This journal has often published systematic review in which cognitive approaches form a comparator, or in which third-wave methods such as Acceptance and Commitment therapy are used. The submission guidelines are included in appendix 4A.
Word count: 6,516

# A systematic review of Acceptance and Commitment therapy and mindfulness-based approaches for chronic abdominal pain conditions


## Abstract

Chronic abdominal-pelvic pain (CAPP) is debilitating and associated with distress, functional disability and reduced quality of life. CAPP is additionally associated with delays in diagnosis and treatment. Current NICE guidelines recommend cognitive behavioural therapy (CBT), pharmacology and more recently acceptance and commitment therapy (ACT) as interventions for chronic pain conditions broadly. Mindfulness-based approaches (MBA) have also been posited as useful, though have not yet been recommended. Despite the impact of CAPP on individuals and current interest in ACT and MBA in treating chronic pain generally, there has been no synthesis of the research supporting these interventions for CAPP. This systematic review of the literature aims to provide an overview of the current research into ACT and MBA for CAPP in both males and females.


## Introduction

Nociplastic pain is pain not arising from neuropathy or nociceptor activation, but rather from functioning of periphery and central nervous system sensory pathways leading to increased sensitivity of these pathways (Cohen, Vase & Hooten, 2021; Fitzcharles, Cohen, Clauw, Littlejohn, Usui & Hauser, 2021). This is explained as central sensitization to pain (Nijs, Malfliet, & Nishigami, 2023) which can lead to chronic pain. Chronic pain can be muscular-skeletal or visceral organ-related, persisting for at least 3 months (Vincent & Evans, 2021). This systematic review focuses on nociplastic chronic abdominal and pelvic pain conditions (CAPP), defined here as chronic persistent visceral pain in the abdomino-pelvic area. CAPP is associated with debilitating co-morbidities such as functional disability and reduced quality of life (Ashburn & Staats, 1999; Daniels & Khan, 2010; McGarrity, Peters, & Thompson, 2000; Sewell, Churilov, Mooney, Ma, Maher, & Grover, 2018), high levels of co-morbid depression and anxiety (Urits, et al., 2020), sleep disturbances (Sun, et al., 2021) and trauma (Fishbain, Pulikal, Lewis, & Gao, 2017; Siqveland, Hussain, Lindstrom, Ruud, & Hauff, 2017).

CAPP conditions are highly prevalent (Yong, Mullins, & Bhattacharyya, 2022), and are associated with difficulties and delays in both treatment and diagnosis (Apkarian, Baliki, & Geha, 2009; Kiesel & Sourouni, 2019; Pimentel, 2018; Vincent & Evans, 2021). Co-morbidity or symptom overlap of CAPP conditions may complicate diagnosis and treatment (Saidi, Sharma, & Ohlsson, 2020) and may not be associated with identifiable pathology (Fitzcharles et al., 2021). Chronic pain is highly burdensome (Mayer, Spickschen, Stein, Crevenna, Dorner, & Simon, 2019) and has a high economic and healthcare impact (Phillips, 2009; Yong et al., 2022).

Pharmacological intervention may be recommended as a treatment, though is considered less effective for nociplastic pain relative to other forms of pain (Bułdyś, et al., 2023; Fitzcharles et al., 2021; National Institute for Health and Care Excellence [NICE], 2021; Popkirov et al., 2020). Alternative interventions, such as psychological treatment, have been recommended, including cognitive behavioural therapy (CBT) (Bułdyś et al., 2023; NICE, 2021). Acceptance and commitment therapy (ACT), has also been explored as an intervention for chronic pain (McCracken, Yu & Vowles, 2022) and in some countries included in treatment guidelines (e.g., NICE, 2021). In this context, ACT aims to develop flexible responses from the individual to their experience of pain and distress, in turn allowing for behaviour more in line with goals and values (Vowles & Thompson, 2011). Mindfulness techniques adapted for chronic pain have also been suggested, allowing awareness to emotions, bodily sensations, and thoughts without judgement, as transient moments. There is a growing evidence base identifying mindfulness-based approaches (MBA) as an efficacious treatment option (Brotto et al., 2019; Chiesa & Serretti, 2011; Day, Jensen, Ehde, & Thorn, 2014).

ACT is based on relational frame theory (RFT) which does not see thoughts or feelings as inherently problematic, unless the context surrounding them is associated with behaviours incompatible with the individual's values (Hayes, 2004). Here, pain would be a context in which thoughts or feelings may lead to behaviours that make living within one's values difficult (Yu & McCracken, 2016). ACT aims to reduce the influence of such thoughts and feelings on behaviour, in order to allow different behaviour choices (Yu & McCracken, 2016). The fear-avoidance (FA) model of chronic pain also identifies interpretation and response to pain as central to the experience of chronic (Schütze, Rees, Preece, & Schultze, 2010). This suggests a vicious circle of pain, where the experience of pain is understood as meaning harm resulting in behavioural avoidance and ultimately disability (Crombez, Eccleston, Van Damme, Vlaeyen, & Karoly, 2012). Approaches such as ACT and MBA aim for acknowledgement of pain-related thoughts, without continuing engagement in the negative cycles associated with these thoughts (Brotto et al., 2019), interrupting the vicious cycle of pain (Brotto et al., 2019), thus reducing the negative impact of pain. There are both theoretical and applied overlaps between ACT and MBA- for example, present moment awareness. CBT arguably has an emphasis on thought content, compared to ACT which has an emphasis on the context in which thoughts are considered. Some have argued that this latter option in appropriate in working with chronic pain, as pain and the emotions associated with the pain will not necessarily change (Graham, Gouick, Krahe, & Gillanders, 2016). MBA may also have a similar effect in reducing the individual's engagement with such thoughts and feelings, which may be helpful as predicted in both FA and RFT (Fletcher & Hayes, 2005).

The efficacy of CBT has recently been summarised (Urits et al., 2020), though research exploring ACT and MBA for CAPP has not- instead exploring chronic pain broadly (Hilton et al., 2017; Veehof, Trompetter, Bohlmeijer, & Schreurs, 2016; Veehof, Oskam, Schreurs, & Bohlmeijer, 2011). CAPP conditions are often associated with delay between onset of symptoms and diagnosis

(Kiesel & Sourouni, 2019; Pimentel, 2018), have heterogeneous mechanisms (Walsh, 2021), wide ranging symptoms (Kiesel & Sourouni, 2019), and involvement of complex organ systems (Vincent & Evans, 2021). Given the impact of CAPP (Ashburn & Staats, 1999; Daniels & Khan, 2010; McGarrity et al., 2000; Urits et al., 2020) and potential therapeutic and cost-efficacy of ACT and MBA (NICE, 2021) in chronic pain, a systematic review is timely. Identifying the efficacy of these approaches vs. alternative standard interventions will provide a basis for future directions in research and treatment for CAPP.

## Methods

### *Eligibility criteria*

Inclusion and exclusion criteria for the papers identified for this study are in Table 1.

*Table 1 Inclusion and exclusion criteria for papers*

| | Inclusion | Exclusion |
|---|---|---|
| Types of publication/research | Randomised controlled trials (RCTs) or controlled trials without randomisation; written in English; published in a peer reviewed publication. | Cross-sectional studies; qualitative analyses; case-studies; non-reviewed publications. Secondary analysis of same samples were excluded unless presenting novel outcomes. |
| Participants: diagnoses (CAPP conditions included) | Endometriosis-associated pain (EAP); Dysmenorrhea; Dyspareunia; Adenomyosis with associated pain; Vulva pain syndrome (VPS; previously known as vulvodynia); Provoked Vestibulodynia (PVD); Unprovoked Vestibulodynia (UPVD); Bladder pain syndrome (BPS; previously known as interstitial cystitis); Irritable bowel syndrome (IBS); Inflammatory bowel | Muscular-skeletal chronic pain; Fibromyalgia; Chronic pain secondary to cancer; Chronic pain arising from mesh surgery; Chronic visceral pain originating outside the abdomen/pelvis. |

| | | |
|---|---|---|
| | disease (IBD); Crohn's disease (CD); Ulcerative colitis (UC); Chronic visceral pain (CVP); Chronic pelvic pain syndrome (CPP); Specific internal organ pain (e.g., abdominal, stomach); male Chronic Pelvic Pain syndrome (MCPPS); Prostatitis, Prostatodynia; Prostate pain; Tension Floor Myalgia (TFM); Perineal pain. | |
| Participants: demographics | ≥18 years old; human | <18; non-human animals |
| Interventions | Acceptance and commitment therapy (ACT); All Mindfulness-based approaches (MBA), including but not limited to: Mindfulness; Mindfulness-based cognitive behavioural therapy (MCBT); Mindfulness-based stress reduction (mb-SR)<br><br>Control interventions: cognitive behavioural therapy (CBT), pharmacology, psychotherapy, waitlist control; education-based interventions; treatment as usual; relaxation; problem-solving; emotional regulation paradigms.<br><br>Interventions and controls could be delivered via individual or group formats, as self-guided programs, remotely | Any other than stated. Exclusively yoga-based interventions were not included. |

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|---|---|---|
| | or in-person. | |
| Outcomes | Pain-related distress reduction; acceptance of pain; awareness of pain/other physical experiences than pain; quality of life measures (QoL); global mindfulness measures (e.g., five facet mindfulness questionnaire); mental health measures (anxiety, depression); pain interference; biological measures of CAPP condition (e.g., inflammation markers); symptom measures (e.g., for IBS, bowel habit measures). | Any not mentioned in inclusion are considered outside of scope. |

*Databases*

Searches were run on the Medline, Embase, AMED, cumulative index to nursing and allied health literature (CINAHL), British Nursing Index (BNI), Scopus and PsychInfo databases via the Ovid platform, and the Cochrane Library database. The reference lists of all included articles were manually searched. Database searches were initially conducted on 3rd May 2022 and re-run-on 26th July 2023 and 6th May 2024 prior to submission of this report.

*Search strategy*

Search strategies are in appendix 1A. Terminology was in consultation with colleagues at a chronic pelvic pain centre and through the database thesaurus function supported by university librarians. Final search terms were approved by all authors. Search output was exported to an EndNote library.

*Selection process*

Papers passed through six stages; at of the first four stages the process was duplicated for a proportion of papers. The full data set was checked (FP) with duplication done separately by BR. 20% of titles and abstracts, 25% of full texts and 33.3% of the quality assessments were double rated. This was blind, facilitated by importing the final EndNote library in to the Rayyan platform (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016) which enables double blinding during the decision process, and after unblinding provides a summary of (dis)agreement across all papers from which kappa scores can be calculated.

1. Duplicate papers discarded during EndNote import and via Rayyan platform.
2. Title checks – discarding papers judged clearly irrelevant by their titles.
3. Abstract checks –discarding those irrelevant according to inclusion/exclusion criteria.
4. Full text checks –discarding those irrelevant according to inclusion/exclusion criteria.
5. Agreement – any disagreements regarding the inclusion of papers was discussed between the two researchers.
6. Data extraction and quality assessment.

*Data collection*

Half of included papers were independently extracted by BR to act as a quality check on the data extraction of the full set by FP. This process was conducted independently, with each researcher completing their allocations before comparing. Data was extracted independently directly into an Excel proforma. In situations where the required data was not available in the published article, authors were conducted by FP to ask for additional information if possible. Any disputes were to be resolved by reference to EE and SL. No conflicts arose.

*Data*

Outcome data was decided in agreement with EE, a specialist clinician (table 1), aiming to identify improvement for individuals receiving treatment. Ideally, outcomes were standardised and validated questionnaires or objective measures, though papers using idiosyncratic measures were included. Outcome measures required a minimum of two timepoints: pre-intervention and post-intervention.

*Effect measures*

Effect sizes were reported where possible. If effect size wasn't reported (or calculable) the authors were contacted; where no response was given effect sizes were not reported.

*Quality assessments*

Included papers were assessed using the Standard Quality Assessment Criteria (SQA) (Kmet, Cook, & Lee, 2004), which rates quantitative papers across 14 criteria. Papers are scored 0-2, with lower scores indicative of lower quality. FP used this system on all included papers; BR applied it to 33.3% as an accuracy check. Details are included in appendix 1C. There are no set cut-off scores for SQA quality ratings, though others have used >.70 as indicative of "good" quality (Lee et al., 2020; Lee, Packer, Tang, & Girdler, 2008). Quality assessment was conducted to help interpretation of the presented findings; no papers were to be excluded at the results stage based on quality rating.

**Results**

Searches were run in June 2021, July 2023 and May 2024. Figure 1 shows the stages through screening for all searches, with 34 papers included. 25% of the included papers were double screened, with 100% agreement between authors FP and BR (kappa = 1). Data extraction was done in duplicate by BR for 50% of papers, with complete agreement. The authors FP and BR quality assessment of 33.3% of the included papers showed an agreement of 94%. Tables 2-5 present the data extracted. Results reported in the tables are not separated by search dates.

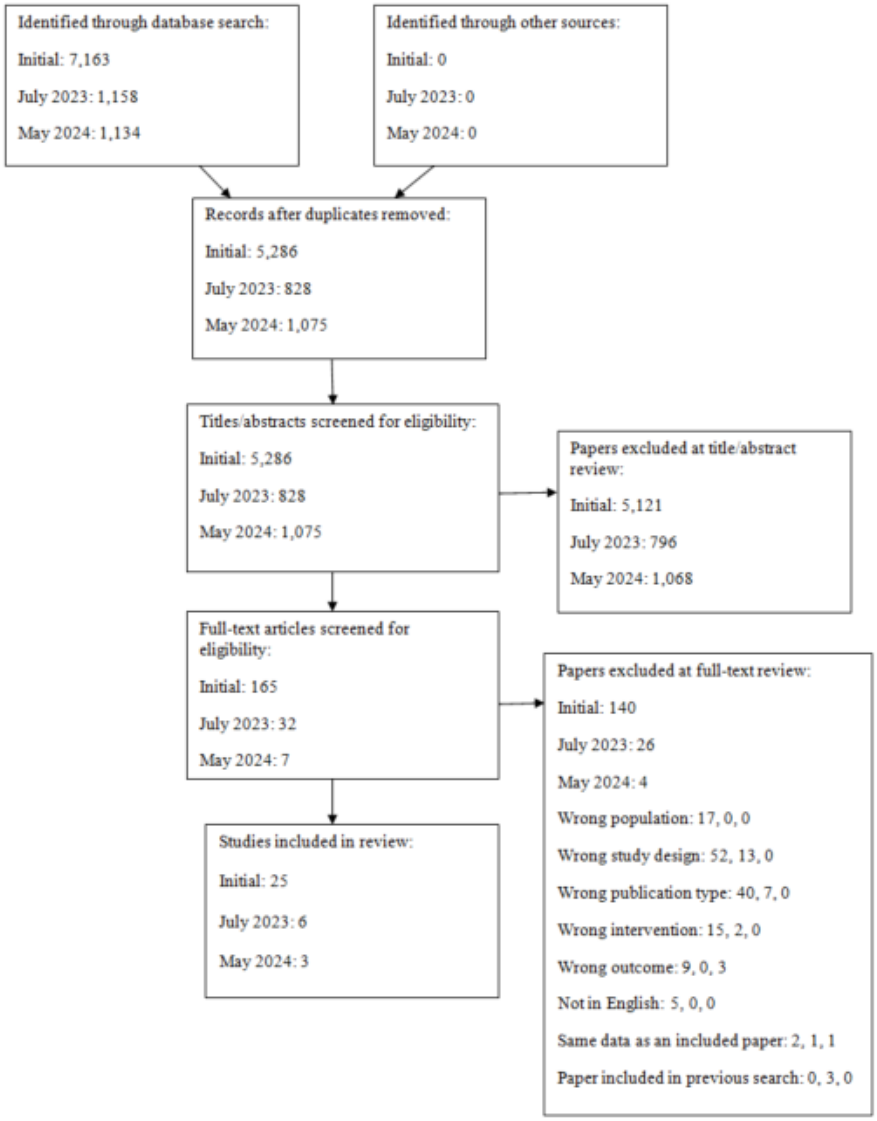



*Figure 1: PRISMA flowchart of study inclusion process (numbers in brackets represent papers from July 2023 re-run of searches). In cases where full-texts met more than 1 exclusion criteria, one criterion was chosen to represent this exclusion. A list of the exclusion criteria was written and then papers were*

*identified as excluded by the first criteria they met. Order of criteria list was: same data/sample as another included study, inappropriate population, inappropriate study design, inappropriate publication type, inappropriate intervention type, inappropriate outcome. This was to prevent duplication of the excluded papers when providing overall counts.*

A meta-analysis was not conducted as outcome data identified and application of interventions across conditions were varied enough to mean that the numbers of studies used for direct statistical comparison would be very small and at times it was not possible to gather all data required for statistical comparison in a meta-analysis. These factors are important in identifying where meta-analysis is appropriate (Mackenzie & Brennan, 2019; Campbell et al., 2020), and it is difficult to comment meaningfully on effect of interventions through a meta-analysis with significant heterogeneity. Narrative systematic reviews are considered appropriate when the subject necessitates "a meaningful synthesis of research evidence that may be complex or broad and that require detailed, nuanced description" (Sukhera, 2022, pp 414).

*Characteristics of identified studies*

Of the 34 papers included, nine explored ACT and 26 explore MBA interventions; one paper included both ACT and MBA interventions (Taghvaeinia et al., 2024). Intervention group sample sizes range from 12- 67. Ten of the included studies were female-only (28.5% of studies); seven of these all-female studies were female-associated conditions. Ethnicity data was only reported for seven studies with all but one of these papers reporting most participants as white/Caucasian (ranging from 66.7%-87%). The reported (mean) average age of intervention arm participants in included papers range from 19.8 - 46.3, and from 20.1 – 44.4 in the control arms. The included studies were from a range of geographic locations (Table 2).

Almost half (48.5%) of the studies included recruited patients with IBS. Four recruited IBD patients. Two studies recruited samples with vulvodynia (8%), with only one study (4% each) recruiting each of the following conditions: vestibulodynia, chronic pelvic pain, interstitial cystitis (bladder pain syndrome) and endometriosis. All studies used some form of assessed diagnosis (diagnostic questionnaire, historic diagnosis, or screening call).

*Table 2 Basic study information and quality ratings*

| Paper (Country) | Design | Intervention (N) | Group/ individual | Control (N) | Condition | Gender (% female) | Mean age (SD) intervention, control | Primary outcome (measure) | Further outcomes (measures) | Drop out (%) | Quality rating score |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Aghalar et al., 2020 (Iran) | Randomised, controlled | ACT (15) | Unclear | Waitlist (15) | IBS | Not stated | 33.43 (7.66, whole sample) | Illness beliefs (BIPS) | N/A | Not reported | 0.57 |
| Ashraf et al., 2022 (India) | Randomised, controlled | Mindfulness (30) | Unclear | Treatment as usual (17) | IBS | Both (13.3% intervention, 5.8% control) | 32.65 (8.14) 34.65 (10.59) | IBS severity (BS-SSS) | Mindfulness (FFMQ), QoL (WHO-QoL-Brief) | Not reported | 0.44 |
| Gaylord et al., 2011 (USA) | Randomised, controlled | Mindfulness (36) | Group | Social group (39) | IBS | Female (100%) | 44.72 (12.55) 40.89 (14.68) | IBS severity (IBS-SS) | QoL (IBS-QoL) Mood (BSI-18) Visceral sensitivity (VSI) | 9 (12%)^ | 0.96 |
| Bredero et al., 2022 (Netherlands) | Randomised, controlled | Mindfulness (56) | Group | Waitlist (57) | IBD | Both (64% intervention, 34% control) | 47.3 (12.7) 46.0 (14.8) | Fatigue (CIS-20) | Fatigue (FSI), mood (BDI, GAD-7), symptoms (IBD-Q) | 18.3% intervention, 5.9% control. | 0.89 |
| Brotto et al., 2015 (USA) | Non-randomised, controlled | Mindfulness (48) | Group | Waitlist (17) | Vulvodynia | Female (100%) | 39.0 (13.8) 40.4 (11.1) | Pain self-efficacy (PISES) | Pain hypervigilance (PHAQ) Pain catastrophising (PCS) | 12 (12.3%) | 0.77 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | Sex-associated pain (FSFS)<br>Mood (BDI)<br>Anxiety (STAI) | | |
| Brotto et al., 2019 (Canada) | Partially randomised, controlled | Mindfulness-based CBT (67)* | Group | CBT (63) | Vestibulodynia | Female (100%) | 33.72 (7.48)<br>31.24 (8.99) | Pain during intercourse (0-10 rating scale) | Pain catastrophising (PCS)<br>Pain vigilance (PVS)<br>Sex-associated pain (FSFS)<br>Sexual distress (FSDS)<br>Chronic pain acceptance (CPA) | 22 (16.9%)^ | 0.85 |
| Cebolla et a1., 2021 (Spain) | Non-randomised, controlled | Mindfulness-based (35) | Group | Waitlist (22) | IBD | Both (not specified) | 44.13 (SD missing, whole sample) | QoL (IBDQ) | Perceived stress (PSS)<br>Mood & anxiety (HADS)<br>Mindfulness (FFMQ)<br>Life orientation (LOT) | 33 (36.6%) | 0.82 |
| Forbes et al., 2020 (UK) | Randomised, controlled | Mindful meditation (27) | Individual | Muscle relaxation (23)<br>Waitlist | Chronic pelvic pain | Female (100%) | 34.8 (9.9)<br>35.7 (5.7)<br>35.0 (8.0) | Pain acceptance (CPAQ-8) | Pain-related disability (PRDS)<br>QoL (RAND- | 15 (16.6%)^ | 0.93 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | (25) | | | | | 36)<br>Mood & anxiety (HADS)<br>Mindfulness (CMRS)<br>Self0efficacy (PSES)<br>Sexual health (SHOW-Q)<br>Individualised medical outcome (MYMOP) | | |
| Garland et al., 2012 (USA) | Randomised, controlled | Mindfulness (39) | Group | Support group (36) | IBS | Female (100%) | M & SD not reported | IBS severity (IBS-SS) | Pain catastrophizing (PCS)<br>QoL (IBS-QoL)<br>Mood (BSI-18)<br>Visceral sensitivity (VSI)<br>Reinterpreting pain (RPSS)<br>Non-reactivity | 31 (31.9%) | 0.89 |
| Ghandi et al., 2018 (Iran) | Randomised, controlled | Mindfulness-based Stress Reduction (8) | Group | Emotional regulation (8)<br>Wait (8) | IBS | Both (% not reported) | M & SD not reported, range 18-45 | IBS severity (IBS-SS) | QoL (IBS-QoL) | 25 (51.4%) | 0.63 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Goren et al., 2021 (Israel) | Randomised, controlled | Cognitive Behavioural & Mindfulness-Based Stress Reduction (COBMINDEX) (55) | Individual | Waitlist (61) | Crohn's Disease | Both (65%) | 33.6 (13)<br>32.4 (11) | Disease activity (HBI) | QoL (SIQoL)<br>Mood (BSI-18)<br>Disease severity (CRP, calprotein)<br>QoL (MOS-12, EuroQual)<br>Mindfulness (FMI)<br>Fatigue (FACIT-F) | 23 (16.5%) | 0.93 |
| Guillet et al., 2019 (USA) | Randomised, controlled | Mindfulness-based Cognitive Therapy (14) | Group | Education support group (17) | Vulvodynia | Female (100%) | 34.4 (6.2)<br>29.1 (6.1) | Vestibular pain (tampon test) | Pain catastrophizing (PCS)<br>Mood (BDI-PC)<br>Anxiety (GAD-7)<br>Sexual distress (FSFI, FSDS) | 0 (0%) | 0.82 |
| Hanson et al., 2023 (Denmark) | Randomised, controlled | Mindfulness ACT (combined) (20) | Group & individual | Pseudo – intervention (19)<br>Waitlist (19) | Endometriosis | Female (100%) | 28.9<br>33.8<br>32.8 | Pelvic pain intensity & unpleasantness ratings | QoL (endo-QoL), vaginal pressure (PPDT), endo symptoms (NRS), pain acceptance (CPAQ), workability (WAI) | 2<br>3<br>3<br>(13.7%) | 1 |

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|---|---|---|---|---|---|---|---|---|---|---|---|
| Henrich et al., 2020 (UK) | Randomised, controlled | Mindfulness-based Cognitive Therapy (36) | Group (+ 1 individual session) | Waitlist (31) | IBS | Female (100%) | 35.58 (13.7)<br>35.48 (14.7) | IBS severity (IBS-SS) | QoL (IBS-QoL)<br>Mood (DASS-21)<br>Visceral anxiety sensitivity (VASS)<br>Pain catastrophising (PCS) | 23 (34.3%)^ | 0.89 |
| Hess et al., 2022 (Sweden) | Randomised, controlled | ACT-based (32) | Self-paced/individual | Waitlist (47) | Vulvodynia | Female (100%) | 24.2 (5.2)<br>24.7 (3.3) | Pain during intercourse (0-10 rating scale) | Pain acceptance (CPAQ-R)<br>Pain (tampon test) | 42 (42.4%)^ | 0.81 |
| Jedel et al., 2022 (USA) | Randomised, controlled | Mindfulness (20) | Group | Pseudo intervention (23) | Ulcerative colitis | Both (50% group, 65% control) | 44.8 (13.5)<br>38.7 (10.5) | Frequency of flares (Mayo/Mayo DAI) | IBD symptoms (IBDQ)<br>Pain (PSQ)<br>Mindfulness (FFMQ)<br>Mood (BDI), Anxiety (STAI) | Not reported | 0.89 |
| Ito et al., 2020 (Japan) | Randomised, controlled | ACT-based (14) | Mix group & self-paced individual | Waitlist (12) | IBS | Both (61.5%) | 19.86 (1.2)<br>20.1 (1.0) | IBS severity (IBS-SI) | QoL (IBS-QoL)<br>Mood (BDI)<br>Anxiety (STAI) | 9 (34.6%)^ | 0.70 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Kanter et al., 2016 (USA) | Randomised, controlled | Mindfulness-based Stress Reduction (8) | Group | Treatment as usual (11) | Interstitial Cystitis | Female (100%) | 46.3 (15.2)<br>44.4 (13.9) | Global response (GRA) | Pain rating (0-10 rating scale)<br>QoL (SF-36)<br>Acceptance (AAQII)<br>Psych flexibility (CFQ)<br>Mindfulness (FFMQ) | 1 (5%) | 0.70 |
| Ljotsson et al., 2010 (Sweden) | Randomised, controlled | Mindfulness-based Cognitive Therapy (42) | Self-paced individual | Waitlist with online forum access (42) | IBS | Both (72%) | 36.4 (10.1)<br>32.8 (8.6) | IBS symptoms (GSRS-IBS) | QoL (IBS-QoL)<br>Mood (MADRS-5)<br>Pain self-efficacy (PSEQ) | 5 (5.8%)^ | 0.81 |
| Maathz et al., 2023 (Sweden) | Randomised, controlled | ACT (22) | Self-paced individual | Waitlist (22) | Vestibulodynia | Female (100%) | 25.3 (2.99)<br>28.24 (6.07) | Feasibility (not reported in this review) | Sexual distress (FSFI, FSDS-R)<br>Acceptance (CPAQ)<br>Mood (HADS)<br>QoL (SWLS) | 3 (6.8%) | 0.85 |
| Mirsharifa et al., 2019 (Iran) | Randomised, controlled | ACT (15) | Unclear | Treatment as usual/wait list (15) | IBS | Both (63.3%) | 31.9 (SD missing, whole sample) | Mood (BDI) | Tolerance & self-efficacy (PCQ)<br>Visceral sensitv. (VSI) | 10 (25%) | 0.67 |

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|---|---|---|---|---|---|---|---|---|---|---|---|
| Mohamadi et al., 2019 (Iran) | Randomised, controlled | Mindfulness-based Cognitive Therapy (20) | Group | Treatment as usual/wait list (20) | IBS | Both (47.5%) | 28.6 (3.2)<br>29.9 (4.5) | Perceived stress (PSS) | QoL (IBS-QoL)<br>Visceral sensitivity (VSI)<br>Disability (SDS)<br>Treatment credibility scale | 0 (0%) | 0.64 |
| Moreira et al., 2021 (Brazil) | Randomised, controlled | Brief Mindfulness-based (31) | Group | Treatment as usual (32) | Endometriosis | Female (100%) | 37.7 (7.3)<br>34.7 (8.1) | Pain intensity (0-10 rating) | QoL (SF-36)<br>Perceived stress (PSS)<br>Mindfulness (FFMQ) | 17 (26.9%) | 0.89 |
| Neilson et al., 2016 (Australia) | Non-randomised, controlled | Mindfulness-based Stress Reduction (27) | Group | Treatment as usual (25) | IBD | Both (76% intervention, 59% control) | 38.5 (10.6)<br>33.8 (12.2) | QoL (WHO-QoL) | Mood & anxiety (HADS)<br>Mindfulness (FFMQ) | 7 (11.7%) | 0.78 |
| Pourkazem et al., 2024 (Iran) | Randomised, controlled | Mindfulness-based Stress Reduction (15) | Unclear | Compassion-focussed therapy (15)<br>Waitlist (15) | IBS | Not stated. | Not stated, range for total sample stated as 20-40 years. | Cognitive emotional regulation scale (CERS) | NA | Not reported. | 0.45 |

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|---|---|---|---|---|---|---|---|---|---|---|---|
| Schoultz et al., 2015 (UK) | Randomised, controlled | Mindfulness-based Cognitive Therapy (22) | Group | Treatment as usual (22) | IBD | Both (73% intervention, 82% control) | 22.5 (12.0) 22.5 (15.4) | Disease activity (CDAI, SCCAI) | IBD-QoL (IBD-Q) Mood (BDI) Anxiety (STAI) Dispositional mindfulness | 10 (22.7%)^ | 0.89 |
| Shahkaram et al., 2024 | Randomised, controlled | ACT (15) | Unclear | Unified protocol for transdiagnostic treatment (UP) (15) | IBS | Both (86.7% intervention, 80% control) | 33.5 (6.7) 33.7 (3.7) | Depression & anxiety (DASS-21) | Rumination (RRS) Satisfaction with life (SWSL) | 12 (28.5) | 0.61 |
| Shakernejad et al., 2021 (Iran) | Randomised, controlled | ACT-based (15) | Group | Treatment as usual (15) | IBS | Both (60%) | 34.5 (18.4) 42.8 (18.0) | QoL (QoL-Q) | Disease activity (faecal calprotein) | 0 (0%) | 0.78 |
| Taghvaeinia et al., 2024 (Iran) | Randomised, controlled | ACT (22) MBSR (22) DBT (22) | | Unspecified control (22) | IBS | Both (40.9% ACT, 31.6% MBSR, 35% DBT, 31.8% control) | 35 (6.1) ACT 36 (7.7) MBSR 37.8 (8.5) DBT 37.2 (8.3) control | IBS symptom severity (IBS-SSS) | QoL (IBS-QoL) anxiety (BAI) Low mood (BDI) | 5 (5.6%) | 0.67 |
| Regav et al., 2022 (Israel)* | Randomised, controlled | Mindfulness-based Cognitive Therapy (72) | Individual | Waitlist (70) | Crohn's Disease | Female (67% intervention, 58% control) | 34.4 (11.7) 33.6 (9.4) | Work productivity (not reported in this review) | Pain (HBI, SIBDQ) | 18 (12.6%) | 0.89 |

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|---|---|---|---|---|---|---|---|---|---|---|---|
| Wynne et al., 2019 (Ireland) | Randomised, controlled | ACT-based (37) | Group | Treatment as usual (42) | IBD | Both (54% intervention 55% control) | 40.6 (11.2)<br>39.9 (12.2) | Mood (DASS-21) | Disease activity (CDAI, Mayo score)<br>QoL (SF-36)<br>Perceived stress (0-10 rating)<br>Psych flexibility (AAQ)<br>Disease activity (faecal calprotein, cortisol) | 43 (35.2%)^ | 0.85 |
| Zernicke et al., 2013 (Canada) | Randomised, controlled | Mindfulness-based Stress Reduction (43) | Group | Treatment as usual (47) | IBS | Both (90% intervention, 87% control) | 45 (12.4)<br>44 (12.6) | IBS severity (IBS-SSS) | QoL (IBS-QoL)<br>Mood (POMS)<br>Stress (C-SOSI)<br>Spirituality (FACIT-SP) | 30 (33.3%)^ | 0.85 |
| Zomorodi et al., 2014 (Iran) | Randomised, controlled | Mindfulness-based Therapy (12) | Group | CBT (12)<br>Treatment as usual (12) | IBS | Both (50% intervention, 48% each control) | 34.3 (4.2)<br>29.4 (5.8)<br>33.4 (5.3) | IBS symptoms | | 0 (0%) | 0.67 |
| Zomorodi | Randomised, | Mindfulness- | Group | CBT | IBS | Both (50% | 34.3 (4.2) | QoL (IBS- | | 0 | 0.67 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| et al., 2015 (Iran) | controlled | based Therapy (12) | (12) Treatment as usual (12) | intervention, 48% each control) | 29.4 (5.8) 33.4 (5.3) | QoL) | (0%) |

*Included paper is further analysis of Goren et al, 2021 using the same patients but a different outcome and different timepoint (3m FU rather than immediately post intervention).

Table 3 details interventions.

*Table 3 Study intervention information*

| Paper | Condition | Number of sessions | ACT<br>Length of sessions | Length of intervention (total time where identifiable) | Delivery type | Delivered by (authors description) |
|---|---|---|---|---|---|---|
| Hess et al., 2022 | Vulvodynia | 6 | Self-paced | 6 weeks | Individual, self-directed | Research assistant |
| Maathz et al., 2023 | Vesitbulodynia | 6 | Self-paced | 6 weeks | Individual, self-directed | Therapist |
| Aghalar et al., 2020 | IBS | 8 | 90 minutes | 8 weeks (12 hours) | Unclear | Therapist |
| Ito et al., 2020 | IBS | 1 organised, rest self-paced | Self-paced, across 2 months | 8 weeks | Combination individual self-paced & group | Clinical psychologist |
| Mirsharifa et al., 2019 | IBS | 6 | 90 minutes | 6 weeks (9 hours) | Unclear | Not reported |
| Shahkaram et al., 2024 | IBS | 8 | 45-90 minutes | 8 weeks (6-12 hours) | Unclear | Not reported |
| Shakerneja et al., 2021 | IBS | 8 | 120 minutes | 8 weeks (16 hours) | Group | Not reported |
| Taghvaeinia et al., 2024* | IBS | 8 | 12 minutes | 8 weeks (16 hours) | Group | ACT training coach |
| Wynne et al., 2019 | IBD | 8 | 120 minutes | 8 weeks (16 hours) | Group | ACT-trained clinical psychologist |
| *Paper appears in both ACT and MBA tables as it provides comparison of these interventions. | | | | | | |

| Paper | Condition | Number of sessions | MBA<br>Length of sessions | Length of intervention | Delivery type | Delivered by |
|---|---|---|---|---|---|---|
| Brotto et al., 2015 | Vulvodynia | 4 | Not reported | 4 weeks | Group | Not reported |
| Guillet et al., 2021 | Vulvodynia | 8 | 135 minutes | 8 weeks (18 hours) | Group | Trained clinician |
| Brotto et al., 2019 | Vestibulodynia | 8 | 135 minutes | 8 weeks (18 hours) | Group | Trained clinician |
| Forbes et al., 2020 | CPP | 60 | 10-20 minutes, progressively | 60 days (10-20 hours) | Individual, self-directed | Headspace app |
| Kanter et al., 2016 | Interstitial cystitis | 7 | 120 minutes & 1 full day | 7 weeks (12 hour + 1 day) | Group | Mindfulness trained clinician |
| Hansen et al., 2023 | Endometriosis | 8 | 3 hours | 10 weeks (24 hours) | Group | Clinical Psychologist |
| Moreira et al., 2021 | Endometriosis | 7 | 90 minutes | 7 weeks (10.5 hours) | 4 weeks group, 3 weeks individual self-directed | Mindfulness trained clinician |
| Ashraf et al., 2022 | IBS | 8 | 45 minutes | 8 weeks (6 hours) | Group | Clinical psychologist |
| Gaylord et al., 2011 | IBS | 8 | 120 minutes | 8 weeks (16 hours) | Group | Experienced instructor |
| Garland et al., 2012 | IBS | 8 | 120 minutes | 8 weeks (16 hours) | Group | Mindfulness trained clinician |
| Ghandi et al., 2019 | IBS | 8 | 90 minutes | 8 weeks (12 hours) | Group | Psychotherapist |
| Henrich et al., 2020 | IBS | 6 | 120 minutes | 6 weeks (12 hours) | Group & 1 individual facilitated session | Clinical psychologist with relevant experience |
| Ljotsson et al., 2010 | IBS | 5 | Self-paced, weekly | 5 weeks | Individual, self-directed | Graduate student with CBT training |
| Mohamadi et al., 2019 | IBS | 8 | 150 minutes | 8 weeks (20 hours) | Group | Clinical psychologist with relevant experience |

**MBA**

| Paper | Condition | Number of sessions | Length of sessions | Length of intervention | Delivery type | Delivered by |
|---|---|---|---|---|---|---|
| Pourkazem et al., 2024 | IBS | 8 | 90 minutes | Not stated | Not stated | Not stated |
| Taghvaeinia et al, 2024* | IBS | 8 | 120 minutes | 8 weeks (16 hours) | Group | Clinical psychologist with relevant experience |
| Zernicke et al., 2013 | IBS | 8 | 90 minutes | 8 weeks (12 hours) | Group | Registered nurse with relevant experience |
| Zomorodi et al., 2014 | IBS | 8 | 120 minutes | 8 weeks (16 hours) | Group | Not reported |
| Zomorodi et al., 2015 | IBS | 8 | 120 minutes | 8 weeks (16 hours) | Group | Not reported |
| Bredero et al., 2022 | IBD | 8 | 150 minutes & one 3-hour session | 8 weeks (20.5 hours) | Group | Trained mindfulness practitioner |
| Cebolla et al., 2021 | IBD | 8 | 120 minutes | 8 weeks (16 hours) | 4 group sessions, 4 individual self-directed | Trained mindfulness practitioner |
| Neilson et al., 2016 | IBD | 9 | 150 minutes & 1 full day | 9 weeks (20 hours + 1 day) | Group | Clinical psychologists and psychiatrist with relevant supervision |
| Schoulz et al., 2015 | IBD | 9 | 120 minutes & 1 full day | 9 weeks (18 hours + 1 day) | Group | Trained mindfulness practitioner |
| Goren et al., 2021 | Crohn's disease | 7 | 90 minutes | 7 weeks (10.5 hours) | Group | Clinical social worker with relevant experience |
| Regev et al., 2022 | Crohn's disease | 7 | 60 minutes | Spread over 3 months (7 hours) | Individual | Social workers |
| Jedel et al., 2022 | UC | 8 | 90-120 minutes & optional half day | 8 weeks | Group | Trained mindfulness practitioner |

*Paper appears in both ACT and MBA tables as it provides comparison of these interventions.

**ACT for CAPP**

Nine ACT studies were included: six of IBS, one of IBD, one of vestibulodynia patients and one of vulvodynia. The included studies used a range of different outcomes (table 4). Two ACT papers had an active control group.

*Pain outcomes:*

In one study of vulvodynia, ACT was found to have a significant impact (both immediately post treatment and at 9m FU) on pain during intercourse, pain acceptance and pain-related behaviours with large to small effect sizes respectively ($d$ = 1.4; $d$ = .046) (Hess Engström et al., 2022). However, the same study did not find an effect of ACT on a non-intercourse measure of pain (the tampon test- a standardised and validated measure in which a tampon is inserted and removed, with a pain rating completed (Foster et al., 2009). Pain during sex was shown to improve in following ACT compared to control in vestibulodynia ($d$ = 0.37), as was pain catastrophising ($d$ = 0.78) and pain acceptance (1.07) (Maathz et al., 2023).

*QoL:*

QoL improved immediately after ACT intervention and at 3m FU in one IBD study (Wynne et al., 2019) and post-intervention in one IBS study (Taghvaeinia et al., 2024) though another IBS study did not find this (Ito & Muto, 2020). Satisfaction with life was shown to significantly improve after ACT relative to a waitlist control, in patients with vestibulodynia with a large effect size ($d$ = 1.18) (Maathz et al., 2023).

*Disease severity/symptom severity:*

ACT was shown to have a significant impact on symptom severity in IBS in one study (Taghvaeinia et al., 2024), but did not have an effect in two other studies (Ito & Muto, 2020; Shahkaram et al., 2024) or disease activity in IBD (Wynne et al., 2019).

*Mood, stress, psychological capital:*

ACT was also found to have a positive impact on mood and psychological capital in IBS immediately post treatment, though the effect size was small and the study was of low quality (Mirsharifa, Mirzaian & Dousti, 2019) (table 2). Another study identified an effect of ACT on mood and anxiety in IBS (Taghvaeinia et al., 2024); a third study also found this but did not provide direct comparison to the control despite data being available (Shahkaram et al., 2024). ACT had a positive impact on anxiety in vestibulodynia (Maathz et al., 2023).

*Illness perception:*

ACT had a significant positive impact on illness perception immediately post treatment, including measures of illness sequences, personal control, thoughts about the nature or illness, worrying about illness, with medium effect sizes (0.4- 0.44) (Aghalar, Moradi, Saraj, & Hafezi, 2020). ACT also had a positive effect on affect response to illness in IBS post intervention, with a large effect size (0.63) (Aghalar et al., 2020).

*Drop-out, delivery formats, timeframes:*

ACT interventions in this study lasted 6-10 weeks; UK guidelines recommend minimum three months intervention window for psychological approaches to chronic pain (NICE, 2021). Delivery was either group or self-directed individual, with no directed 1:1 intervention in any study. Three studies used clinical psychologists to deliver the intervention. Drop-out rates ranged 0-42.4% (with one study not reporting drop-out: Aghalar et al., 2020).

*Study quality:*

Quality review outcomes ranged from 0.57 (Aghalar et al., 2020) to 1 (Hansen et al., 2023), with lower scores largely reflecting lack of researcher blinding or poor reporting of study details. 55% of these ACT studies scores >.70, which can be classes as "good" quality (Lee et al., 2008; Lee et al., 2020). ACT studies with poorer quality ratings (<.70) were largely IBS-focused (Aghalar et al., 2020; Mirsharifa et al., 2019; Shahkaram et al., 2024; Taghvaeinia et al., 2024) and identified improvements in illness beliefs (Aghalar et al., 2020), mood (Mirsharifa et al., 2019; Shahkaram et al., 2024; Taghvaeinina et al., 2024), anxiety (Taghvaeinia et al., 2024) and QoL (Taghvaeinia et al., 2024).

*Table 4 Main outcomes, ACT studies. A simplified table showing the outcomes used by each study is included in appendix 1D, for clarity.*

| Paper | Condition | Control | Time points | Statistical tests | Main findings | Effect size (ES) for significant findings |
|---|---|---|---|---|---|---|
| Hess et al., 2021 | Vulvodynia | Waitlist | Pre, Post, FU (9 m) | General linear model | Pain (during intercourse): Significant reduction in self-reported pain during intercourse 6 weeks post intervention, remaining at 9 months post intervention (for primary vulvodynia, not secondary), ACT>control.<br>Pain (tampon test): No significant difference between groups.<br>Pain acceptance: Significant improvement in acceptance if willingness to try sexual intercourse is controlled for ACT>control, but otherwise no significant change.<br>Pain-related behaviour: Significant different controls>ACT in terms of intercourse attempts, with intervention group making fewer attempts. No significant difference between groups in regards to sexual activities other than intercourse. | Pain during intercourse: $d$ = 1.4<br>Pain (tampon test): N/A<br>Pain acceptance: $d$ = 0.46<br>Pain-related behaviour: Not reported. |
| Maathz et al., 2023 | Vestibulodynia | Waitlist | Pre, Post | ANOVA | Pain (during intercourse): No significant difference between groups.<br>Pain acceptance: Significant increase in pain acceptance for ACT>control.<br>Pain catastrophizing: Significant decrease, ACT>control.<br>Mood: No significant difference.<br>Anxiety: Significant reduction in anxiety ACT> control.<br>QoL/Satisfaction with life: Significant improvement, ACT>control. | Pain (during intercourse): $d$ = 0.37<br>Pain acceptance: $d$ = 1.07<br>Pain catastrophizing: $d$ = 0.78<br>Anxiety: $d$ = 0.67<br>QoL/satisfaction: $d$ = 1.18 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | Relationship satisfaction: No significant difference. | |
| Aghalar et al., 2020 | IBS | Waitlist | Pre, Post | Multivariate analysis of covariance | Illness perception: A significant reduction in all aspects of illness perception ACT>control (illness sequences, personal control, nature of illness, control through treatment, worrying about illness, affectional response to illness), with the exception of disease duration and reported knowledge about illness. | Illness perception: Illness sequences $d$ = 0.46, personal control $d$ = 0.43, nature of illness $d$ = 0.43, control through treatment $d$ = 0.44, worrying about illness $d$ = 0.4, affectional response to illness $d$ = 0.63 |
| Ito et al., 2020 | IBS | Waitlist | Pre, Post, FU (2 m) | ANOVA | Symptom severity: No significant change<br>QoL: No significant change | Symptom severity: N/A<br>QoL: N/A |
| Mirsharifa et al., 2019 | IBS | Waitlist | Pre, Post | MANCOVA | Mood: Significant reduction in low mood, ACT>control.<br>Psychological capital (hope, optimism, tolerance): Significant improvement, ACT>control. | Mood: $\eta 2 = 0.29$<br>Psychological capital: $\eta 2 = 0.08$ |
| Shahkarem et al., 2024 | IBS | UP | Pre, Post | Paired t-test | Mood: Significant reduction in low mood pre- to post for both interventions, groups not compared.<br>Anxiety: Significant reduction pre- to post for both interventions, groups not compared.<br>Rumination: Significant reduction pre- to post for both interventions, groups not compared.<br>Life satisfaction: No significant difference pre- to post intervention. | Mood: ACT $d$ = 1.44, UP $d$ = 1.29<br>Anxiety: ACT $d$ = 1.16, UP $d$ = 1.71<br>Rumination: ACT $d$ = 1.52, UP $d$ = 1.50 |
| Shakerneja et al., 2021 | IBS | TAU | Pre, Post, FU (3 m) | ANOVA | Activity levels: Significant improvement in ACT but not controls. Significant effect of group only if pre-intervention activity level was controlled for. | Not reported |

| | | | | | | |
|---|---|---|---|---|---|---|
| Taghvaeinia et al., 2024* | IBS | MBSR, DBT, Undefined control | Pre, Post | Repeated measures MANOVA | Symptom severity: lower symptom severity self-rating ACT> MBSR, DBT and control.<br>QoL: Higher QoL ratings ACT> MSBR, DBT and control.<br>Anxiety: Lower anxiety self-rating, ACT> MBSR, DBT and control.<br>Low mood: Lower depression self-rating, ACT> MBSR, DBT, control. | Symptom severity: $d = 0.20$<br>QoL: $d = 0.15$<br>Anxiety: $d = 0.18$<br>Low mood: $d = 0.22$ |
| Wynne et al., 2019 | IBD | TAU | Pre, Post, FU (3 m) | ANOVA | Mood: Significant reduction in stress and mood, ACT>control. No significant change in anxiety.<br>Disease activity: No significant change<br>QoL: Significant reduction in disease worry, ACT>control at post and FU. Significant improvement in general well-being, ACT>control at post and FU (for per protocol analysis, not for ITT). No significant change in burden or daily ability. | Mood: Not reported<br>Disease activity: N/A<br>QoL: Not reported |

*Paper appears in both ACT and MBA tables as provides direct comparison of these interventions.
For effect size meanings, see appendix 1B.

**MBA for CAPP**

Twenty-six MBA studies were included; 12 were studies of IBS (46%), four studies of IBD (15%), two of vulvodynia (8%), two of endometriosis (8%) and one study each in vestibulodynia, CPP, interstitial cystitis, ulcerative colitis (UC) and Crohn's disease (3% each). Table 5 shows the findings. Waitlist or TAU was used as the only control arm in 16 studies (61%). Support or social groups were used as the active control in three studies (11%), CBT in three studies (11%), emotional regulation in one study (3%), educational psychology groups in one (3%), DBT in one (3%), ACT (3%) and muscle relaxation in one (3%). Five studies (19%) used both a waitlist/TAU control arm and an active control (two CBT, one emotional regulation, one DBT and ACT, and one muscle relaxation).

*QoL:*

Nine studies identified significant improvement following MBA relative to the control arm (Ashraf, Akhouri, Bhardaj, & Siddiqui, 2022; Cebolla, Gonzalez-Moret, Cortes, Soria, Banos, & Lison, 2021; Garland, Gaylord, Palsson, Faurot, Mann, & Whitehead, 2012; Gaylord et al., 2011; Henrich et al., 2020; Ljótsson et al., 2010; Moreira, Gamboa, & Pino Oliveira, 2022; Neilson et al., 2016; Taghvaeinia et al., 2024). Two of these show improvement relative to a social group control (Garland et al., 2012; Gaylord et al., 2011) (immediately post intervention and at 3m FU respectively), one to a CBT control group both immediately post intervention and at 2m FU (Zomorodi, Tabatabaee, Arbabi, Falah, & Daryani, 2015) and five studies to TAU/waitlist (Ashraf et al., 2022; Ljótsson et al., 2010; Moreira et al., 2022; Neilson et al., 2016; Zomorodi et al., 2015) (all immediately post intervention and at FU, with the exception of Neilson et al., 2016 where the effect did not remain at 8m FU and Ashraf et al., 2022 who did not include a FU timepoint). The effect sizes indicated by these studies represent a wide range from small $\eta^2 = 0.01$ and $\eta^2 = 0.07$ (Cebolla et al., 2021; Gaylord et al., 2011) to large ($d = 0.93$ and $d = 1.73$) (Ljótsson et al., 2010; Neilson et al., 2016); all available effect sizes are in Table 5. One study found a medium effect for ACT on QoL relative to MBSR, DBT or control pre to post intervention ($d = 0.15$) (Taghvaeinia et al., 2024). A further five studies found a significant improvement in QoL after MBA intervention over time but no group effect compared to waitlist/control (Goren et al., 2022; Henrich, Gjelsvik, Surawy, Evans, & Martin, 2020; Jedel et al., 2022; Mohamadi et al., 2019; Zernicke et al., 2013). Two of these identified change immediately post intervention and at FU (Henrich et al., 2020; Zernicke et al., 2013), two measured only immediately post intervention (Goren et al., 2022; Mohamadi et al., 2019).

Five studies found no significant effect of MBA on QoL (Bredero et al., 2023; Forbes et al., 2020; Ghandi et al., 2018; Kante et al., 2016; Schoultz, Atherton & Watson, 2015). All of these studies compared MBA to TAU/waitlist; one also compared MBA to an emotional regulation control arm with no effect (Ghandi et al., 2018).

*Mood:*

Improvement in mood following MBA was shown in several studies (Garland et al., 2012; Guillet, Cirino, Hart, & Leclair, 2019; Ljótsson et al., 2010; Neilson et al., 2016; Schoultz et al., 2015). Three of these studies compared MBA to TAU/waitlist (Bredero et al., 2023; Ljótsson et al., 2010; Neilson et al., 2016; Schoultz et al., 2015). Ljottson et al (2010) provided additional chat forum access to their waitlist, whilst the remaining used support groups as a control arm (Garland et al., 2012; Guillet et al., 2019). Significant findings were shown immediately post intervention and remained at FU for two of the studies (Neilson et al., 2016; Schoultz et al., 2015), one noted change only immediately post intervention (Ljótsson et al., 2010) and one recorded change at FU only (Guillet et al., 2019). Bredero et al (2022) reported change post intervention with per protocol analysis but did not include a FU time point. See Table 5 for FU lengths. Available effect sizes for these results are shown in Table 5 and range from medium ($d$ = 0.43) (Ljótsson et al., 2010) to large ($\eta p^2$ = 0.173) (Schoultz et al., 2015). A further four studies identified significant improvement in mood following MBA intervention across time, but no effect of group (Brotto et al., 2015; Henrich et al., 2020; Jedel et al., 2022; Zernicke et al., 2013). Change was noted immediately post intervention, remaining at FU for two (Henrich et al., 2020; Zernicke et al., 2013). One study found ACT improved mood more so than MBSR pre- to- post intervention ($d$ = 0.22) (Taghvaeinia et al., 2024). Finally, two studies identified no change in mood following MBA intervention when compared to a social group, muscle relaxation or TAU (Ashraf et al., 2022; Brotto et al., 2019).

*Disease severity/symptom severity:*

Seven studies identified a significant impact of MBA relative to controls (Gaylord et al., 2011; Ghandi et al., 2018; Goren et al., 2022; Henrich et al., 2020; Ljótsson et al., 2010; Zernicke et al., 2013; Zomorodi et al., 2014). One of these compared MBA to a social group (Gaylord et al., 2011), one to CBT (Zomorodi et al., 2014), another to emotional regulation (Ghandi et al., 2018) and four to TAU/waitlist (Goren et al., 2022; Henrich et al., 2020; Ljótsson et al., 2010; Zernicke et al., 2013). All available effect sizes for these outcomes are shown in table 5; effect sizes range from small ($\eta^2$ = 0.10) (11) to large ($d$ = 0.64) (Ljótsson et al., 2010). Changes were noted immediately post treatment for 5 studies (Gaylord et al., 2011; Goren et al., 2022; Ljótsson et al., 2010; Zernicke et al., 2013; Zomorodi et al., 2014), retained at FU in two of these (Gaylord et al., 2011; Zernicke et al., 2013). Two studies noted significant change at FU but not immediately post treatment (Ghandi et al., 2018; Henrich et al., 2020). One study found ACT had a stronger effect than MBSR on reducing symptom severity ratings in IBS (Taghvaeinia et al., 2024). One study noted significant reduction in flares as a measure of disease severity in UC relative to controls (Jedel et al., 2022); a further study identified significant impact of MBA on disease/symptom severity over time (immediately post treatment), but no effect of group when compared to the control (TAU/waitlist) (Kanter et al., 2016).

One additional study reported significant reduction in symptoms after MBA but did not explicitly report comparison to controls and had a poor-quality rating (Ashraf et al., 2022). Conversely, one found no significant reduction in disease/symptom severity for MBA intervention (Schoultz et al., 2015). Interestingly, though a significant reduction in disease/symptom severity for MBA relative to a CBT control arm was identified by Zomorodi and colleagues (see above), this same study found no difference between MBA and their second control arm, TAU (Zomorodi et al., 2014).

*Pain outcomes:*

Pain outcomes in included papers were varied. Pain self-efficacy was shown to improve after immediately after MBA vs. TAU/waitlist in both of the studies assessing this (Brotto et al., 2015; Kanter et al., 2016). One also identified a significant improvement in pain hypervigilance, pain catastrophising and allodynia immediately post treatment and at 6m FU relative to waitlist controls (Brotto et al., 2015). One further study identified a significant improvement in pain outcomes (including specifically pelvic pain, dyschezia and pain unpleasantness), relative to TAU immediately post intervention and at 8-week FU (Moreira et al., 2022). Effect sizes for these findings range from small ($\eta^2 = 0.08$, pain hypervigilance) (Brotto, et al., 2015) to large ($f^2 = 0.68$, pain unpleasantness) (Moreira et al., 2022) (table 5). A further three studies identified significant reduction in pain catastrophising after MBA immediately post treatment (and at FU for two of these studies) but with no effect of group (Brotto et al., 2019; Garland et al., 2012; Guillet et al., 2019). Similarly, these studies identified a time but not a group effect for MBA in the tampon test (Guillet et al., 2019) and pain acceptance (Brotto et al., 2019). Clinician-rated abdominal pain was reduced after MBA relative to waitlist controls in Crohn's disease in one study (Regev et al., 2023). One study measured reinterpretation of pain sensations following MBA intervention or a support group control arm (Garland et al., 2012), identifying significant improvement in those in the MBA arm, relative to control, immediately post intervention.

No significant effect was identified in pain acceptance and pain disability for one study comparing MBA to muscle relaxation (Brotto et al., 2019) nor in a 0-10 pain rating in another (Kanter et al., 2016).

*Anxiety:*

Six studies used anxiety as an outcome, with three identifying significant improvement after MBA (Gaylord et al., 2011; Guillet et al., 2019; Neilson et al., 2016). In one case this was identified only immediately post treatment relative to TAU (Neilson et al., 2016), whilst in the other two it was relative to a social group (Gaylord et al., 2011; Guillet et al., 2019), at FU only and immediately post intervention and at FU respectively. A further two studies found a significant improvement in anxiety after MBA intervention, though no effect of group was found (Cebolla et al., 2021; Schoultz et al.,

2015)- both studies used waitlist as a control and identified change immediately post intervention and FU respectively.

Two studies found no effect of MBA on anxiety at all (Bredero et al., 2023; Brotto et al., 2015).

*Stress:*

Four studies explored stress, with two of these studies identifying a significant improvement in measures of stress after MBA immediately post intervention, relative to TAU/waitlist control arms (Mohamadi et al., 2019; Moreira et al., 2022). The effect size for these outcomes were small, $d = 0.16$ (Mohamadi et al., 2019), $f^2 = 0.13$ (Moreira et al., 2022). The remaining two studies measuring stress noted a significant improvement after MBA but no effect relative to TAU/waitlist control (Cebolla et al., 2021; Zernicke et al., 2013), immediately post intervention and at FU.

*Sex-related outcomes:*

Two studies measured sex-related distress, function or pain (Brotto et al., 2015, 2019). Sex-related pain was shown to significantly reduce in the MBA arm compared to a CBT control group in one study, with a large effect size ($d = 0.60$ and $d = 0.63$ post and FU respectively) (Brotto et al., 2019). Sex-related distress and sex-related function were both shown to improve after MBA, but with no group effect when compared to CBT (Brotto et al., 2019) or waitlist (Brotto et al., 2015), both immediately post intervention and at 6-month FU.

*Visceral sensitivity:*

Visceral sensitivity was shown to significantly improve immediately after MBA intervention relative to waitlist control in one study, with a large effect size ($d = 0.64$) though effect did not remain at 3-month FU (Ljótsson et al., 2010).

*Other:*

One study looked at adaptive and maladaptive cognitive responses to events (identifying themes of self/other blame, rumination and catastrophising). This study identified that MBA reduced maladaptive cognitive response scores relative to controls, but that the active control group receiving compassion-focused therapy actually had the best outcome (Pourkazem, Ghazanfari, & Ahmadi, 2023). However, this result is tempered by the poor-quality status of this paper (table 2).

*Drop-out, delivery formats, timeframes:*

Study interventions lasted between 4 (Brotto et al., 2015) to 10 weeks (Hansen et al., 2023), with one study not reporting intervention duration (Pourkazem et al., 2023). Delivery methods included group and individual self-directed or a combination of the two. Only one study used 1:1

therapist-directed format (Regev et al., 2022). Drop-out rates ranged from 0% (Guillet et al., 2021) to 36.6% (Cebolla et al., 2021) with 2 studies not reporting (Pourkazem et al., 2023; Jedel et al., 2022).

*Study quality:*

Quality ratings ranged from 0.44 (Ashraf et al., 2022) to 1 (Hansen et al., 2023) with lower scores largely reflecting missing study information. Overall, 76% of included MBA papers scores >.70, indicating "good" quality (Lee et al., 2008; Lee et al., 2020). The papers with lower quality scores (<.70) were IBS-focused (Pourkazem et al., 2024; Zomorodi et al., 2014; Zomorodi et al., 2015; Ghandi et al., 2018; Mohamadi et al., 2019; Ashraf et al., 2022) and identified improvements in varied areas, such as IBS symptom severity (Ashraf et al., 2022; Ghandi et al., 2018; Zomorodi et al., 2014; Zomorodi et al., 2015), cognitive emotional regulation (Pourkazem et al., 2023) and QoL (Ashraf et al., 2022).

*Table 5 Main outcomes, MBA studies. A simplified table showing the outcomes used by each study is included in appendix 1D, for clarity.*

| Paper | Condition | Control | Time points | Statistical tests | Main findings | Effect size for significant findings |
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| Brotto et al., 2015 | Vulvodynia | MBA intervention waitlist | Pre, Post, FU (6m) | ANOVA | Pain self-efficacy: Significant increase in pain self-efficacy M>control, post & FU. Control (waitlist) when given the intervention later showed bigger effect size than immediate treatment group.<br>Pain hypervigilance: Significant decrease in pain hypervigilance M>control at post & FU.<br><br>Pain catastrophising: Significant decrease in rumination and helplessness catastrophising, M>control at post & FU; significant effect of intervention but not time x group (group here is immediate vs. delayed treatment).<br>Allodynia: Significant decrease at post & FU, but no main effect of group.<br><br>Mood: Significant decrease in low mood at post but no effect of group.<br><br>Anxiety: No significant effect on state anxiety.<br>Sex-related distress: Significant decrease at post & FU, but no effect of group.<br><br>Sexual function: No significant difference in change between groups. | *Pain self-efficacy: $\eta^2 = 0.26$<br><br>*Pain hypervigilance: $\eta^2 = 0.08$ time only (not group or group x time due to available data).<br>*Pain catastrophising: $\eta^2 = 0.20$ helplessness, $\eta^2 = 0.24$ rumination: time only (not group or group x time due to available data).<br>*Allodynia: $\eta^2 = 0.36$ time only (not group or group x time due to available data).<br>*Mood: $\eta^2 = 0.69$ time only (not group or group x time due to available data).<br>Anxiety: N/A<br><br>*Sex-related distress: $\eta^2 = 0.18$ time only (not group or group x time due to available data).<br><br>Sexual function: N/A |
| Guillet et al., 2019 | Vulvodynia | Support group | Pre, Post, FU | ANOVA | Tampon test: Significant improvement from pre to FU for both groups, but no | Not reported |

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| | | | (3m) | | effect of group.<br><br>Pain catastrophising: Significant improvement from pre to post and FU, but no group effect.<br><br>Mood: Significant improvement in mood from pre to FU in intervention group only.<br><br>Anxiety: Significant improvement from pre to post and FU intervention>control. | |
| Brotto et al., 2019 | Vestibulodynia | CBT | Pre, Post, FU (6m)* | Multi-level mixed model | Pain catastrophising: Significant reduction in catastrophising at post & FU, but no effect of group.<br>Pain acceptance: Significant improvement at post and FU, not no time x group effect.<br><br>Sex-related pain: Significantly greater reduction in sex-related 0-10 pain ratings, M>CBT at post and FU timepoints. Also, improvement in sex-related function at post and FU, but no effect of group.<br>Sex-related distress: Significant reduction in distress at post and FU, but no effect of group. | Pain catastrophising: $d$ = 0.91 difference pre to post, $d$ = 1.23 different pre to FU<br>Pain acceptance: $d$ = 0.50 difference pre to post, $d$ = 0.60 difference pre to FU.<br>Sex-related pain: $d$ = .60 at post & $d$ = 0.63 at FU; sex-related function $d$ = 0.36 post & $d$ = 0.77 FU.<br><br>Sex-related distress: $d$ = 0.74 post, $d$ = 1.05 FU. |
| Forbes et al., 2020 | CPP | Muscle relaxation or TAU | Pre, Post, FU (3m, 6m) | Linear mixed effects | Pain acceptance: No 'strong' effect on pain acceptance.<br>Pain-related disability: No 'strong' effect on pain-related disability.<br>QoL: No 'strong' effect on QoL.<br>Mood: No 'strong' effect on mood. | N/A |
| Kanter et al., 2016 | Interstitial cystitis | TAU | Pre, post | Change score | Symptom severity: Greater number of symptoms rated as improved at post, intervention>control but not significant. | |

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| | | | | | Symptom scores from OSPI measure also indicated significant change at post, but no difference in scores between groups.<br>Pain: No significant difference between groups.<br>Pain self-efficacy: Significant improvement M>control, at post.<br>QoL: No significant difference in change between groups. | |
| Hansen et al., 2023 | Endometriosis | TAU/Generic psychol. intervention | Pre, post | ANCOVA | Pain: Significant reduction M>control at 3m FU. | |
| Moreira et al., 2021 | Endometriosis | TAU | Pre, Post, FU (8w) | Multiple linear regression | Pain rating: Significant reduction in pelvic pain, dyschezia and pain unpleasantness M>control at post & FU.<br><br>QoL: Significant increase in the mental health & vitality QoL domain M>control, at post & FU.<br>Perceived stress: Significant improvement M>control at post but not FU. | Pain rating: pelvic pain $f^2 = 0.16$ post & 0.25 FU, dyschezia $f^2 = 0.23$ post & 0.6 FU, pain unpleasantness $f^2 = 0.68$ post & 0.41 FU.<br>QoL: mental health $f^2 = 0.35$ post & 0.26 FU, vitality $f^2 = 0.09$ post & 0.23 FU<br>Perceived stress: $f^2 = 0.13$ at FU |
| Ashraf et al., 2022 | IBS | TAU | Pre, post | ANOVA, logistic regression | Symptom severity: Significant reduction in symptoms at post in M.<br>QoL: Significant improvement at post, M>control. | Not reported. |
| Gaylord et al., 2011 | IBS | Social group | Pre, Post, FU (3m) | ANOVA | Symptom severity: Significant reduction in pain severity at post & FU, M>control. Significant reduction in pain frequency and life interference at FU, M>control.<br>QoL: Significant improvement in QoL, M>control at FU.<br>Mood: No significant change.<br>Visceral anxiety: Significant improvement in visceral anxiety, M>control at FU. | *Symptom severity: pain severity, $\eta^2 = 0.98$ at post & $\eta^2 = 0.14$ at FU. Value for pain frequency not reported.<br>*QoL: $\eta^2 = 0.07$.<br><br>Mood: N/A<br>Visceral anxiety: Not reported. |

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| Garland et al., 2012 | IBS | Support group | Pre, Post | Repeated measure t-test | Symptom severity: Significant reduction in for symptom severity in M but not control group, at post.<br>Pain catastrophising: Significant reduction in pain catastrophising in M but not control group, at post.<br>Visceral sensitivity: Significant improvement in sensitivity in M but not control group, at post.<br>Cognitive coping: Significant improvement in sensitivity in M but not control group, at post.<br>QoL: Significant increase in QoL in M but not control group, at post.<br>Mood: Significant improvement in psychological distress in M but not control group, at post. | Not reported |
| Ghandi et al., 2019 | IBS | Emotional regulation or TAU | Pre, Post, FU (2m) | ANCOVA | Symptom severity: Significant reduction in severity M> emotional regulation but not TAU, at FU, if pre scores are controlled for.<br><br>QoL: No significant change. | *Symptom severity: Not reported<br><br>QoL: N/A |
| Henrich et al., 2020 | IBS | Waitlist | Pre, Interim, Post, FU (6w) | Mixed design ANOVA | Symptom severity: Significantly greater reduction in severity, intervention>control at FU in ITT. Per protocol analysis indicated no significant change.<br>QoL: Significantly greater improvement in QoL, intervention>control at post and FU- but no main effect of group.<br>Mood: Significantly greater reductions in depression intervention > control at post & FU- but no main effect of group.<br>Anxiety: Significantly greater reductions in anxiety intervention > control at post & | Symptom severity: $\eta^2 = 0.10$<br><br>QoL: $\eta^2 = 0.17$<br><br>Mood: depression $\eta^2 = 0.07$ (for time but not group or time x group)<br>Anxiety: $\eta^2 = 0.09$ (for time but not group or time x group) |

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| | | | | | FU- but no main effect of group.<br>Stress: Significantly greater reductions in stress intervention > control at post & FU- but no main effect of group. | Stress: $\eta^2 = 0.14$ (for time but not group or time x group) |
| Ljotsson et al., 2010 | IBS | Waitlist with online forum | Pre, Post, FU (3m) | ANOVA | Symptom severity: Large treatment effect identified, significantly greater in M>control at post. No significant difference between groups at FU.<br>Visceral sensitivity: Significant difference between groups, M>control at post.<br>QoL: Large effect size identified, significantly greater in M>control at post and FU.<br>Mood: Small treatment effect identified, significantly greater in M>control at post. | Symptom severity: total pain *d* = 0.64, primary symptoms *d* = 0.83, both at post.<br>Visceral sensitivity: *d* = 0.64 at post.<br>QoL: *d* = 0.93.<br>Mood: *d* = 0.43 at post. |
| Mohamadi et al., 2019 | IBS | Waitlist | Pre, Post | Repeated measures ANOVA | Perceived stress: Significant improvement in M>control.<br>QoL: Significant improvement in QoL, but no effect of group. | Perceived stress: *d* = 0.16<br>QoL: *d* = 0.15 (time but not group or time x group) |
| Pourkazem et al., 2024 | IBS | CFT<br>Waitlist | Pre, Post, FU (3m) | ANOVA, Bonferroni paired | Adaptive cognitive regulation: Significant improvement in M>waitlist and CFT>waitlist, but no difference M and CFT. Unclear if difference between pre and post or just pre and FU, only group*time interaction shown, without each time comparison.<br>Maladaptive cognitive regulation: Significant improvement in M>waitlist and CFT>waitlist, and CFT > M. Unclear if difference between pre and post or just pre and FU, only group*time interaction shown, without each time comparison. | Adaptive cognitive regulation: Eta coefficient = 0.579<br>Maladaptive cognitive regulation: Eta coefficient = 0.64 |
| Taghvaeinia et al., | IBS | MBSR, DBT, Undefined | Pre, Post | Repeated measures | Symptom severity: lower symptom severity self-rating ACT> MBSR, DBT | Symptom severity: *d* = 0.20 |

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| 2024** | | control | | MANOVA | and control.<br>QoL: Higher QoL ratings ACT> MSBR, DBT and control.<br>Anxiety: Lower anxiety self-rating, ACT> MBSR, DBT and control.<br>Low mood: Lower depression self-rating, ACT> MBSR, DBT, control. | QoL: $d$ = 0.15<br><br>Anxiety: $d$ = 0.18<br><br>Low mood: $d$ = 0.22 |
| Zernicke et al., 2013 | IBS | TAU | Pre, Post, FU (6m) | Mixed linear model | Symptom severity: Significant improvement in symptoms M>controls at post & FU.<br>QoL: Significant improvement in M and controls at post & FU, no effect of group.<br>Symptoms of stress: Significant reduction in stress M and controls at post and FU. No difference between groups at FU.<br>Mood: Significant improvement in M and controls post & FU, no effect of group. | Symptom severity: $d$ = 0.50 post & $d$ = 0.16 FU.<br>QoL: $d$ = 0.49 post & $d$ =0.31 FU.<br><br>Symptoms of stress: $d$= 0.60 post & $d$ = 0.19 FU (no group difference at FU).<br>Mood: $d$ = 0.21 post & $d$ = 0.04 FU (time but not group or group x time). |
| Zomorodi et al., 2014 | IBS | CBT or TAU | Pre, Post | One-way ANOVA | Symptom severity: Significant reduction in M>CBT at post, but not control or CBT to control. | Symptom severity: $\eta p^2$ = 0.41 |
| Zomorodi et al., 2015 | IBS | CBT or TAU | Pre, Post, FU (2m) | One-way MANOVA | QoL: Significant reduction M>CBT at post and FU. M also significantly different to controls but values not reported. | Not reported |
| Bredero et al., 2022 | IBD | Waitlist | Pre, post | t-tests | Fatigue: Significant reduction in subjective fatigue, M>controls.<br>QoL: No significant difference.<br>Anxiety: No significant difference.<br>Mood: No significant difference under ITT analysis, but under per-protocol significant reduction in depression, M>controls. | Fatigue: $d$ = 0.46<br><br>Mood: $d$ = 0.29 |
| Cebolla et al., 2021 | IBD | Waitlist | Pre, Post | Change index | QoL: Significant increase in QoL, M>control at post.<br>Perceived stress: Significant improvement | QoL: $\eta^2$ = 0.01<br><br>Perceived stress: $\eta^2$ = 0.05 (time |

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| | | | | | in M but not control, and no effect of group.<br><br>Anxiety: Significant improvement in anxiety in M but not control, and no effect of group. | but not group or group x time)<br>Anxiety: $\eta^2 = 0.03$ |
| Neilson et al., 2016 | IBD | TAU | Pre, Post, FU (8m) | Effect size, ANOVA | QoL: Significant improvement in physical and psychological QoL M>controls at post but not FU.<br>Mood: Significant improvement in depression scores M>controls at post and FU.<br>Anxiety: Significant improvement in anxiety M>controls at post but not FU. | QoL: physical $d = 1.72$ post & 0.39 FU, psychological $d = 1.06$ post & 0.43 FU.<br>Mood: $d = 0.56$ post & $d = 0.70$ FU.<br>Anxiety: $d = 0.71$ post & $d =$ 0.45 FU. |
| Schoultz et al., 2015 | IBD | Waitlist | Pre, Post, FU (6m) | ANOVA | Disease activity: No significant effect.<br>QoL: No significant effect.<br>Mood: Significant effect of group on depression M>control, post & FU.<br>Anxiety: Significant improvement in anxiety over time (post & FU), but no effect of group. | Disease activity: N/A<br>QoL: N/A<br>Mood: $\eta p^2 = .173$ (not reported separately for post & FU)<br>Anxiety: $\eta p^2 = .147$ trait anxiety, .135 state anxiety. |
| Goren et al., 2021 | Crohn's disease | Waitlist | Pre, Post | t-test | Disease activity: Significant decrease in both groups, intervention>control.<br><br>QoL: Significant increase in QoL in intervention from pre to post, also in controls but smaller (significance of difference between not reported)<br><br>**Abdominal pain: Significant decrease in abdominal pain, M>controls at post. | Not reported |
| Regev et al., 2023 | Crohn's disease | Waitlist | FU (3m) | ANCOVA | Pain: Significantly reduced pain in M>controls at 3m FU. | |
| Jedel et al., 2022 | Ulcerative colitis | General psychoeducation | Pre, Post, FU | t-test | Symptom frequency: Significant decrease in frequency of flares M>controls post & | Not reported |

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| | (6m, 12m) | FU.<br><br>QoL: Significant improvement in emotional health in M group, but no group by time interactions in QoL broadly.<br>Mood: Improvement in mood ratings in M at post & FU, no change in control. | |

*A 12m FU is also mentioned but no statistics reported for it.
**Paper reported in both ACT and MBA tables as provides comparison of these interventions.
For meaning of effect sizes, see appendix 1B.

**Discussion**

This systematic review explored the use of ACT and MBA treatments for CAPP in adults. Overall, the review identified evidence to support both ACT and MBA but acknowledges ongoing gaps in the literature and need for further research.

Reviewing the ACT studies, some studies reported improvement in pain-related outcome measures (Hess Engström et al., 2021), mood (Mirsharifa et al., 2019) and illness perception (Aghalar et al., 2020), though several found no evidence for ACT in relation to disease or symptom severity in CAPP (Ito & Muto, 2020; Taghvaeinia et al., 2024; Wynne et al., 2019). Change in feelings of personal control, thoughts about their illness and worry about their illness encompassed by illness perception are factors aligned with the values of ACT, which involves present-focus, acceptance of undesirable unavoidable experience (e.g., pain) (Feliu-Soler, Montesinos, Gutierrez-Martinez, Scott, McCracken, & Luciano, 2018). ACT does not have a focus on symptom reduction rather on aligning behaviours and values (Feliu-Soler et al., 2018), which could lead to improved QoL, but may explain lack of effect on symptom severity.

It is important to highlight how few studies explored ACT for CAPP and that this limits the conclusions that can be drawn. Existing reviews of ACT have explored chronic pain broad sense (Feliu-Soler et al., 2018; Hann & McCracken, 2014; Hughes, Clark, Colclough, Dale, & McMillan, 2017; Veehof et al., 2011). Investigation of interventions in CAPP conditions specifically is key; for example, chronic pain in IBS has links to visceral hypersensitivity (Elsenbruch, 2011), which would be distinct from chronic pain conditions that do not involve the viscera in the same way. IBS was the most commonly studied condition, showing a positive impact on mood (Mirsharifa et al., 2019; Shahkaram et al., 2024; Taghvaeinia et al., 2024), illness perception (Aghalar et al., 2020) and activity levels (Shakernejad et al., 2021). Different CAPP conditions, which involve various organ systems, will possibly be affected by different physiological and hormonal influences (Osborne & Davis, 2022), suggesting CAPP conditions may not be directly comparable to each other in terms of presentation or treatment. This highlights the need for further research into individual CAPP conditions. It may be that different forms of chronic pain or indeed different forms of CAPP are best served by different approaches, but currently the literature is too limited to speculate. It is also notable that 45% of the ACT studies rated as below “good” (i.e., scored <.70; Lee et al., 2008; Lee et al., 2020) in the quality review, suggesting findings should be taken tentatively and indicating a need for better quality research overall in investigations of ACT in CAPP. These findings related to lack of researcher blinding but also poor reporting of methodology.

Far more MBA than ACT papers were identified in this review. The included papers demonstrate some support for improvement in QoL (Cebolla et al., 2021; Garland et al., 2012; Gaylord et al., 2011; Goren et al., 2022; Henrich et al., 2020; Ljótsson et al., 2010; Mohamadi et al., 2019; Moreira et al., 2022), mood (Garland et al., 2012; Guillet et al., 2019; Henrich et al., 2020; Ljótsson et al.,

2010; Neilson et al., 2016; Schoultz et al., 2015; Zernicke et al., 2013), reduced anxiety (Gaylord et al., 2011; Guillet et al., 2019; Neilson et al., 2016), stress (Cebolla et al., 2021; Mohamadi et al., 2019; Moreira et al., 2022; Zernicke et al., 2013), sex-related distress (Brotto et al., 2015, 2019), cognitive coping (Garland et al., 2012) and visceral sensitivity (Ljótsson et al., 2010), to varying degrees. As in ACT, MBA are reported to impact pain-related outcome measures (including pain self-efficacy, hypervigilance, catastrophising, acceptance, sex-related pain and self-ratings) in CAPP (Brotto et al., 2015, 2019; Garland et al., 2012; Guillet et al., 2019; Kanter et al., 2016; Moreira et al., 2022). Though not unanimous, there was support for positive outcomes- for example, QoL improvement was supported to some degree by 11 of the papers measuring this outcome, and 8 of the 10 papers exploring mood similarly showed improvement.

Unlike ACT, there is some support for a reduction in symptom severity following MBA (Gaylord et al., 2011; Ghandi et al., 2018; Goren et al., 2022; Henrich et al., 2020; Ljótsson et al., 2010; Zernicke et al., 2013; Zomorodi et al., 2014). Without specifically exploring the mechanisms behind changes shown in these MBA studies relative to ACT it is difficult to outline why there is a difference in symptom severity outcomes, given psychological interventions for pain rarely focus on symptom reduction as a rule. All the MBA studies showing reduction in symptom severity after intervention recruited IBS patients. Possibly, there is a mechanism or experience in IBS that is particularly responsive to MBA type interventions; for example, there is evidence that symptom severity in IBS is associated with awareness of gastrointestinal symptoms (Black et al., 2020) and altered relationship to awareness forms part of MBA interventions, suggesting one possible mechanism.

The findings are distributed across CAPP conditions (e.g., IBS, vulvodynia, and endometriosis) with small numbers in each condition, so it would not be accurate to draw any strong conclusions recommending one intervention over the other for CAPP broadly. Quality analysis was conducted to identify risk of bias in published studies and consider the impact of this on interpretation of findings the usefulness of the studies in clinical practice. Of the included ACT studies, 45% were rated as below “good” quality in the quality review, whereas this was only the case for 30% of the MBA studies. This suggests a better-quality pool of data to draw conclusions from, though again highlights issues with researcher blinding and accurate methodological reporting that undermines impact of the reported findings. Low scores reflected a lack of blinding, which raises the risk of placebo effect in the observed findings. There were also low scores for poor reporting of samples and randomisation, which makes it difficult to synthesis and accurately compare between studies and hard to truly identify the quality of studies in regards to sample quality or intervention provided. The quality ratings when compared between ACT and MBA suggest that the findings from ACT may be less conclusive than those from MBA studies, but not to a level where one intervention can be recommended over the other for CAPP. The poorer quality studies were predominantly exploring IBS and identified improvements in outcomes including symptom severity (Ashraf et al., 2022; Ghandi et al., 2018; Taghvaeini et al., 2024; Zomorodi et al., 2015), QoL (Ashraf et al., 2022; Taghvaeini et al., 2024;

Zomorodi et al., 2015), mood and anxiety (Mirsharifa et al., 2019; Shahkaram et al., 2024; Taghvaeini et al., 2024) and illness perception (Aghalar et al., 2020). One study identified no change in QoL (Mohamadi et al., 2019) and another identified no change in life satisfaction (Shahkaram et al., 2024) following MBA and ACT for IBS respectively. This implies caution should be used regarding the use of MBA and ACT for IBS particularly, as many of the interventions in this patient group did not score highly in regards to quality. It also specifically recommends caution regarding the interpretation of positive outcomes in QoL, mood, anxiety, symptom severity and illness perception after ACT and MBA intervention for IBS. Following, more rigorous exploration of these interventions in IBS is recommended before meaningful conclusions can be drawn about implementing them in this specific patient group. As other CAPP conditions in this review (i.e., vulvodynia, vestibulodynia, Crohn's disease, IBD, CPP, endometriosis, ulcerative colitis) were explored in papers with higher quality ratings, the findings within this review relating to these conditions may be more reliable. However, these conditions had far fewer included studies in the review which means the findings are still somewhat limited.

A further limitation of the literature identified in this review is the lack of studies exploring sex-specific CAPP conditions. Many chronic pain conditions are more prevalent in females (Osborne & Davis, 2022), and specific physiological and hormonal differences between the sexes may contribute to important differences in pain and pain signalling (Osborne & Davis, 2022). Despite including male CAPP terminology in the database searches, no male specific conditions were identified. This suggests a lack of research in to third-wave treatments for CAPP in male chronic pain, despite these interventions being in official guidance (NICE, 2021). This is supported by previous work identifying a sex imbalance in MBA for male vs. female conditions outside of CAPP (Banbury, Lusher, Snuggs & Chandler, 2023); limited evidence indicates MBA may have different impacts on men compared to women, such as better impact on rumination in women (Villa & Hilt, 2014) and differential effects of meditation on brain activation (Luders, Thompson, & Kurth, 2015). Exploring ACT and MBA for CAPP in male conditions is important, given this.

None of the reviewed interventions lasted beyond a maximum of 10 weeks. Guidelines have suggested 12 weeks as optimal for psychological interventions in chronic pain (NICE, 2021), indicating that none of the papers included gave a sufficient window for the interventions to take effect and were acting outside UK guidelines. It may be that these interventions work better than reported here, if used for the recommended timeframe. The length of interventions in these studies minimises how strongly conclusions can be drawn from the findings, particularly in the UK. Additionally, the interventions here were all group-based or if 1:1, most were self-directed (i.e., only one of the studies investigated efficacy of a 1:1 therapist-lead intervention). As only 1 included study explored direct 1:1 intervention, the review can only speak to outcomes from group or self-directed 1:1 ACT and MBA for CAPP. Future work should assess how services provide these interventions clinically and explore whether the literature supports this use.

Methodologically, both ACT and MBA studies collected follow-up data which ranged from 3-9 months post intervention. This does limit conclusions into the long-term effect of interventions, as CAPP can be a life-long condition and the likelihood of remission decreases the longer it persists (Landmark, Dale, Romundstad, Woodhouse, Kaasa, & Borchgrevink, 2018) longer term follow-up would allow better understanding of the appropriateness of these interventions for chronic pain specifically. It is also noteworthy that dropout rates in the included studies ranged from 0-42%, across ACT and MBA interventions. The latter figure is from an ACT study (Hess Engström, et al., 2022) is considerable and raises questions about use of self-paced ACT intervention in vulvodynia, given almost half of the participants withdrew. Other studies in both MBA and ACT had dropout rates of 0-36%, indicating this issue is not limited to ACT or vulvodynia, and raises questions about the samples and interventions for figures towards the higher end of this range. It may be that aspects of the interventions with higher drop out were unpalatable or unhelpful, or that there is a distinct group of people for which specific interventions are less well suited (Bell, Kenward, Fairclough, & Horton, 2013).

This review provides an initial overview of the topic and identifies issues with present data (especially identifying concerns about how many ACT studies were of less than "good" quality that currently exist). The review used a wide range of databases and included varied outcomes to reflect the breadth of chronic pain experience. This study aimed to use clear and precise inclusion/exclusion criteria and a rigorous search methodology to promote completeness. The review conducted a quality review to identify risk of bias and used methods to minimise bias in the review itself, such as blinded double-rating extraction and decision-making on both inclusion and quality review data. This is a narrative review and therefore is open to subjective interpretations of data; some suggest that narrative reviews are less able to inform decision-making in healthcare when compared to meta-analysis (McKenzie & Brennan, 2019). Due to researcher capability, this review does not include studies published in languages other than English and thus cannot be said to be a comprehensive overview.

Though it appears both MBA and ACT may have promise relative to inactive control conditions, this does not allow recommendation of one intervention over the other currently. Comparisons of existing and new treatments are an important future direction given the focus on providing efficient and effective care.

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# Impact of adopting a baseline screening for dementia model for individuals with Down's Syndrome: insights from a service improvement project at Buckinghamshire Community Learning Disability Health Team (CLDHT)

Running title: Possible service impact of a baseline screening approach to dementia pathway in Down's Syndrome

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The submission guidelines are included in appendix 4B.

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# Impact of adopting a baseline screening for dementia model for individuals with Down's Syndrome: insights from a service improvement project at Buckinghamshire Community Learning Disability Health Team (CLDHT)


## Abstract

Dementia is a neurodegenerative disease characterised by cognitive decline. Alzheimer's disease (a dementia subtype) affects around 88% of people with Down's Syndrome (DS) by the age of 65. In the general population, dementia is identified by comparing an individual's scores on neuropsychological assessments against matched controls. This is not possible for people with DS due to the large variability in cognitive abilities between age- matched individuals. The United Kingdom (UK) Government has recommended baseline cognitive testing of individuals with DS at the age of 30, to provide a comparison score for later identification of dementia. Buckinghamshire Community Learning Disability Health Team (Buckinghamshire CLDHT) wished to understand potential impact of improving their service by introducing a baseline assessment as part of their dementia pathway, to align with national guidelines. This was to be achieved through identifying: other local services models, the number of individuals in Buckinghamshire who would be eligible for baseline assessments, an audit of the current dementia pathway used by the service, and staff thoughts on introducing baseline assessments in this population. Findings indicated 183 individuals with DS in Buckinghamshire GP recorded as of March 2022, with potentially over 130 eligible for a baseline screening approach. The staff focus groups indicated concerns about team workloads, prioritisation of need alongside other clinical responsibilities and whether electronic systems were fit for purpose. Recommendations from this project concern allocation of responsibility for assessments across team members, and staff training.


## Introduction

Down's Syndrome (DS) has an estimated prevalence of 5.9-6.8 per 10,000 pregnancies in the United Kingdom (UK) (Alexander, Ding, Foskett, Petri, Wandel, & Khwaja, 2016), with approximately 419,000 people living with DS in Europe (de Graaf, Buckley, & Stotko, 2021). DS is characterised as an additional copy of chromosome 21 and is associated with physical complications and Learning Disabilities (LD) (Hithersay, et al., 2019; Hultén, Patel, Tankimanova, Westgren, Papadogiannaki, Jonson, & Iwarsson, 2008). Individuals with DS are at higher risk of developing dementia when compared to the general population (Ballard, Mobley, Hardy, Williams, & Corbett, 2016; Stanton & Coetzee, 2004), and other people with LD (British Psychological Society, 2015). Dementia is a neurodegenerative disorder associated with the ageing process and characterised by cognitive decline (Cao, et al., 2020). Estimates suggest prevalence of 697 per 10,000 people globally (Cao et al., 2020; Prince, Wimo, Guerchet, Ali, Wu, & Prina, 2015). The average age at diagnosis of 55 (Sinai, et al., 2018), with up to 88% of such individuals receiving a dementia diagnosis by the age

of 65 (Hithersay et al., 2019; McCarron, McCallion, Reilly, Dunne, Carroll, & Mulryan, 2017). In comparison, the average age at dementia diagnosis for white British individuals without DS is 86 in White populations, 82 in South Asian and 81 in Black ethnicities (Mukadam, Lewis, Mueller, Werbeloff, Stewert, & Livingston, 2019; Mukadem, Marston, Lewis, Mathur, Rait, & Livingston, 2023). Alzheimer's disease (AD) is the most common sub-type of dementia and is associated with impaired cognition, behaviour and function and characterized by presence of amyloid beta plaques and neurofibrillary tangles (Porsteinsson, Issacson, Knox, Sabbagh, & Rubino, 2021). AD is particularly prevalent in the DS community, due to the role of chromosome 21 in both AD and DS (Mrak & Griffin, 2004).

The number of individuals with DS and dementia is increasing (Ballard et al., 2016). Dementia in individuals with DS is a diagnostic challenge, as considerable variability in cognitive functioning across individuals with DS (Krinsky-McHale, Devenny, Kittler, & Silverman, 2008; Nieuwenhuis-Mark, 2009), makes comparisons against norms complex. There are some DS-specific measures of cognitive decline but these are challenging to apply and validate (Ballard et al., 2016). Lack of baseline data to permit comparisons and allow identification of comparative decline is another issue. Not having baseline data for immediate comparison when cognitive decline is suspected later in life may prolong the diagnostic process and slow access to additional support where required. This is a concern for equity, as in neurotypical populations diagnosis is based on comparison to population norms and therefore is concluded quicker than in DS populations, who will typically have to be monitored for a minimum of 6 months to ascertain change, in the absence of accurate diagnostic tools and absence of population norms due to high variability of baseline cognition in this group.

Dementia in DS is associated with high rates of mortality (Hithersay et al., 2019) and co morbidities (Bayen, Possin, Chen, de Langavant, & Yaffe, 2018). Prompt diagnosis is key in providing a good standard of care (Nieuwenhuis-Mark, 2009) and early diagnosis of dementia allows a greater period of choice and community involvement, prior to significant cognitive change (Phillips, Pond, & Goode, 2011). A working group recommended gathering baseline cognitive functioning data prior to age 35 in people with DS and following up with regular reassessments (Burt & Ayleward, 2000). The UK guidelines for Dementia and people with LD recommends that people with DS are given an initial dementia assessment once over the age of 30 in order to provide a baseline measurement of their cognitive ability for later comparison against any cognitive change (British Psychological Society, 2015; Public Health England, 2018). Previous approaches require a 6 month wait period from initial assessment (to collect a baseline) to second assessment (to identify change from baseline). This is at odds with the NHS Mandate which gives a target of 6 weeks from referral to receiving a dementia diagnosis in the general population (Department of Health and Social Care, 2017). Previous work auditing a screening approach to dementia in DS identified that of 66 people screened, 29 were identified as having possible dementia-related symptoms, with 41% of these

individuals having reported no concerns about dementia or dementia-type symptoms prior to the screening (Major & McBrien, 2011). This suggests that 41% of these individuals would have not been identified as requiring support if they had not used a screening approach, in that service. This has been used in relevant guidelines to emphasise the potential to miss individuals with DS requiring early-stage support for dementia when a baseline screening approach is not used (Faculty for People with Intellectual Disabilities, 2015), though it should be acknowledge that this is small sample and a single publication which may limit generalisability. A screening approach would aim to screen as close to 100% of eligible people as possible; current estimates suggest 88% of people with DS are diagnosed with dementia by age 65 (Hithersay et al., 2019; McCarron, McCallion, Reilly, Dunne, Carroll, & Mulryan, 2017). This would suggest that (if the data generalizes) 88% of the DS population aged 65 or younger in Buckinghamshire currently receive a reactive assessment after dementia symptoms are reported. A move to introducing screening would mean 100% of (consenting) individuals aged 30 or older would need a proactive dementia assessment (and later, a reactive assessment if/when symptoms of dementia arise). This then might suggest that the number of dementia assessments required will increase, which may have an impact on the team. There is a need for change to address both inequity and the potential to miss the chance for early intervention in a considerable amount of individuals.

The biopsychosocial model of dementia identifies biological and psychosocial factors, which can be fixed or tractable (Spector & Orrell, 2010) and has been used in the development of guidelines for dementia care (National Institute for Health and Care Excellence, 2007). It suggests that dementia should not be viewed as passive decline due to fixed biological factors but rather as a condition where adaptation is possible through intervention on tractable factors (Spector & Orrell, 2010) and the importance of individual personhood is recognised (Kitwood, 1990). For example, social interactions may have a positive effect in slowing cognitive deterioration via improving psychological well-being and mental stimulation (Spector & Orrell, 2010) which might allow individuals to stay in their homes for longer as recommended in the World Health Organisation global action plan for dementia (WHO, 2017). This SIP explores whether it is practicable and feasible to introduce a baseline screening approach in this service, as the first iteration in longer-term exploration of whether a baseline approach improves outcomes in individuals with DS and dementia. This would contribute to a service improvement through aligning more closely with LD specific guidelines for dementia, but also improving treatment equity between LD and the general population.

The Plan, Do, Study, Act (PDSA) cycle is a model for exploring, developing and implementing change within services and is often used in healthcare (Taylor, McNicholas, Nicolay, Darzi, Bell, & Reed, 2014). The four stages of the cycle include: plan (deciding the change to be explored), do (conduct the exploration), study (reflect on the impact of change) and act (plan the next stage of exploration- e.g., offering recommendations) (NHS England, 2022; Taylor et al., 2014). This project adopted a single cycle of PDSA.

**Aims (plan)**

Buckinghamshire CLDHT provides dementia assessments for individuals with DS following referral for concerns about memory change or loss of skills (via GP, CLDHT staff, carers or family). Given the UK recommendation for baseline assessments around the age of 30 for individuals with DS (British Psychological Society, 2015; Public Health England, 2018), the service is interested in the impact of implementing baseline assessments as part of their routine service provision.

**Methods (do)**

*Phase 1: Scoping*

Lead Psychologists in Community LD Teams within the same Integrated Care System (ICS; Oxford Health NHS Foundation Trust, Berkshire Healthcare NHS Foundation Trust) were contacted by the trainee and asked:

To outline their current dementia in DS pathway, and-

A) How many staff members are directly involved in your dementia pathway?
B) Which professions are represented?
C) Have you hired any additional staff to manage workload?

Though not contacted/in the same ICS, Surrey and Borders NHS Foundation Trust also volunteered this information. A decision was made between FP and the other authors to include the information from Surrey and Borders as it represented the baseline assessment approach Bucks CLDHT hoped to use and gave some initial idea of the staffing requirements (see table 1). Though this data is not directly translational to Bucks CLDHT as the teams are unique, it was felt that this would provide some context for a team who hoped to move towards baseline screening.

*Phase 2: audit*

The audit used existing CLDHT records. Data was from individuals with DS aged 18 plus, referred for a dementia assessment.

All dementia referrals from March 2015-March 2022 were reviewed (to allow for interruption during COVID-19). Data from referrals was cross-checked against the service electronic record system (PARIS) and data from GPs, to identify:

1. The number of individuals in Buckinghamshire with DS
2. Number of individuals within Buckinghamshire CLDHT with DS and dementia.
3. Average age at dementia diagnosis.
4. Average wait time, referral to diagnosis.
5. Demographic information
6. Onward referrals within service following diagnosis.

*Phase 3: Buckinghamshire CLDHT staff focus group*

All CLDHT staff involved in dementia assessments (see below) were invited to take part. The service consists of approximately 50 staff.

Focus groups explored staff perspectives on the current dementia care pathway and on possible implementation of baseline assessments for people with DS. The focus groups took place on Microsoft Teams, recorded and transcribed by the trainee. The questions were:

1. What, if any, aspects of the current dementia assessment process in Bucks CLDHT do you think work well for team members/professionals?
2. What, if any, aspects of the current dementia process do you think work less well, or are challenging for team members/professionals?
3. In what ways, if any, do you think the current dementia assessment process may be meeting the needs of your service users and their families/carers?
4. In what ways, if any, do you think the current dementia assessment process doesn't meet the needs of your service users with DS and their families/carers?
5. What do you think about the idea of introducing baseline dementia assessments around the age of 30 for people with DS?

The questions were reviewed by a family carer of someone with DS. Some clarity in wording/phrasing of the focus group questions were made in response.

*Analysis*

Reflexive thematic analysis with a constructivist approach (Braun & Clarke, 2021; 2022) was adopted, as this aims to be grounded in the data (a purely inductive approach is considered implausible; (Braun & Clarke, 2022)), rather than deductive, and to use a semantic-level experiential approach. This overall approach utilizes researcher subjectivity and pre-existing knowledge of the subject, as well as social positioning. Reflexivity is an important aspect of this (see reflexive statement in appendix 2D). The analysis followed Braun & Clarke's (2022) 6 stages:

- Data familiarisation.
- Coding: key words/phrases identified creating initial codes.
- Initial theme production: codes used to identify overarching themes.
- Theme development and review: themes reviewed by the trainee and RV.
- Defining and naming themes
- Writing the report

RV reviewed the themes to assess whether theme names were true to the initial coding and to provide feedback on the clarity of theme names; this is not necessary but is permitted in reflexive thematic analysis (Braun & Clarke, 2006). This also provided space for a reflective conversation on

identification of codes and creation of themes in the context of being a trainee and having had a placement in Bucks CLDHT. Themes were then reported in the discussion and contributed to the recommendations arising from the project.

*Phase 4: recommendations*

Synthesising the data collected in phases 1-3, recommendations were provided to the service via:

1. Feedback to the lead Psychologists in Buckinghamshire CLDHT.
2. Presentation to Buckinghamshire CLDHT in a business meeting.
3. Written recommendations.

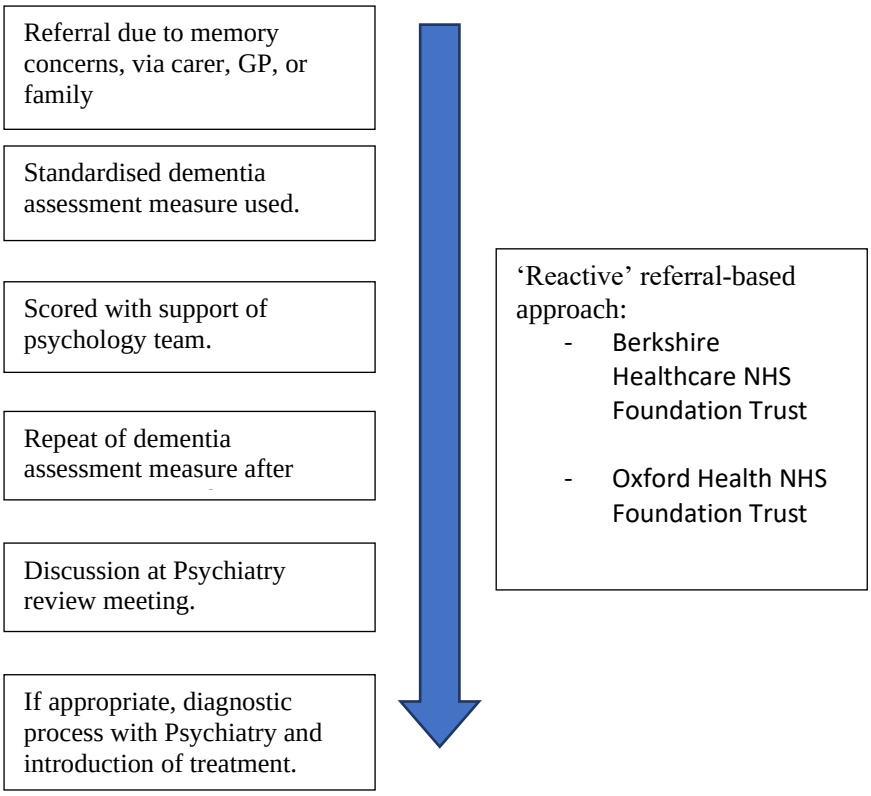
**Ethical approval**

Under trust guidance, this project did not require an ethics application. Registration of the project with the Bucks Practice Audit and Clinical Effectiveness (PACE) team was completed as per trust guidance (code SL092).

**Findings (study)**

*Phase 1: feedback from other services*

The different services/Trusts provided details of their pathway, showing 'reactive' or baseline-assessment styles (figure 1).


Referral due to memory concerns, via carer, GP, or family
Standardised dementia assessment measure used.
Scored with support of psychology team.
Repeat of dementia assessment measure after
Discussion at Psychiatry review meeting.
If appropriate, diagnostic process with Psychiatry and introduction of treatment.
'Reactive' referral-based approach:
- Berkshire Healthcare NHS Foundation Trust
- Oxford Health NHS Foundation Trust

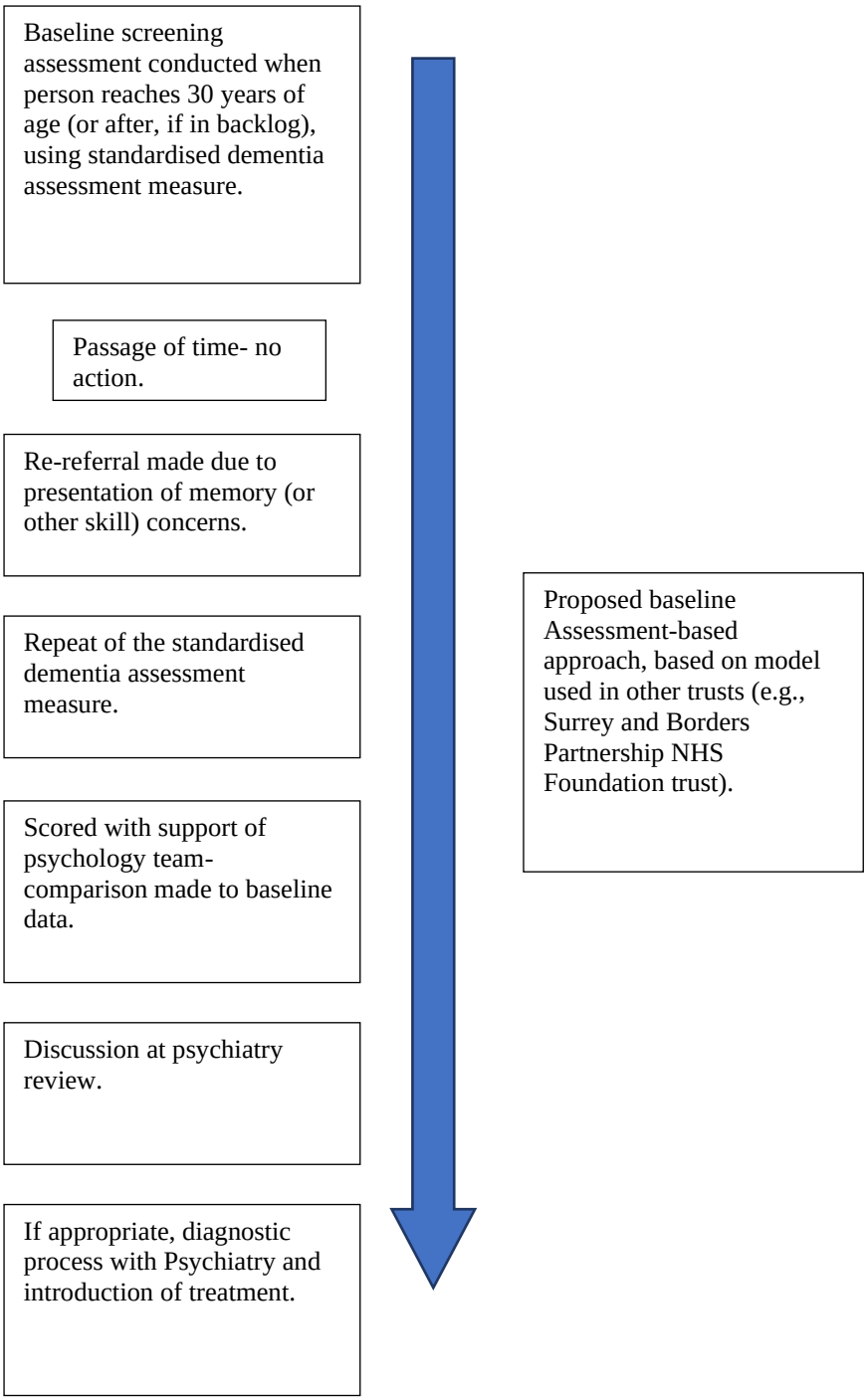



*Figure 1: Reactive assessment (top) and baseline assessment (bottom) pathways*

As shown in figure 1 a 'reactive' dementia assessment approach requires a wait of minimum six months after initial assessment to assess ongoing decline, due to the absence of baseline data. The 'baseline comparison' approach doesn't require this wait, as the assessment is compared to pre-existing baseline data. As shown in table 1 below, switching to a baseline assessment approach may require additional staffing- though this will depend on service specific factors, such as current staffing and size of population served.

*Table 6: Responses from other CLDHTs*

| Service | Number of staff members directly involved | Which professions are represented? | Have you hired additional staff to support your current dementia screening/assessment pathway? |
|---|---|---|---|
| Oxford Health NHS Foundation Trust | 25 | Psychology, SLT, OT, Nursing, Psychiatry | Not yet hired, but 2 Assistant Psychologists planned for move to clinic model. |
| Berkshire Healthcare NHS Foundation Trust | Not reported | Psychology, OT, Nursing | No |
| Surrey and Borders NHS Foundation Trust | 8 | Psychology | Yes- additional 6 Assistant Psychologists and 2 Dementia Co-ordinators |

SLT = Speech & Language Therapy; OT = Occupational Therapy

*Phase 2: Audit of Buckinghamshire CLDHT data*

Table 2 details the number of individuals in Buckinghamshire who are diagnosed with DS. This data was provided by Buckinghamshire GP surgeries.

*Table 7 Data on DS population made available by Buckinghamshire GP network.*

| | Current age (data from March 2022) | | | |
|---|---|---|---|---|
| | 18-39 | 40-49 | 50-59 | 60+ |
| N | 183 | 80 | 44 | 7 |

Table 3 shows average age at diagnosis and wait time between referral and diagnosis, from electronic patient records from March 2015- March 2022.

*Table 8 Data on all individuals with DS and dementia from Buckinghamshire CLDHT database*

| Number of individuals with DS and dementia identified | % female | Mean age at diagnosis (years) | Mean wait time from referral to diagnosis (weeks) |
|---|---|---|---|
| 16 | 62.5% | 56 | 69 |

Mean age at diagnosis includes 13 individuals (81.25%; diagnosis date missing for 3). The mean time from referral to diagnosis includes 10 individuals (62.5%; date of referral and/or date of diagnosis data missing for 6). Living situation at the time of diagnosis was detailed as: living with family (n=6, 37.5%), living in supported accommodation/care home (n=9, 56.25%) or living independently (n=1, 6.25%). The breakdown of ethnicity was: White British (n=10, 62.5%), South-East Asian (n=3, 18.75%), not stated (n=3, 18.75%).

*Phase 3: focus groups*

All staff members involved in dementia assessments were invited to take part (Table 4). Two focus groups were held to maximise attendance; data was later combined.

*Table 9 Focus group details. Numbers represent each participant to identify their comments in the thematic analysis text below. Total number of participants across focus groups was 13, with number per focus group indicated on the bottom line of the table.*

| Focus group 1 | Focus group 2 |
|---|---|
| Speech and Language therapist (1, 2) | Psychiatrist (9) |
| Speech and language assistant (3) | Consultant Psychologist (10) |
| Occupational Therapist (4) | Psychologist (11) |
| Therapy assistant in dysphagia and dietetics (5) | Assistant psychologist (12) |
| Practice development trainer & talking mats team member (6) | Honorary Assistant Psychologist (13) |
| Physiotherapist (7) | |
| Specialist Nurse (8) | |
| Total participants focus group 1: 8 | Total participants focus group 2: 5 |

*Thematic analysis*

Three themes were identified, with 10 subthemes (table 5). Coding, themes and subthemes were identified by the trainee and reviewed by author RV (expert in older adults with dementia). A

thematic map is included in appendix 2C, along with rational for theme and subtheme placement/inclusion.

*Table 10 Themes and subthemes summary.*

| Theme | Subthemes |
|---|---|
| Blue sky thinking- key considerations for a new pathway | The straw that might break the camel's back.<br>It takes a village.<br>Singing from the same hymn sheet.<br>Necessary foundations. |
| The best laid plans – considering issues with the current system that should be considered when implementing a new system | Too many cooks?<br>Prevention is the best cure.<br>Systems working against us. |
| Person-centred care- putting the individual at the centre. | Unheard voices.<br>To know or not to know- that is the question.<br>All's fair? |

**Theme 1: Blue sky thinking- key considerations for a new pathway.**

*Subtheme: The straw that might break the camel's back.*

This subtheme identified pressure on clinical time, both under the current system and how this may be affected by a new pathway. "*The assessments themselves are quite hefty*" *(8)* and prospective assessments of all eligible "*wouldn't be realistic from a capacity perspective" (4).* This concern appeared related to staffing pressure ("*even if you were fully staffed… which we are not*" *(10)*) and "*how stretched all the care staff and organisations*" *(10)* are more broadly. Staff wondered "*is dementia the highest need"* as *"priority wise… the top [is] placement breakdown, police involvement, suicide…*" as well as "*more pressing safeguarding needs*" *(11)*. One staff member commented "*we are drowning in work*" *(10)* raising the concern that "*adding anything more, especially for people who are well*" *(10)* may severely impact staff.

Staff also identified how these issues may be circumnavigated, such as by introducing specific staff: "*if you have a separate dementia assessment team [that would be] an entirely different picture*" *(8)* and prioritising *"[having] the systems in place, [having] the staffing*" *(9)*. However, the impact on clinical time remained a concern as other services offering baseline assessments had found the process *"unmanageable" (10)*. A specific concern was around offering post-diagnostic support: *"we could identify your need sooner with… baseline assessments, but you may not get [help] because there isn't much out there" (11)*.

*Subtheme: It takes a village.*

Several raised the idea of greater *"sharing [of] responsibility of doing the initial screening" (1)* and highlighted *"it doesn't have to be a nurse or psychologist to complete that" (8)* as *"the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) … doesn't need a clinician" (11)*. The priority of sharing the responsibility was raised in the context of capacity - *"nursing would not be able to facilitate anything beyond oversight" (8)* and solutions were offered in a similar vein *"the assessment would probably have to come through specific workers employed for the purpose" (8).* Nursing and psychology were identified as already taking much of the responsibility for the pathway *("it's psychology and nursing that have kept [the database] going", "it can look quite psychology, psychiatry and nursing heavy" (10)*) but also any future pathway too (*"it's going to be a lot more coming to psychology" (11)*). Some team members hoped that a new pathway would give the opportunity for "*the rest of the MDT to get their hands on… and to feel a bit more confident and skilled up" (11).*

*Subtheme: Singing from the same hymn sheet.*

The importance of clarity was identified within the current pathway, *"having it written down is containing"* especially when considering *"working with social workers who aren't LD specialists anymore. They might be quite used to working with older adults where they go into services like memory clinics" (11)*. Additionally, within team processing of people was assisted by clear documentation which *"not only [provides structure] for clinicians that are actually going through this assessment for the wider team and having better understanding on who is doing what and why they are doing it, and when they are doing it" (11)* and further was helpful to new members of staff as *"it's very useful to see…OK that's the person and this is the pathway we follow" (13).*

*Subtheme: Necessary foundations.*

Awareness of current knowledge gaps and potential opportunities to plug these and improve a future pathway was also raised. This mostly centred on improving confidence with diagnostic tools (*"I don't think I've ever independently completed a DSQIID…." (2), "I think there's a lot of people, particularly new starts… who sort of known they may have to do one at some point but don't necessarily know how to do it" (12)*). Confidence in spotting symptoms or how it might *"not always occur to put two and two together and think dementia" (8)* was also raised. In relation to people with DS, the idea of *"training that was specifically post-diagnostic [focused] for people in different stages of their dementia" (11)* was suggested.

**Theme 2: The best laid plans – considering issues with the current system that should be considered when implementing a new system.**

*Subtheme: Too many cooks?*

*"Lots of professionals get involved at the same time" (10)* once someone joins the current dementia pathway, which staff worried *"can be a bit overwhelming" (10)*, as they go from *"just being open to maybe nursing… to needing onward referral to several members of the team" (8)*. However, it was felt there was *"not much getting around it" (8)*. Things can also start to happen relatively quickly: *"it's almost 0-60" (10)*. The group noted that MDT-style working is an *"established area of clinical practice for us" (8)*. There was also the feeling that *"people are genuinely quite appreciative of our input" (8).*

*Subtheme: Prevention is the best cure.*

Several participants identified potential issues with the pathway, such as it being *"reactive" (8)* and *"treatment is essentially starting too late" (9)* as things currently stand. There was a feeling that *"along the way, we are still missing people"* and *"no matter how early we get in, it almost isn't clear that they've got dementia until suddenly it's very clear… my overall sense is that we still may be a little bit too slow" (10).*

This aligns with the proposed benefits of a baseline assessment approach promoting *"clinical benefit in identifying people and starting treatment sooner" (8)*, as well as getting *"equipment…[and] future planning done earlier" (8)*. The team felt a proactive approach might *"start building relationships with people that little bit earlier, and hopefully relieve some fears later on down the line" (1)* as *"if they've got a named contact… then it means we can nip issues in the bud and support them to stay in their own homes for longer" (8).*

*Subtheme: Systems working against us.*

At a practical level there was a feeling that *"sometimes, our systems are working against us" (10)*. Issues were raised around data protection, such as *"we were told we couldn't have a database for people with DS because of… security issues"* and that in the past when using excel spreadsheets and paper notes *"we might have been a little more up on who had DS and who was presenting with risk, so it is slightly depressing that our systems that are meant to help us, might be hindering" (10).* Recording diagnosis reliably was a concern as *"sometimes it was on the psychiatry letter, sometimes it wasn't. Sometimes it was on the core assessment, sometimes it wasn't" (10)*. Staff felt data was often duplicated or recorded in an unhelpful manner- for example, the system includes a box that should be ticked when an LD is present which *"feels entirely unfit for purpose as by definition, all our service users are going to be ticking that box" (9)*, and *"it doesn't tell you what the disability is… it could be autism, it could be all sorts of other disabilities" (11)*. Wider issues about recording data

using ICD10 criteria were also raised, as there was *"a debate about whether only medical doctors, could do that, or if psychologists could" (10).*

**Theme 3: Person-centred care- putting the individual at the centre.**

*Subtheme: Unheard voices.*

A common theme raised around dementia in DS was that *"we haven't got their voice" (6)* and how the current approach is *"very much informant-based, based on the perception of people around them" (10)*, though there have been attempts to *"include the person… to get the direct picture" (8)* the overall feeling was that currently there was no way to *"support people to self-report, where they can, rather than relying on staff" (6)*. The team felt strongly about trying to change this: *"I just think it's really important… that we hear the service users' voice" (6)*. Solutions included *"asking the person directly, do you have any concerns about your memory" (8)* but also identified communication systems that may facilitate this: *"research in talking mats… in dementia has said that one of the outcomes has been that they've been able to recognise a [cognitive] decline"*, which could look like *"a simple check list [of questions] with talking mats to support the person" (6)*. Part of the reason for reliance on carer/staff response currently was thought to be due to (cognitive) capacity for individuals to answer the questions as some staff felt *"[they] haven't come across someone who has… wound up with a new diagnosis of dementia, that would be able to engage" (8)*, or that *"by the time they come to us… they've often declined to the point where they are lacking capacity to have those discussions" (8).* Conversely, some staff identified a hope for proactive screening was that *"early identification would be able to support conversations [around a diagnosis] with the person" (6).*

The importance of the voice of individuals with DS in planning a new pathway was also raised. Staff wondered *"what the DS community think about early screening" (6)* and that the discussion around a new pathway has been between a *"group of clinicians here and there is no one from the DS community" (6)*. Co-production was identified as a priority, as it is *"key to pathways and things now"* and the team felt they *"should be… including the voice of people with DS." (6).*

*Subtheme: To know or not to know, that is the question.*

Several wondered how to make sure the team are *"sensitively handling those discussions"* and whether *"it is going to unduly worry people with DS, talking about dementia at the age of 30" (8)*. This connected to a broader idea of consent and ethics: *"when you are born with a disability, people will tell you all the risks and all of the related concerns that might come… because they want you to have access to treatment don't they? But I don't know if anyone asks you… do you want to know?" (10)*. Overall, there was a concern that *"we might be…bringing a lot of worry and distress in" (10)* as *"sometimes parents don't want to future proof, they want to think about the here and now" (4)*. That there needs to be *"consideration on how we present it to the service users" (8)* was

noted, because of these concerns. Some were optimistic that *"having the screening in some ways can help them prepare" (2)* for the possibility of dementia in the future.

*Subtheme: All's fair…?*

Direct comparison between the current pathway and mainstream services arose. In mainstream services *"you can go through the GP, go to memory clinic and then it's a fairly short process… maybe 6-8 months"* whereas *"it gets a bit trickier to identify dementia in people who have already go pre-existing… LD to begin with" (8)*, which can often lead to later identification of initial issues and *"a fair bit of deterioration prior to [the team] getting involved" (8)*. Overall, there was an identification of *"so many confounding factors in our population" (10)*- for example, *"there's been an issue of whether people have brain scans or not, which of course is tricky with our service users… you can do more harm than good if looking for plaques and tangles and you've got DS, you've got those aplenty" (10)*. This highlights the need for a specialist approach to a DS dementia pathway and how *"there are some bits that are still… not quite clear for our population" (10).*

Staff noted that individuals with DS are used to *"routine health checks, going in and having questions asked" (7)* and highlighted that proactive healthcare is developing in mainstream services too- *"we are advocating more and more for breast cancer screening… we are moving towards and NHS that is trying to be proactive", "initially it would have been quite scary for people to think about cancers and stuff, but now it's become the norm for us to go and do those tests" (10)* suggesting that a move towards equality might suggest proactive healthcare in LD services too.

**Discussion**

This project explored considerations around introducing a baseline assessment dementia pathway for DS, using audit data and the perspectives of current staff. The initial phase of the project identified that no other services within the ICS are using a baseline assessment model.

The audit was designed to contextualise decision-making about introducing baseline assessments. GP surgery data identified the number of individuals with DS in Buckinghamshire (i.e., who would potentially access Buckinghamshire CLDHT) as 314 people (as of March 2022). The data indicated that 131 were aged over 40 suggesting a sizeable number of people in Buckinghamshire may be eligible for a baseline assessment already. The audit indicated 16 people with DS and dementia diagnosed since approximately 2016, with diagnosis taking an average of 69 weeks from referral, far beyond the 6 weeks promoted for the general population in the NHS Mandate (Department of Health and Social Care, 2017). This should be viewed in the context of the current 'reactive' pathway, which requires repeat assessments six months apart before confirming diagnosis (for those without a baseline assessment). Further, this workload should be viewed within the needs of the wider population served by the team. The audit identified an average age of 56 years at diagnosis, aligning with the literature (Sinai et al., 2018).

Qualitative analysis was used to explore staff perspectives on the current pathway and potential baseline assessments. Several ideas were raised by staff. These related to issues with the current pathway (current referral processes, flaws with electronic systems and the unintended impact of large-scale MDT working), ideas which could improve any new pathway (e.g., considering impact on clinical time, ensuring unity across the team and building in training opportunities), and ethical considerations.

This latter idea was voiced almost unanimously in the team, indicating ethical and moral complexities of baseline assessment programmes in LD populations, and the lack of opportunities for the DS community to have their voices heard. These findings can be understood within a biopsychosocial model which recognises the fixed biological aspects (i.e., genetic predisposition to dementia in DS) whilst suggesting that targeting the factors that are tractable might improve outcomes (e.g., quicker/earlier diagnosis may allow better adaptations to encourage continued embedment in the community and ability to live at home for longer). Qualitative and quantitative data identified issues with equitability as the diagnostic pathway stands currently, which also speaks to systemic psychosocial issues with care provision and consideration of populations such as those with DS. As identified in the theme 'All's fair...?' this relates to social aspects such as systemic issues with inequality between individuals with LD and the general population but also the psychological impact of introducing baseline screening and how individuals with DS may feel when informed of the risk of dementia years before potential symptom presentation. Indeed, the biopsychosocial-ecological development of the original model acknowledges the importance of wider social network and the bidirectional impact of dementia on these networks as well as the possible protective effect of these networks for the individual with dementia (Podgorski, Anderson, & Parmar, 2021). Following, improving equity of access to dementia diagnosis for those with DS may improve outcomes for these individuals.

**Recommendations (act)**

*Table 11: Recommendations; a response from the service is shown in appendix 2E.*

| Finding | Recommendation |
|---|---|
| **Clinical/workload pressures & staffing.**<br>Staff hold concerns about the pressure of a baseline assessment approach adding to clinical load. Teams already feel stretched and the responsibility for dementia assessments sits unevenly | • Deciding how to maximise or increase clinical time is to be prioritised if a new pathway is to be introduced.<br>• Identifying ways to share the workload across individuals and professions should be a |

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| within professional groups. Baseline assessments might reduce capacity to respond to more urgent clinical needs.<br><br>The concern of being overwhelmed by baseline referrals may not be borne out, as the data suggests that 2 people per year with DS were diagnosed by the team over the past few years (when averaged out). As such, if baseline assessments were introduced there may be little impact on staff time after the initial baseline assessment push. | discussion early in planning, if a new pathway is introduced.<br><br>• Identifying how many people with DS turn 30 in Bucks per year, to project costs of baseline assessments to clinical time over upcoming years (assuming referrals are made at 30 years of age as routine, or if referred to service over the age of 30 for any reason), is a priority. If everyone referred took up the offer of baseline assessment there currently would be around 183 individuals eligible (the number aged over 30 currently in Bucks). Depending on how many would require an assessment each year, there may be no need for increased staffing; however, services using a baseline screening model have employed specific staff for this role.<br><br>• Dedicating staff to baseline assessments should be a priority. This should be discussed with team managers and commissioners if baseline assessments are introduced by the service. Fully exploring the necessity of extra staff recruitment requires consideration of all 4 recommendations above, at the time of introducing baseline assessments. This will enable the service to meet UK guidance on provision of baseline assessments. |
| **Practical issues.**<br>Staff highlighted practical issues that might present issues if adopting a baseline assessment approach, including issues with the data systems, how documentation is presented and shared, and thoughts about gaps in knowledge | • The team need to agree a way to consistently record diagnoses such as DS and dementia on the current electronic patient record and team databases in order to enable quick identification of everyone with these diagnoses.<br>• The new pathway process should be documented and shared within and without the |

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| that might need specific training opportunities.<br><br>Staff reported how suddenly many professionals can become involved once someone is added to (the current) dementia pathway, and how this might feel overwhelming.<br><br>Training needs were highlighted. Some team members felt they lacked confidence in conducting some dementia assessments, or in noticing dementia-related behaviours, without support from Psychology, Psychiatry or Nursing colleagues | team (e.g., easily shared documents, documents displayed in appropriate areas).<br><br>• Sharing process information (accessibly) with individuals referred to a new baseline assessment pathway (and their carers/family) will be key to prepare families for the number of professionals who may become involved in their care.<br>• Further training would be a means to tackle this and would potentially assist with the impact on clinical time that a baseline assessment pathway would have (see above). Providing quality training on the assessment measures used by the service is a priority to a) address training needs and b) share the workload equitably. |
| **Communication.**<br>Staff mentioned concerns about how accessible communication about baseline assessments for dementia might be and how they'd hope to maximise this in the interest of service user buy in and ethical practice. | • Discussing options around baseline assessments for dementia and the pathway process information with individuals referred to a new baseline assessment pathway (and their carers/family) is key for the new pathway.<br>• Finding means to communicate clearly with individuals with DS (and their network) will be integral to this. Suggestions such as easy-read documents and talking mats were discussed as useful ways to achieve consent and autonomy. |
| **Co-production.**<br>One of the most frequently raised ideas was how crucial co-production of any new pathway would be. This was mentioned by all staff members as a priority for service development. | • This is in the context of co-production being a priority in service development more broadly.<br>• Carers of people with DS were asked for their input on the focus group questions explored in this project- at a minimum, this level of involvement would be expected. |

| | |
|---|---|
| | • Co-production is becoming more visible across research and services and should be prioritised in the set-up of new pathways that have direct impact on the lives of people under the care of these pathways. |

*Limitations*

Though all team members involved in the current dementia pathway were invited to take part, not all participated which might mean a loss of nuance. Additionally, the professionals attending each focus group coincidentally was divided into a group of Psychology/Psychiatry and a group of other Allied Health Professions. This could have altered how ideas were shared due to different professional priorities. An issue with this project is use of a single cycle of PDSA, when iterative cycles are the best way to use this framework to its strengths. Guidelines for conducting qualitative research identify credibility, dependability, confirmability, transferability, and reflexivity as core to trustworthy research (Guba, Lincon, & Denzin, 1996; Stenfors, Kajamaa, & Bennett, 2020). A particular issue for this project is transferability, given that findings cannot be generalized outside of Bucks CLDHT. Additionally, the focus group was largely opportunistic sampling in that staff members with availability attended: a different approach would have been to take a longer-term approach to allow for greater participation from all staff.

*Future directions*

As above, this represents a single cycle of PDSA which is best used as part of ongoing cycles of reflective practice. The next steps for this project would benefit from approaching individuals with DS, both with and without dementia, and their families and caregivers to hear the voices of those with lived experience. This could centre on asking questions around their feelings about baseline screening for dementia, as well as how to optimise the ongoing participation of service users in both development of this practice and in their own healthcare, as changes to service practice are made. This should form an ongoing evaluation if baseline screening is rolled out, to evaluate whether the pathway benefits service users. This would continue to sit within a biopsychosocial approach, as alteration of tractable psychosocial factors may be improved by baseline screening as needs are identified in a range of psychosocial domains, with a resultant improvement in outcomes for diagnosed individuals.

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# Exploring relationships between adverse childhood experiences, negative self-beliefs, self-compassion and body mass index (BMI) in women.

Running title: Adverse childhood experiences, negative self-beliefs, self-compassion and BMI in women.

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The submission guidelines are included in appendix 4C.

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# Exploring relationships between adverse childhood experiences, negative self-beliefs, self-compassion and body mass index (BMI) in women.


## Abstract

Overweight/obesity is associated with both physical and psychological correlates. Though psychological intervention is mentioned in guidelines, the nature of psychological support for this group is undefined. As such, a better understanding of the psychological factors in overweight/obesity is timely. This study explores applicability of a cognitive model originally designed for use in disordered eating, in overweight/obesity. The role of adverse childhood experiences (ACEs), negative self-beliefs (NSB), and self-compassion in body mass index (BMI) is explored in an online sample of 222 adult females, grouped by normal weight (BMI 18.5-24.9) and overweight/obese (BMI >25). Results indicate significantly lower mood and greater self-loathing in the overweight/obese group. There was no difference in self-compassion between the groups. No predictive relationship between ACEs or NSB and BMI was identified, nor any mediating effect of NSB or moderating effect of self-compassion on these relationships. Findings partially support the application of this cognitive model in a general population sample of overweight/obese and indicate the importance of mood. Self-loathing may be a relevant NSB in overweight/obese populations. Considering the likely heterogeneity of overweight/obese populations is important in future work.


## Introduction

Health conditions associated with overweight/obesity impact global economy and healthcare expenditure (le Roux, Hartvig, Haase, Nordsborg, Olsen, & Satylganova, 2021). Future impact on global economies estimates an increase from 2.19% of global gross domestic product in 2019 to 3.29% in 2060 (Okunogbe, Nugent, Spencer, Powis, Ralston, & Wilding, 2022). The National Health Service (NHS) in the United Kingdom estimated that 25.9% of adults in England were classed as obese, and a further 37.9% classed as overweight in 2021 (UK Parliament, 2023). There is a higher prevalence in women globally, with 39.4% of women estimated to be overweight in 2019, compared to 38.5% of men (Chooi, Ding, & Magkos, 2019; Cooper, Gupta, Moustafa, & Chao, 2021; Manrique-Acevedo, Chinnakolta, Padilla, Martinez-Lemus, & Gozal, 2020). Multiple mechanisms for this between-sex difference have been proposed, including environmental, behavioural and lifestyle differences (Howe, Patel, & Galobardes, 2010; Manrique-Acevedo et al., 2020), and hormonal factors such as pregnancy (Creanga, Catalano, & Bateman, 2022) and menopause (Opoku, Abushama, & Konje, 2023).

Overweight/obesity is a risk factor for health conditions such as cardiovascular disease (Cercato & Fonseca, 2019; Dikaiou et al., 2021; Sommer & Twig, 2018) and type II diabetes (Boles, Kandimalla, & Reddy, 2017; Klein, Gastaldelli, Yki-Jarvinen, & Scherer, 2022). The risk of developing some cancers is also higher in overweight/obesity (Lazarus & Bays, 2022; Tzenios, 2023).

Overweight/obesity also has psychological co-morbidities. It is associated with shame, low self-esteem and psychological distress, and high levels of social stigma (Ratcliffe & Ellison, 2015), as well as demonstrated bidirectional relationships with depression and anxiety (Avila et al., 2015; Rajan & Menon, 2017), and a strong link between depression and obesity in women specifically (Rajan & Menon, 2017).

Multiple interfacing factors underlie overweight/obesity. Genetics may account for up to 50% of variability in body weight in overweight/obesity (Bouchard, 2021), whilst hormone changes related to menopause, or hormonally-driven conditions such as polycystic ovary syndrome may link to weight gain in women (Awoke et al., 2022; Davis et al., 2012; Knight, Anekwe, Washington, Akram, Wang, & Standord, 2021). Socio-economic status has been linked to higher rates of overweight/obesity (Charo & Lacoursiere, 2014), and there are links between longer working hours/night-working and overweight/obesity in some populations of women (Eum & Jung, 2020). Developmental experiences such as disrupted attachment and childhood trauma have been linked to raised body mass index (BMI) in men and women (Diener et al., 2016; Santos, Martins, Fernandes, Bost, & Verissimo, 2021; Schroeder, Schuler, Kobulsky, & Sarwar, 2021; Wilkinson, Rowe, Robinson, & Hardman, 2018; Wiss & Brewerton, 2020), possibly via insecure attachment leading to poor emotional regulation and negative beliefs about the self, with eating as a strategy adopted for emotional regulation (Santos et al., 2021).

Guidelines for supporting overweight/obese populations include surgical, pharmacological, lifestyle and psychological options (NHS England, 2023). The NHS offers psychosocial, pharmacological (Cignarella, Busetto, & Vettor, 2021; Khalil, Ellwood, Lord, & Fernandez, 2020) and surgical (Gulinac et al., 2023) interventions. The latter two are effective in reducing BMI but have associated physical health impact (Cignarella et al., 2021; Gulinac et al., 2023) and weight regain is common (Sarma, Socklingham, & Dash, 2021; Wilding et al., 2022) with anxiety, emotional eating and binge eating proposed mechanisms in this (Athanasiadis, Martin, Kapsampelis, Monfared, & Stefanidis, 2021). Psychological interventions supporting weight-loss have some evidence-base (e.g., Chu et al., 2019). Though psychological intervention features in guidelines, the nature of this is not defined (Dandgey & Patten, 2023). Together, this suggests that better understanding of the psychological mechanisms involved in overweight/obesity is necessary to provide good clinical care.

The Cooper et al. model of disordered eating describes under- and over-eating in both the presence or absence of compensatory strategies (Cooper, Todd, & Wells, 2008; Young & Cooper, 2013). The model suggests that triggers lead to engagement of negative self-beliefs (NSB) and activation of negative automatic thoughts, setting off a cyclical relationship between emotion, thoughts, and beliefs (both positive and negative) about eating, eating behaviours and negative automatic thoughts (Figure 2). NSB refer to global and rigid beliefs about the self, which may arise in early development (Fairchild & Cooper, 2010), possibly arising from experiences of childhood trauma and abuse (Su & Stone, 2020). The model has been applied to bulimia nervosa (BN) and binge-eating

(BE) samples (Cooper et al, 2008; Young & Cooper, 2013); evidence suggests there may be a link between overweight/obesity and these diagnoses (Srivastava et al., 2022) so it may be that the model could identify certain features contributing to overweight/obesity. The model has been explored the general population, identifying a link between greater NSB and higher BMI (Cooper & Young, 2016). Additionally, negative self-schema/negative self-beliefs are associated with higher weight individuals in several studies (Anderson, Rieger, & Caterson, 2006; Basile, Tenor, & Mancini, 2019), and NSB have been shown to mediate relationships between childhood experience and weight in women (Cooper et al., 2008; Young & Cooper, 2013). If this cognitive model is applicable, cognitive interventions such as cognitive behavioural therapy (CBT) may be fruitful in tackling NSB, which theoretically may contribute to the maintenance of unhelpful behaviours and emotions associated with weight change (Cooper et al., 2008). CBT for weight-loss and maintenance of loss has some support in the literature (Chu et al., 2019; Werrij, Jansen, Mulkens, Elgersma, Ament, & Hospers, 2009).

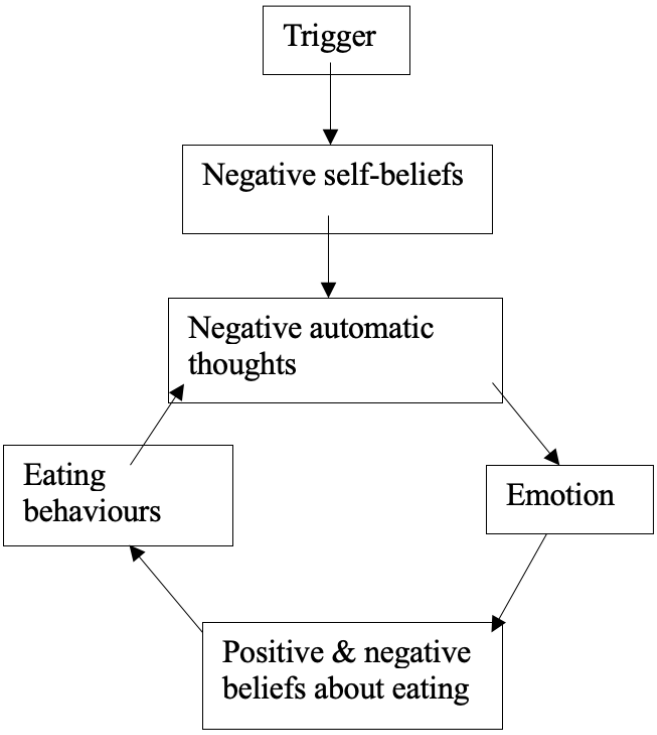



*Figure 2 Cooper et al (2008) cognitive model of Bulimia Nervosa (BN) and Binge Eating (BE)*

Evidence suggests higher self-compassion may be protective against later psychological distress in those with higher ACEs (Hazzard et al., 2021; Hirsch, Hall, Wise, Brooks, Chang, & Sirois, 2021) and be associated with reduced self-stigma, shame and improved emotional resilience to diet-lapses (Brenton-Peters, Consedine, Boggiss, Wallace-Boyd, Roy, & Serlachius, 2021; Thøgersen-

Ntoumani et al., 2021). It may be that improving self-compassion is a useful way to target NSB, as self-compassion could have a protective function. Figure 2 depicts these proposed relationships.

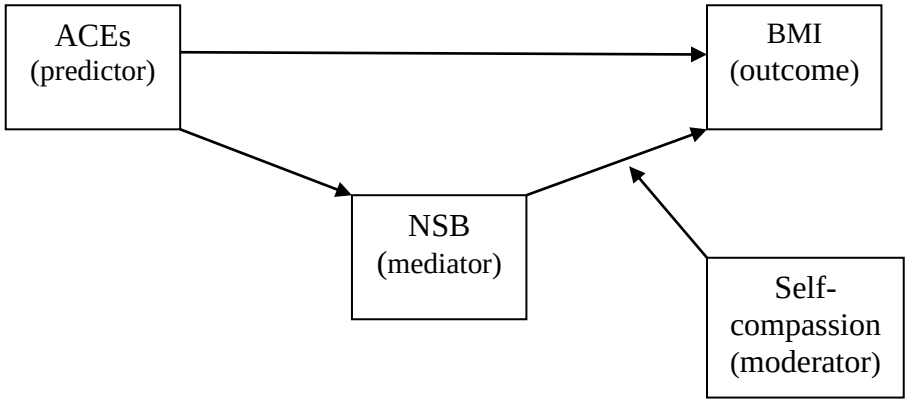



*Figure 3 Proposed relationships between Adverse Childhood Experiences (ACEs), Body Mass Index (BMI), Negative Self-beliefs (NSB) and self-compassion. Arrows indicate direction of influence.*

If self-compassion plays a role in the relationship between ACEs, NSB and weight then interventions that focus on building this such as compassion-focused therapy (CFT) may be applicable; there has been some exploration of CFT as a treatment for weight-stigma/shame (Carter, Steindl, Parker, Gilbert, & Kirby, 2023; Steindl et al., 2017), and in tackling overeating (Marques et al., 2024). This approach views self-compassion as a state (e.g., Neff, 2023), which can be theoretically modified through psychological interventions such as CFT. If self-compassion functions as a moderator of pre-existing relationships between NSB and BMI, it could be targeted which would inform use of compassion-based approaches in treatment seeking overweight/obese groups. Identifying if these relationships exist and whether Cooper et al's (2008) cognitive model outlining these relationships is applicable in overweight/obesity is a first step.

*BMI*

The World Health Organisation (WHO) uses body mass index (BMI) to categorise individuals based on nutritional status, calculated as weight (in kilograms) divided by the square of their height in metres (World Health Organisation, 2010). These categories are summarised as normal weight (18.5-24.9), overweight (BMI ≥25) and obese (BMI ≥30) (World Health Organisation, 2021).

Developed for use at population level, BMI is used as a means of identifying risk for several health conditions in individuals (World Health Organisation, 2010). This use of BMI has been critiqued (World Health Organisation, 2021) but it remains widely used in research and clinically. Overall, BMI is thought to have low specificity and sensitivity as a measure (Rothman, 2008). A key concern is that BMI does not account for individual differences such as physical activity and should

not be used to represent membership of weight categorisations (e.g., overweight, obese) (Gutin, 2018). Additionally, there are issues with the accuracy of correlations between body fat and BMI as well as inconsistencies in the link between BMI and health risk again dependent on ethnicity, sex, and age (Callahan, 2023). It has been suggested that BMI could more accurately be used to indicate possible future risk, rather than to represent a "transition from disease-free to diseased" (Gutin, 2021, pp 1444). BMI has been considered problematic for well over a decade; critics identify that it doesn't distinguish fat from bone or muscle (Burkhauser & Cawley, 2006) contributing to the issues with the validity of BMI in different ethnicities, between the sexes and across the lifespan (Rothman, 2008; Callahan, 2023). Broader critiques suggest BMI as it is currently used contributes to weight stigma and leads to problematic assumptions about bodies as directly representing an individual's health status or adherence to social values (Gutin, 2021).

**Aims and hypotheses**

This project explores the relationship between ACEs, NSB and self-compassion and BMI in a general population sample of adult women.

*Primary hypothesis:*

Comparing overweight/obese (BMI >25) individuals to a normal weight (BMI 18.5-24.9) control group:

a) Number of ACEs will be significantly higher in the overweight/obese group compared to normal BMI.
b) NSB will be significantly higher in overweight/obese than in normal BMI.
c) Self-compassion will be significantly lower in overweight/obese than normal BMI.

*Secondary hypotheses:*

1) Higher number of ACEs will predict higher BMI.
2) Higher NSB scores will predict higher BMI.
3) Higher number of ACEs will predict higher NSB scores.
4) The relationship between ACEs and BMI will be mediated by NSB, such that lower NSB will be associated with a reduced relationship.
5) The relationship between NSB and BMI will be moderated by self-compassion scores, such that greater self-compassion will reduce the relationship.

**Methods**

Ethical approval for this study was granted by the University of Oxford CUREC-1 pathway, reference R92324/RE001. Materials were reviewed by two individuals with BMI >25 and two with BMI 18.5-24.9; small changes in wording were made to the information sheet in response.

**Participants**

Adult (≥ 18 years of age) female participants who could read English and give informed consent (appendix 3A) were recruited online via social media and word of mouth. Advertising was within the UK, but no geographical restrictions were set for participation.

**Materials**

Five self-report questionnaires were used in this study (Table 12).

*Table 12 Details of questionnaires used in study.*

| Measure | Information |
|---|---|
| *Eating Disorder Core Beliefs Questionnaire (ED-CBQ)* (Fairchild & Cooper, 2010) | The ED-CBQ is a 40-item self-report questionnaire rating strength with which individuals identify with listed core beliefs, from "feels very much untrue" to "feels very much true", the majority of the time. The scale reportedly has appropriate construct validity and internal consistency (Burton et al., 2016; Fairchild & Cooper, 2010). The questionnaire has been used in BE/BN samples as well as in a community sample (Cooper et al, 2016). The ED-CBQ has 5 sub-scales, scored as follows: self-loathing (sum of items 7, 8, 9, 15, 20, 25, 27, 28, 29 and 40/10), unassertive/inhibited (sum of items 14, 17, 30, 33, 36, 37, 38 and 39/8), high standards for self (sum of items 4, 10, 11, 18, 22, 23, 24 and 31/8), demanding (sum of items 3, 5, 12, 13, 16, 21, 26, 32, 34 and 35/10) and abandoned (sum of items 1, 2, 6 and 19/4). Internal consistency for this measure has been shown to range from $\alpha$ = .76 to $\alpha$ = .96 (Cooper & Fairchild, 2010). |
| *Adverse Childhood Experiences Questionnaire (ACE-Q)* (Anda et al., 2004; Felitti et al., 1998). | The ACE-Q is a 10-item self-report measure in which individuals report whether they were exposed to a range of traumatic experiences prior to the age of 18. The ACE-Q has demonstrated reliability and construct validity in community samples (Afifi et al., 2020; Nishimi et al., 2020) and mental health populations (e.g., Van der Feltz-Cornelis & de Beurs, 2023). The ACE-Q is scored with 0 for 'no' responses and 1 for 'yes' responses, with a total possible score of 10. The ACE-Q has been shown to have an internal consistency in a non-clinical population study ($\alpha$ = .64) (Kovacs-Toth, Olah, Kuritarne, & Fekete, 2023). |
| *Self-Compassion Short-Form Questionnaire* | The SCSFQ is a 12-item self-report measure of self-compassion, which is well validated with good internal consistency (Neff et al., 2021; Raes et |

| | |
|---|---|
| *(SCSFQ)* (Raes et al., 2011). | al., 2011). The SCSFQ scores responses 1-5 with 6 items reverse scored (items 1, 4, 8, 9, 11 and 12). The SCSFQ has reported internal consistency scores of up to $\alpha = 0.86$ in the literature (Raes, et al, 2011). |
| *Generalised Anxiety Disorder-7 Questionnaire (GAD-7)* (Spitzer et al., 2006). | The GAD-7 is a 7-item self-report measure assessing frequency of anxiety symptoms over the previous 2 weeks. The GAD-7 is well validated and has good reliability in both psychiatric (Beard & Björgvinsson, 2014) and general (Byrd-Bredbenner et al., 2021) populations. Items are scored 0-3 and summed. Clinical cut offs for total scores are 5-9 mild anxiety, 10-14 moderate and >15 severe anxiety. Internal consistency values of as high as $\alpha = 0.921$ have been documented (Shelvin et al., 2022). |
| *Patient Health Questionnaire (PHQ-8)* (Kroenke et al., 2001, 2009). | The PHQ-8 is a self-report measure identifying frequency of eight depression symptoms over the past 2 weeks. Adapted from the PHQ-9 (Kroenke, Spitzer & Williams, 2001) with the removal of question 9 (which relates to self-harm), the PHQ-8 is a useful measure of depression (Kroenke et al., 2009) and is scored in the same manner (responses scored 0-3). PHQ-8 uses clinical cut offs of 5, 10, 15 and 20 for mild, moderate, moderately severe and severe depression respectively (Kroenke & Spitzer, 2002). A meta-analysis of 27 European countries identified an average internal consistency of $\alpha = .870$ (de la Torre et al., 2023). |

**Procedure**

Adverts provided a link to the study Qualtrics page. Participants indicated they met inclusion criteria (female, ≥ 18 years of age) and their consent with tick-boxes. Age, height and weight were self-reported, before each of the questionnaires were completed (Table 12) and finally a debrief page was shown. At the bottom of questionnaire was information about how to seek help from NHS/third sector if distressed.

**Data storage and management**

No identifiable data were collected. Anonymous data were downloaded and stored on the University of Oxford secure SharePoint system for a minimum of 3 years from study completion, following Oxford University GDPR and CUREC1 regulations.

**Analysis plan**

Data were processed in Microsoft Excel and analysed using IBM SPSS v 29.0 (IBM, 2023). Mediation (model 4) and moderation (model 1) analysis were conducted using the PROCESS v4.2 SPSS package (Hayes, 2017; IBM, 2023). Data were split into "normal" (18.5-24.9) and "overweight/obese" (>25) BMI for group comparisons. Those with BMI <18.5 were excluded. Assumptions were tested for all analyses (appendix 3B). As part of this, data was tested for normality and appropriate tests chosen in response to this as detailed in the results section.

All primary and secondary analysis will be run unadjusted and then adjusted for PHQ-8 and GAD-7, due to established relationships between anxiety and depression and overweight/obese (Avila et al., 2015; Rajan & Menon, 2017), childhood trauma (McKay et al., 2021) and scores on the ED-CBQ measure of NSB (Fairchild & Cooper, 2010). Adjusted models also included age as age was shown to be significantly different between groups (see primary hypothesis 1 results) and to be a significant predictor of BMI (secondary hypotheses section). Adjusted linear regressions (secondary analysis) included these factors on step 1.

*Primary analysis:*

Independent-samples t-tests for group comparison on ACEs, NSB (ED-CBQ) subscales, SCSFQ, PHQ-8 and GAD-7 scores were planned unless data was shown to be non-parametric, in which case Mann Whitney-U tests are appropriate. Significantly higher scores in all variables except self-compassion were predicted in the overweight/obese group. Group comparisons adjusted for PHQ-8, GAD-7 and age (see above for rationale) were then planned, using analysis of covariance (ANCOVA). ANCOVA are also considered appropriate for use if data is parametric or non-parametric (Olejnik & Algina, 1984).

*Secondary analysis:*

1) Linear regression of ACEs on BMI.
2) Linear regression of NSB sub-scale scores on BMI.
3) Linear regression of ACEs on NSB.
4) Mediation analysis will assess whether the relationship between ACEs and BMI is mediated by NSB scores.
5) Moderation analysis will assess whether the relationship between NSB scores and BMI is moderated by self-compassion.

As described above, all these regression analyses were run unadjusted and then adjusted for GAD-7, PHQ-8, and age, with adjusted variables added on step 1.

**Power analysis**

The ED-CDQ has not previously been used for group comparison of overweight/obese, so power calculation for used data from a questionnaire identifying similar themes (Anderson et al., 2006) suggesting independent-samples t-test with 2 groups and a medium effect size ($d = 0.5$) required 105 individuals per group. Power calculations for linear regression with 3 predictors (ACEs, PHQ-8 and GAD-7 score), a medium effect (Cohen's $f^2 = 0.15$) and power of .95 required a sample size of 119. Calculations were computed using G*Power (Erdfelder, Faul, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007), see appendix 3C.

**Results**

In total, 248 individuals completed the online survey; after removal of incomplete responses there were 222 datasets. Descriptive statistics are in Table 13. Almost half (42%) reported no exposure to childhood trauma; 20% reported exposure to one trauma. Chi-squared comparison of ethnicity between groups (divided into white, non-white due to low numbers in several categories) was non-significant ($X^2 = 0.2786$, df = 1, p = 0.61). Cronbach's alpha was calculated for each measure ACEs ($\alpha = .75$), GAD-7 ($\alpha = .89$), PHQ-8 (.88) and NSB ($\alpha = .686$) when calculated as a full sample. These largely match the literature (see table 1), though the NSB $\alpha$ is low. When divided into normal versus overweight/obese the $\alpha$ values did not improve ($\alpha = .674$ and $\alpha = .663$ respectively). Acceptable Cronbach's alpha values are usually over .70 (Tavakol & Dennick, 2011).

*Table 13: N, Mean and frequency data for demographics and questionnaire scores, by BMI grouping, and between-group comparison output from Mann-Whitney U tests.*

| | Total sample M (SD) | BMI 18.5-24.9 (Normal) M (SD) | BMI >25 (Overweight/ obese) M (SD) | Mann-Whitney U | z | p |
|---|---|---|---|---|---|---|
| N | 222 | 122 | 100 | | | |
| BMI | 25.3 | 21.9 (1.8) | 30.0 (5.0) | | | |
| **Age** | 37.8 | 36.3 (11.7) | 39.8 (11.6) | **4790.5** | **-2.86** | **.004**** |
| ACES | 1.6 (1.9) | 1.5 (2.0) | 1.6 (1.9) | 5863.0 | -.651 | .515 |
| **PHQ-8** | 5.6 (4.9) | 5.0 (4.9) | 6.2 (4.8) | **4926.0** | **-2.48** | **.013*** |
| GAD-7 | 6.2 (4.8) | 6.1 (5.0) | 6.1 (4.6) | 5986.5 | -.365 | .715 |
| NSB total | 117.4 (28.1) | 115.5 (26.8) | 116.9 (26.8) | 5958.0 | -.422 | .673 |
| NSB self-loathing | 0.5 (0.9) | 0.4 (.79) | 0.5 (0.9) | 5491.5 | -1.48 | .139 |
| NSB unassertive | 2.1 (1.0) | 2.0 (1.0) | 2.1 (1.0) | 5838.0 | -.674 | .500 |
| **NSB high standards for self** | 3.9 (0.9) | 4.0 (0.9) | 3.7 (1.0) | **4769.5** | **-2.905** | **.004**** |
| NSB demanding | 1.9 (1.1) | 1.8 (1.1) | 1.9 (1.1) | 5539.5 | -1.297 | .195 |
| NSB abandoned/isolated | 1.5 (1.4) | 1.4 (1.4) | 1.5 (1.2) | 5750.0 | -.862 | .389 |
| SCSFQ | 3.5 (0.9) | 3.6 (1.1) | 3.4 (0.9) | 5623.5 | -1.585 | .113 |
| *Ethnicity (%)* | *%* | *%* | *%* | | | |
| White | 59.6 | 78.7 | 83.2 | | | |
| British/Irish/other | | 13.9 | 6.9 | | | |
| Multiple ethnicity | 21.3 | 1.6 | 2.0 | | | |
| Asian | 11.1 | 3.3 | 4.9 | | | |
| Black | 0 | 0 | 0 | | | |
| British/African/Carrib. | 1.7 | 0.8 | 1.0 | | | |
| Arab | 0 | 0 | 0 | | | |
| Other | 0 | 0 | 0 | | | |

* Significant at p<.05

**Significant at p<.005

M: Mean; SD: Standard Deviation; BMI: Body Mass Index; ACEs: Adverse Childhood Experiences; PHQ-8: Patient Health Questionnaire 8; GAD-7: Generalized Anxiety Disorder-7; NSB: Negative self-beliefs; SCSFQ: Self-compassion Short Form Questionnaire) PHQ-8 uses clinical cut offs of 5, 10, 15 and

20 for mild, moderate, moderately severe and severe depression respectively. The GAD-7 uses clinical cut offs of 5, 10 and 15 representing mild, moderate and severe anxiety respectively.

*Primary hypotheses*

The assumption of normality of data distribution was violated in the variables intended for group comparison (appendix 3B). Evidence suggests Mann-Whitney U tests are robust in this scenario. ACEs, NSB sub-scales, SCSFQ, GAD-7, PHQ-8 scores and age were compared between normal and overweight/obese groups (Table 13), indicating significantly higher age ($p = .013$), lower NSB standards-for-self ($p = .004$) and low PHQ-8 scores ($p = .004$) in overweight/obese group.

ANCOVA compared groups on NSB sub-scale, ACEs and SCSFQ scores adjusted for GAD-7, PHQ-8 and age (Table 13). Grubbs test identified outliers, returning a significant p-value on 4 stepwise iterations. The 4 outliers were removed individually with Grubbs re-run between (all outliers were overweight/obese BMI, ranging from 40.4- 49.7). The final iteration was non-significant, indicating no further outliers (appendix 3B). As such, $n = 96$ for the overweight/obese group in the ANCOVA analysis. Though the assumption of normality was violated (appendix 3B), homogeneity of variances was present (Levene's Test for Equality of Error Variances, all $p>.05$). There is evidence that ANCOVA is robust if homogeneity of variance is met (Olejnik & Algina, 1984). All other assumptions were met (appendix 3B). Findings indicated a significant different in NSB self-loathing between groups, as shown in Table 14.

*Table 14 ANCOVA group comparisons of normal and overweight/obese scores on ACEs, NSB sub-scales and SCSFQ adjusted for GAD-7, PHQ-8 and age*

| | df | f | p |
|---|---|---|---|
| ACEs | 2, 5 | .570 | .567 |
| **NSB self-loathing** | **2, 5** | **7.436** | **<.001**** |
| NSB unassertive/inhibited | 2, 5 | .918 | .401 |
| NSB high standards for self | 2, 5 | 2.442 | .089 |
| NSB demanding | 2, 5 | .463 | .630 |
| NSB abandoned/isolated | 2, 5 | 1.836 | .162 |
| NSB total | 2, 5 | 2.430 | .090 |
| SCSFQ | 2, 5 | 2.102 | .125 |

**Significant at p<.005

ACEs: Adverse Childhood Experiences; PHQ-8: Patient Health Questionnaire 8; GAD-7: Generalized Anxiety Disorder-7; NSB: Negative self-beliefs; SCSFQ: Self-compassion Short Form Questionnaire) PHQ-8 uses clinical cut offs of 5, 10, 15 and 20 for mild, moderate, moderately severe and severe depression respectively. The GAD-7 uses clinical cut offs of 5, 10 and 15 representing mild, moderate and severe anxiety respectively.

*Secondary hypotheses*

Assumptions were met for linear regression, except for outliers. As above, the 4 outliers were removed (n =218 for regression analyses; appendix 3B). There were significant correlations between some variables (*appendix 3D*) as these were not strong correlations, this is acceptable. Multicollinearity was not shown (appendix 3B). Given age was significantly different between groups, a regression was run to establish if age was a significant predictor of BMI, indicating a significant effect $\beta = .069$, SE = .030, p = .022, $r^2 = .022$). This supports continued inclusion of age in adjusted models.

Unadjusted and adjusted models were run for each linear regression. Adjusted models included GAD-7, PHQ-8 and age added on step 1 of each model.

*Secondary hypotheses 1:* An unadjusted linear regression assessing whether ACEs predict BMI was not significant ($\beta = .07$, SE = .182, p = .701, $r^2 = .001$). An adjusted model including GAD-7, PHQ-8 and age added on step 1 did not indicate a significant model either ($\beta = .023$, SE = .188, p = .904, $r^2 = .056$), suggesting ACEs did not predict BMI.

*Secondary hypothesis 2:* There was a significant, negative relationship between NSB high standards for self and BMI (β= -.820; SE= .370; $p$=0.028) in unadjusted models, indicating that having lower standards for oneself were associated with a higher BMI. Adjusted models included GAD-7, PHQ-8 and age added on step 1 of each model. Adjusted models were non-significant suggesting shared variance between the NSB sub-scales and variables adjusted for in the model (Table 4).

*Table 4 Regression analysis, effect of Negative Self-Beliefs on BMI unadjusted and then adjusted for GAD-7 and PHQ-8 scores, and age*

| | β | SE | p | $R^2$ |
|---|---|---|---|---|
| *Unadjusted* | | | | |
| NSB self-loathing | -.076 | .393 | .847 | .000 |
| NSB unassertive | .029 | .353 | .935 | .000 |
| **NSB high standards-for-self** | **-.820** | **.370** | **.028*** | **.021** |
| NSB demanding | .586 | .318 | .067 | .014 |
| NSB abandoned | -.064 | .264 | .809 | .000 |
| NSB total | .001 | .013 | .963 | .000 |
| *Adjusted* | | | | |
| NSB self-loathing | -.921 | .497 | .056 | .070 |
| NSB unassertive | -.295 | .381 | .441 | .057 |
| NSB high standards-for-self | 0.557 | .385 | .149 | .063 |
| NSB demanding | .508 | .380 | .183 | .062 |
| NSB abandoned | .357 | .307 | .247 | .060 |
| NSB total | .297 | .016 | .297 | .059 |

*Significant at p <.05

(df): Degrees of Freedom; GAD-7: Generalized Anxiety Disorder-7; NSB: Negative self-beliefs; PHQ-8: Patient Health Questionnaire-8.

*Secondary hypothesis 3:* Linear regressions explored whether ACEs predict NSB sub-scale scores (Table 5) in unadjusted and adjusted (for GAD-7, PHQ-8 and age) models. This indicated multiple significant models in which ACEs predicted NSB sub-scale score, with only NSB high standards-for-self not significant.

*Table 5 Linear regression, adjusted and unadjusted for GAD-7, PHQ-8 and age exploring whether ACEs predict NSB sub-scales*

| | β | SE | p | $R^2$ |
|---|---|---|---|---|
| *Unadjusted* | | | | |
| **NSB self-loathing** | **.185** | **.028** | **.001** | **.158** |
| **NSB unassertive** | **.144** | **.033** | **.001** | **.276** |
| NSB high standards-for-self | .044 | .032 | .166 | .008 |
| **NSB demanding** | **.180** | **.035** | **.001** | **.317** |
| **NSB abandoned** | **.472** | **.033** | **.001** | **.467** |
| **NSB total** | **7.04** | **.806** | **.001** | **.249** |
| *Adjusted* | | | | |
| **NSB self-loathing** | **.113** | **.025** | **.001** | **.378** |
| **NSB unassertive** | **.095** | **.032** | **.004** | **.196** |
| **NSB high standards-for-self** | **.076** | **.032** | **.019** | **.093** |
| **NSB demanding** | **.109** | **.032** | **.001** | **.343** |
| **NSB abandoned** | **.407** | **.031** | **.001** | **.576** |
| **NSB total** | **5.21** | **.704** | **.001** | **.476** |

*Significant at p <.05

(df): Degrees of Freedom; GAD-7: Generalized Anxiety Disorder-7; NSB: Negative self-beliefs; PHQ-8: Patient Health Questionnaire-8.

*Secondary hypothesis 4:* Mediation analysis requires significant relationships between IV and DV (here, ACEs and BMI) and IV and mediator (ACEs and NSB). Though ACEs did not significantly predict BMI (see secondary hypotheses 1 and 2) there is an argument that it remains appropriate to use mediation and moderation analysis even if this assumption is not met (Hayes, 2017). As such mediation analysis was conducted to explore potential for NSB sub-scales as mediators of relationship between ACEs and BMI (figure 3).

Effects of NSB sub-scales and total on this relationship are shown in Table . Each sub-scale mediation analysis was run separately, adjusting for GAD-7, PHQ-8 and age. The indirect effects indicate NSB to have no significance mediating effect as all 95% CI cross 0.

*Table 6 Mediation analysis- effects of NSB sub-scales on relationship between ACEs (predictor) and BMI (outcome)*

| | β | 95% CI | p | $R^2$ |
|---|---|---|---|---|
| NSB self-loathing | -1.028 | -2.019, -.039 | .004 | .071 |
| *Direct effect* | *.142* | *-.244, .529* | | |
| *Indirect effect* | *-.119* | *-.280, .013* | | |
| NSB unassertive | -.315 | -1.083, .452 | .021 | .057 |
| *Direct effect* | *.053* | *-.327, .433* | | |
| *Indirect effect* | *-.030* | *-.125, .046* | | |
| NSB high standards for self | -.577 | -1.345, .191 | .010 | .063 |
| *Direct effect* | *.065* | *-.310, .441* | | |
| *Indirect effect* | *-.042* | *-.126, .014* | | |
| NSB demanding | .523 | -.246, 1.292 | .012 | .062 |
| *Direct effect* | *-.034* | *-.414, .347* | | |
| *Indirect effect* | *.1095* | *-.013, .2872* | | |
| NSB abandoned/isolated | -.677 | -1.483, .127 | .008 | .066 |
| *Direct effect* | *.297* | *-.196, .790* | | |
| *Indirect effect* | *-.274* | *-.638, .070* | | |
| NSB total | -.022 | -.057, .013 | .015 | .014 |
| *Direct effect* | *.137* | *-.227, .552* | | |
| *Indirect effect* | *-.114* | *-.323, .099* | | |

ACEs: Adverse Childhood Experiences; NSB: Negative self-beliefs; df: degrees of freedom; CI: confidence intervals.

*Secondary hypothesis 5:* The moderation analysis assumptions require establishing if IV predicts DV (NSB predict BMI, see secondary hypothesis 2) and moderator predicts DV (whether SCSFQ predicts BMI: this indicated a significant model $\beta = 23.105$, SE = 1.993, $p < .001$, adjusted for GAD-7, PHQ-8 and age). Analysis was then run to investigate if SCSFQ score moderated the relationship between NSB sub-scales and BMI, for NSB sub-scale analysis separately, adjusting for GAD-7, PHQ-8 and age.

As indicated by p-values and 95% CI, SCSFQ did not moderate the relationship between NSB sub-scales and BMI (Table ).

*Table 7: Moderation analysis of role of self-compassion in relationship between NSB and BMI, adjusted for GAD-7, PHQ-8 and age.*

| | β | 95% CI | p | $R^2$ |
|---|---|---|---|---|
| NSB self-loathing | .227 | -.614, 1.068 | .595 | .087 |
| NSB unassertive | .214 | -.462, .889 | .553 | .073 |
| NSB high standards for self | -.222 | -.927, .483 | .535 | .073 |
| NSB demanding | -.078 | -.520, .676 | .797 | .068 |
| NSB abandoned/isolated | .233 | -.267, .735 | .358 | .077 |
| NSB total | .009 | -.016, .034 | .473 | .078 |

ACEs: Adverse Childhood Experiences; BMI: Body Mass Index; df: degrees of freedom; CI: confidence intervals; GAD-7: Generalized Anxiety Disorder-7; NSB: Negative self-beliefs; PHQ-8: Patient Health Questionnaire-8; SCSFQ: Self-compassion Short Form Questionnaire.

**Discussion**

Results indicated significantly lower mood, lower NSB standards-for-self and higher age in overweight/obese group, relative to normal BMI group. Overweight/obese had greater NSB self-loathing scores when anxiety, mood and age were included in the model. Neither ACEs nor NSB predicted BMI, but ACEs did predict NSB sub-scale scores. NSB did not mediate between ACEs and BMI, nor did self-compassion moderate a relationship between NSB and BMI.

The high standards-for-self sub-scale assesses how much the individual believes themselves to be e.g., perfectionist and self-disciplined (Cooper, Cohen-Tovee, Todd, Wells, & Tovee, 1997). This was significant between groups, but the effect disappeared in the adjusted model. Though lower scores on high-standards-for-self in the overweight/obese group has been shown in previous work (Cooper & Young, 2016), these appear linked to low mood rather than BMI in this study. Perfectionist-traits appear higher in depressed individuals (Egan, Wade, Fitxallen, O'Brien, & Shafran, 2022) as well as in anorexia nervosa (AN; Dahlenburg, Gleaves, & Hutchinson, 2019), a group defined by low BMI that also often experiences low mood (e.g., Thornton et al., 2016). It may be that the relationship between standards-for-self and mood is different in overweight/obese groups, such that lower mood is linked to less perfectionist-type traits in overweight/obesity, relative to other groups (such as AN). CBT-E, a model of eating disorders, includes perfectionism as relevant to development and maintenance of behaviour (Shafran, Cooper, & Fairburn, 2002; Fairburn, Cooper, & Shafran, 2003; Cooper & Fairburn, 2011; Waller et al., 2007), non-inclusion of this in Cooper et al's (2008) model is a limitation.

NSB self-loathing identifies how much individuals believe themselves to be e.g., vile and repugnant. There is evidence of greater self-loathing in obese groups (Edman, Yates, Araguete, &

Draeger, 2011), possibly arising from internalised weight stigma (Meadows, 2018); greater self-loathing in overweight/obese group was also present in this study. Some have suggested that presence of self-loathing may function as a screen for risk of disordered eating in overweight/obesity (Edman et al., 2011), indicating support for the concept of self-loathing as a specific psychological mechanism in overweight/obesity. As in Cooper and colleagues (2008) model, self-loathing may form part of a cycle of NSB, negative emotion and altered eating behaviour. However, as data on eating behaviours was not collected in this study, this finding alone does not provide insight as to how NSB contribute to overweight/obesity via disordered eating. Other models may better explain the heightened self-loathing in overweight/obese. For example, understanding the environment as inherently weight stigmatising leading to negative evaluation of self as an overweight/obese individual with maintenance of this internalized stigma through cognitive and attentional feedback loops (Radcliffe & Ellison, 2015). Evidence suggests that exposure to weight-stigmatising material led to greater food consumption (Puhl & Brownell, 2006; Schvey, Puhl, & Brownell, 2011), indicating a means by which overweight/obesity may be contributed to by negative evaluations of the self and for overweight/obese groups to have greater levels of this too (such as self-loathing). Given self-loathing was higher, CFT (which targets self-hate) may be appropriate in this group. However, self-compassion scores were not different between the two groups which contradict this suggestion. Currently there are no NICE guidelines for specific psychological support for overweight/obese or bariatric populations; this study cannot speak to any model or intervention as best placed in this group.

Absence of relationships between ACEs and BMI was unexpected, and does not follow the wider literature (Diener et al., 2016; Santos et al., 2021; Schlauch et al., 2022; Schroeder et al., 2021; Wilkinson et al., 2018; Wiss & Brewerton, 2020). It may be of relevance that this sample was not recruited based on experiencing childhood trauma. Over 40% of individuals reported no ACEs in this sample; presence of ACEs is more common in other samples (Koenen, Roberts, Stone, & Dunn, 2010), suggesting this group may be particularly low in ACE exposure. Interestingly, ACEs did predict NSB. Although NSB may not directly relate to BMI, they do appear to be associated with negative childhood experiences. This finding highlights a vulnerable group in those experiencing ACEs and who develop NSB.

NSB did not predict BMI, unlike in previous work (Cooper & Young, 2016). Designed to identify core beliefs in eating disorders (Fairchild & Cooper, 2010), it may be that NSB captured by the ED-CBQ are related to disordered eating, rather than directly to BMI. Disordered eating covers varied behaviours including restriction, purging and binging (National Eating Disorders Council, 2024), which may be present in overweight/obesity (Nagata, Garber, Tabler, Murray, & Bibbins-Domingo, 2018), but can also be present in normal BMI populations (Goldschmidt, Grange, Powers, Crow, Peterson, Crosby, & Mitchell, 2011). There are multiple factors associated with overweight/obesity (Awoke et al., 2022; Bouchard, 2021; Davis et al., 2012; Knight et al., 2021; Omer, 2020), beyond eating behaviour. It is likely then that Cooper et al's (2008) model is not

applicable to overweight/obese, but rather to groups with disordered eating who may or may not also be overweight/obese.

Mood was significantly lower in the overweight/obese group. This fits with findings that overweight/obesity is linked to mood and psychological distress (Avila et al., 2015; Pereira-Miranda, Costa, Queiroz, Pereira-Santos, & Santana, 2017; Rajan & Menon, 2017). Evidence suggests low mood is associated with greater distress around weight/body image, heightened eating pathology and higher BMI (Mansur, Brietzke, & McIntyre, 2015; Werrij et al., 2006). Together, this indicates that assessment and treatment of low mood may be an important part of interventions in overweight/obese groups. Previous work suggests BMI in isolation does not explain psychopathology, but rather (as suggested above) that there are important mediating factors in the relationship between mood and overweight/obesity, such as eating pathology (e.g., BE, dietary restriction) and cognitions (e.g., body image dissatisfaction) (Preiss, Brennan, & Clarke, 2013). Cooper et al's (2008) model mentions emotion broadly, rather than a specific role for (low) mood. The Clinical Obesity Maintenance Model (COMM) suggests interplay between mood, emotional dysregulation, and outcomes such as sedentary behaviour and over-eating, grazing, or binge-eating that may underlie weight within a wider formulation that includes executive functioning and health literacy (Raman, Smith, & Hay, 2013). This is in keeping with evidence here that mood was lower in the overweight/obese group, though causality cannot be commented on. An issue in supporting either of these models, though, is that data on eating and activity behaviours was not collected for this study.

As with any population, overweight/obesity samples and the factors underlying weight within these groups, are unlikely to be homogenous. There are a huge range of factors thought to underlie overweight/obesity development and maintenance (Fairley et al., 2015) including genetics (Bouchard et al, 2021), hormonal differences (Awoke et al, 2022; Knight et al, 2021), socioeconomic status (Charo & Lacarsiere, 2014), developmental experiences (Diener et al., 2016; Santos et al., 2021), maternal weight (Weng, Redsell, Swift, Yang, & Glazebrook, 2012) and childhood dietary factors (Pearce & Langley-Evans, 2013). As such, applying a single model to this population may be inappropriate and rather, future work might research models as applicable to sub-groups of overweight/obese with adequate consideration of factors underlying weight. Further, this may be a limitation of Cooper et al's (2008) model as it does not identify or explore the range of potential contributing factors mentioned here, beyond acknowledgement that 'triggers' within the formulation will have relevance to prior experience.

*Limitations & future research*

This project focused on psychological factors associated with BMI in women but did not gather information about the multitude of wider causes underlying overweight/obesity. A key limitation was that no measure of eating behaviour was included, despite eating behaviours features in most models of overweight/obesity. The average BMI in the overweight/obese group was 30; access

to NHS interventions for overweight/obesity typically start at BMI of 30 (NHS England, 2023). As such, this sample is likely not representative of treatment-accessing overweight/obese individuals and may not capture the psychological factors associated with that group. Height and weight are often inaccurate when self-reported, with one study observing over 1.5kg difference in reported versus measure weight in female participants, leading to underestimation of BMI (Nyholm, Gullberg, Merlo, Lundqvist-Persson, Rastam, & Lindblad, 2007). Underestimation of weight may be a particular factor in higher-weight individuals (Davillias & Jones, 2021) which is interesting in the present study which had an overall low mean BMI in the overweight/obese group. Issues with the reliability of self-reported height and weight may be particularly problematic in analysis where BMI is used as a categorical variable, as inaccuracy will limit relationship between predictor (BMI) and outcome (Ng et al., 2019); the relationship between categorical BMI and body fat appears stronger in the obese category, relative to others, suggesting it may be more accurately used in some categories over others (Callahan, 2023). These limitations suggest that the data presented here should be viewed with the caveat that reliance on self-reported height/weight may impact the accuracy of BMI, and thus impact accuracy of reported relationships with other variables. Men were not recruited to this study, so findings are not generalisable without further research. Cronbach's alpha scores for the EB-CBQ/NSB measure were low (Gliem & Gliem, 2003; Tavakol & Dennick, 2011) which indicated reduced internal consistency between subscale items, relative to previous study populations. This value was low when the sample was split in to normal versus overweight/obese BMI groups too, indicating the poor internal consistency is not related to BMI grouping. This reduces reliability of these outcomes in this specific population as a means of measuring specific factors, suggesting findings involving NSB here should be interpreted with caution.

*Conclusions*

The present study identified lower mood, lower standards-for-self and higher self-loathing in an overweight/obese BMI group. The evidence here does not support the use of Cooper et al's (2008) model in overweight/obesity as key relationships predicted in this model were not identified. NSB as measured by ED-CBQ were only higher in overweight/obesity in regard to self-loathing; as this was not causal and other NSB had no relationship to BMI grouping, it suggests that NSB are not meaningful determinants of BMI as Cooper's model predicts. It may be that the model is better applied to disordered eating (which may link to overweight/obese), rather than weight/BMI directly. Improving mood and targeting self-loathing in overweight/obesity via psychological interventions may be important, though lack of group difference in self-compassion suggests improving self-compassion may not be useful. The outcomes here better align to other models of overweight/obesity which better recognise the heterogeneity of this population, especially in recognising overweight/obesity as a multifactorial outcome. As above, this speaks to the involvement of mood as

in the COMM (Raman, Smith, & Hay, 2013) as well as acknowledgement of the wide variety of factors that likely contribute to the development and maintenance of obesity (Fairley et al., 2015).

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## Narrative overview

Having a background in academic research prior to the doctorate, I was excited by the opportunity to engage in research in new and varied populations through the eyes of a clinician. I had felt in academia that my research was often distant from those groups it was designed to help, and that funding provision often resulted in a focus on the most visible or largest populations. As a developing clinician, I hoped the research I conducted as part of the doctorate would be more closely connected to the people I met in services. My journey through these research projects has taught me a lot about the realities of clinical research and the role of a clinical psychologist within this.

An overarching theme across the three projects has been exploring unheard voices. Chronic pain is a debilitating but frequently poorly diagnosed and highly misunderstood condition, with many individuals feeling unheard and dismissed by clinicians (both in my clinical experience, and in narrative research). Individuals with learning disabilities have historically been spoken for and "done to" in medical and social provision; life expectancy of individuals with Downs Syndrome was so poor previously that the huge prevalence and impact of dementia in this group has only more recently been highlighted. People living in larger bodies are highly stigmatised, judged and frequently dismissed in services, with assumptions made about individuals themselves and the role of obesity in health and social outcomes.

### SRL

My SRL arose from an interest in chronic pain. I was curious to learn that much of the research had not distinguished between muscular-skeletal chronic pain conditions and abdominal chronic pain, despite some suggestions that there may be meaningful differences between these forms of pain. I was interested to discover that mindfulness-based interventions were not included in the UK treatment guidelines, though clinical psychologists working in the field had told me it was a useful tool in their clinical work. The process of the SRL was challenging as it was highly detailed work. Reflectively, not generalising findings excessively felt particularly important in this population as my feeling that individuals living with chronic pain have many experiences of being unheard was increasingly confirmed during this process.

### SIP

I took this new insight forward into preparation for my SIP. A key finding from this project was the importance of service user involvement in service planning and development. Though I had anticipated that service user views might form part of the staff reflection on changes to provision, I hadn't been prepared for how frequently this was brought up and how it was highlighted in every area discussed, by representatives across all professions within the service. This experience gave me an

insight in to how many clinicians are passionate about a more person-centred approach to service design and led me to reflect on the significant changes even within the last 10 years in the NHS, in this regard. Further, this felt important in relation to power within service provision, and how the more powerful voices (professionals) must take responsibility for giving a platform to those unheard voices (service users).

**TDRP**

This sense of responsibility to platform unheard voices was again highlighted to me during my TDRP. Despite obesity being increasingly prevalent and individuals living in bigger bodies experiencing continuous stigmatisation both socially and by healthcare professionals, relatively little research has sought to understand underlying psychological mechanisms. Psychological models of obesity are often initially created within eating disorders, before being applied to populations with higher body mass index (BMI). Noticing this, I felt a similar frustration to that felt in my other projects, where assumptions were being made about people without hearing their experiences. This was represented in the data, which may indicate difficulty in translating from eating disorder to overweight/obese populations in research. I was also struck by the sense of simultaneous blame and helplessness that sometimes occurred in models of obesity: at times, I felt that this population are both held responsible for their BMI but also put into a state of powerlessness and dismissal. This project was close to my heart, as it aligned with my specialist placement in bariatrics. Hearing the frustrations of people living in larger bodies (in a society that does not accommodate for them) was often challenging and writing about this population through a health economic/healthcare system lens at times felt blaming or disembodying of these experiences.

*Conclusion*

I hope that the projects I have completed as part of my doctoral thesis have furthered our understanding of populations who are often unheard and powerless. Clinicians are in a powerful position and these projects have highlighted to me how we owe it to the populations we serve to platform their voices and to conduct our research and clinical work in a respectful and person-centred way: “doing-with” rather than “doing-to”. We have a huge responsibility to provide non-stigmatising services and to respect lived experience. I have learned a lot about the clinician I hope to be in the future, in a developing and expanding profession. I am hopeful for our profession, noting throughout this experience how keen practicing clinicians are to hear the unheard.

## Theory-driven research project: executive summary

Overweight/obesity is associated with a number of physical and psychological co-morbidities. It is thought to be more prevalent in women, with UK estimates suggesting 29.7% of women are overweight/obese. Several mechanisms for the onset and maintenance of overweight/obesity have been proposed, including genetic, hormonal, environmental and behavioural factors. Developmental factors such as traumatic childhood experiences have been linked to increased rates of childhood and adulthood obesity as part of this evidence base. Psychological factors such as shame, low mood, stigma and psychological distress have been linked to overweight/obesity. Better understanding of the mechanisms underlying overweight/obesity may help improve interventions to support this population.

A cognitive model that may be applicable to this population is that of Cooper et al (2008). This model was initially developed in females with bulimia nervosa (BN) or binge eating disorder (BE) and identifies negative self-beliefs (NSB), potentially developed through early/childhood experiences, as feeding in to a cyclical relationship between negative automatic thoughts, emotion, beliefs about eating and eating behaviours. Following, it may be conceptualised as NSB mediating a relationship between childhood trauma and BMI.

Self-compassion may have a protective effect against later psychological distress following childhood trauma, and is related to reduced self-stigma and better emotional resilience in overweight/obese individuals. Interventions that focus on self-compassion aim to reduce shame and self-criticism; these themes relate strongly to the themes evoked in negative self-beliefs in the eating disorder literature (e.g., worthlessness, failure, inadequacy). It may be that self-compassion has an impact on negative self-beliefs and there that it may moderate NSB, with the effect of reducing the impact of NSB on the cyclical relationship of Cooper's model (above) and thus the effect of NSB on overweight/obesity.

As yet, these relationships have not been explored in the context of body mass index (BMI) in the general population, nor in direct comparison of normal and overweight/obese BMI groups. This project aimed to do so, identifying whether the described cognitive model linking ACEs to BMI and incorporating the possible influence of NSB and self-compassion on this relationship, is applicable specifically in a female sample.

Females aged 18 or over (n = 222) completed an online survey consisting of five questionnaires (measuring ACEs, self-compassion, NSB and additionally anxiety and depression to allow these to be added to adjusted models) and self-reported weight and height. Participants were split in to 'normal' (18.5-24.9) BMI or overweight/obese (>25) BMI.

Based on the literature, the following hypotheses were explored:

*Primary analysis:*

Independent-samples t-tests for group comparison on ACEs, NSB (ED-CBQ) subscales, SCSFQ, PHQ-8 and GAD-7 scores will show higher scores in all variables except self-compassion are predicted in the overweight/obese group.

*Secondary analysis:*

1) Higher number of ACEs will predict higher BMI.

2) Higher NSB scores will predict higher BMI.

3) Higher number of ACEs will predict higher NSB scores.

4) The relationship between ACEs and BMI will be mediated by NSB, such that lower NSB will be associated with a reduced relationship.

5) The relationship between NSB and BMI will be moderated by self-compassion scores, such that greater self-compassion will reduce the relationship.

Overweight/obese had lower NSB standards-for-self, older average age and lower mood than the normal BMI group. Overweight/obese had higher NSB self-loathing when anxiety, mood and age were included in an adjusted model. Results also identified no predictive relationship between ACEs and BMI, or NSB and BMI, but significant prediction of NSB sub-scale scores by ACEs. NSB did not mediate between ACEs and BMI, nor did self-compassion moderate a relationship between NSB and BMI.

NSB high-standards-for-self was lower in unadjusted comparison of overweight/obese and normal BMI, suggesting the effect may be linked to lower mood, age or anxiety. Previous work has shown higher perfectionist/standards for self in lower mood, which is at odds with this finding. It may be that the relationship between these traits and low mood is different in overweight/obese groups. NSB self-loathing was higher in the overweight/obese group when adjusting for age, mood and anxiety, indicating possible support for the concept of self-loathing as a specific mechanism in overweight/obesity irrespective of these factors. Self-loathing cognitions do have links to disordered eating and poorer emotional well-being in the wider literature. This partially supports application of Cooper et al's (2008) model as self-loathing could form part of a cycle with lower mood and theoretically, disordered eating behaviour. As data on this latter measure was not collected here, further comment is not possible.

Absence of relationship between ACEs and BMI or NSB and BMI in regression analysis was unexpected as these relationships have been shown in the wider literature. It may indicate that ACEs

and NSB might be better understood as linked to eating behaviour patterns rather than BMI itself; this would suggest that targeting NSB may influence eating behaviour, but this may or may not contribute to BMI change. The finding that ACEs did predict NSB sub-scale scores highlights the possible vulnerability of individuals exposed to ACEs. Self-compassion was not different between groups which was also unexpected, especially given greater self-loathing in the overweight/obese group. It may be that this finding relates to the external experience of social stigma around weight, or that self-compassion may link to overweight/obesity via factors such as body image which was not measured here. Mood was also lower in the overweight/obese group, suggesting this may be an important factor to consider when working clinically in this population.

There are several limitations to this study, including absence of measures of eating behaviours. Of note the average BMI in the overweight/obese group was 30, which is at the lower end of obesity as understood within research and the NHS. Finally, it is important to acknowledge the critique of BMI as a measure of health and adiposity and the issues with using this population-based measure to categorise individuals meaningfully.

These findings support further research to explore the relationship between BMI and eating behaviours alongside NSB and encourage perception of the overweight/obesity as a heterogeneous population.

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Thank you to the 2020 cohort with whom I started this journey, and to the 2021 cohort with whom I finished it. In particular I am grateful to the endless support, understanding and willingness to listen to rants of Eimear, Stacey, Jade, Madeline, Emma K, Emma C and Ellie- the Oxford Aunties who often "held the baby" so I could work. And to Lauren, who introduced me to the 2021 cohort and answered my many stupid statistics questions when she had far better things to be doing. Thank you to Sazan, Bertie and Mariann, who understood and acknowledged the complexity of motherhood during training.

To my family- Jono, Kath and Laura, thank you for listening to my woes and cheering my successes. To my sister-in-law Lucy especially, who always "got it" when I asked if I could rant, and who sent the best brownies to cheer me up afterwards. To my in-laws: to Gillian for endless babysitting, and to Ian for letting us invade his home for 6 months whilst I finished training. To Nairn, who has had to solo parent too often and has never complained. I honestly could not have done it without you, you are a wonderful husband and father. To Morris, who reminded me of the more important things in life and to step back and look at the bigger picture. Thank you for needing me to play, to make your tea and to put you to bed as it reminded me that this is just one stage in a bigger life together. To Ronnie-dog, for providing entertainment and an excuse for fresh air daily.

To mum. You knew I was going to start training; I wish you were here to see me finish it. I felt your encouragement throughout.

# Appendices

*SRL*

*Appendix 1A: SRL search strategies*

endometrio* OR "endometrio* syndrome" OR vulvodynia* OR vestibulodynia* OR vulvar pain OR vulvar pain syndrome OR dysmenorrhea* OR adenomyos* OR pelvic floor pain OR pelvic floor muscle pain OR bladder pain OR irritable bowel OR IBS OR inflammatory bowel OR IBD OR Crohn* disease OR chronic visceral pain OR chronic abdom* pain OR chronic stomach pain OR Pelvic Pain OR Chronic Pelvic pain OR Pelvis Pain* OR Pelvic girdle pain OR irritable colon OR interstitial cystitis OR colitis OR ulcerative colitis OR pain* menstruation OR vagina* pain OR dyspareunia OR symphysis pubic dysfunction OR piriformis muscle syndrome OR piriformis syndrome OR male chronic pelv* pain OR prostatitis OR prostat* pain OR tension floor myalgia OR perineal pain AND ACT OR mindfulness* OR "acceptance and commitment"

Amendments to punctuation and the use of AND/OR was made to suit each database. A limiter was added to specify that papers be written in English - no other limiters were included. The re-run searches used an additional limiter of date (2022-2024).

*Appendix 1B: Meanings of effect sizes*

| Effect size measure | Meaning |
|---|---|
| Cohen's d (*d*) | Small: $d = 0.2$ |
| | Medium: $d = 0.5$ |
| | Large: $d = 0.8$ |
| Partial eta-squared ($\eta p^2$) | Small: $\eta p^2 = 0.01$ |
| | Medium: $\eta p^2 = 0.06$ |
| | Large: $\eta p^2 = 0.14$ |
| Eta-squared ($\eta^2$) | Small: $\eta 2 = 0.01$ |
| | Medium: $\eta 2 = 0.06$ |
| | Large: $\eta 2 = 0.14$ |

*Appendix 1C: SQA details*

SQA gives a quality score based on researchers scoring papers from 0-2 on 14 items. The average total raw score for papers in this review was 21.48. Total raw score is then divided by the total possible score for each paper: the total possible score for a "perfectly scoring" paper would be 28, but the number of items for which N/A was selected (rather than a score of 0-2) is subtracted from 28 to give the total possible score for each paper. The average SQA score then for all papers included in this review was 0.79. SQA scores for individual papers are provided in Table 2. Blinding of participants is one of the SQA items. Many of the papers in this review were scored as N/A for this category, as blinding of the control arm in waitlist or treatment as usual would be difficult. The papers also often scored low on the item regarding blinding of researchers. In these cases, they scored 0 (rather than N/A) as the researchers could well have been blinded to the data they were analysing- this was true for 72% of papers. On the other end of the spectrum, the included papers often reported appropriate analysis (96%) and gave sufficient details in the results section to answer the objectives (92%).

*Appendix 1D: Simplified table of outcomes observed. Note Y indicates measurement observed, not whether change is present following treatment.*

| **Paper** | **Outcome measured** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | *Pain* | | | | | | | *Symptoms (non-pain)* | | *Fatigue-related* | |
| | Self-rated (any) | Acceptance | Self-efficacy | Hypervigilance | Catastrophising | Visceral sensitivity | Pain-related behavioural changes | Symptom severity | Disease activity | Fatigue | Activity levels |
| **ACT** | | | | | | | | | | | |
| Hess et al, 2021 | Y | | | | | | Y | | | | |
| Maathz et al, 2023 | | Y | | | Y | | | | | | |
| Aghalar et al, 2020 | | | | | | | | | | | |
| Ito et al, 2020 | | | | | | | | Y | | | |
| Mirsharifa et al, 2019 | | | | | | | | | | | |
| Shahkarem et al, 2024 | | | | | | | | | | | |
| Shakerneja et al, 2021 | | | | | | | | | | | Y |
| Taghvaeimi et al, 2024 | | | | | | | | Y | | | |
| Wynne et al, 2019 | | | | | | | | | Y | | |

| Paper | Outcome | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | *Pain* | | | | | | | *Symptoms (non-pain)* | | *Fatigue-related* | |
| | Self-rated (any) | Acceptance | Self-efficacy | Hypervigilance | Catastrophising | Visceral sensitivity | Pain-related behavioural changes | Symptom severity | Disease activity | Fatigue | Activity levels |
| **MBA** | | | | | | | | | | | |
| Ashraf et al, 2022 | | | | | | | | Y | | | |
| Gaylord et al, 2011 | | | | | | | | Y | | | |
| Garland et al, 2012 | | | | | Y | Y | | Y | | | |
| Ghandi et al, 2019 | | | | | | | | Y | | | |
| Henrich et al, 2020 | | | | | | | | Y | | | |
| Ljotsson et al, 2010 | | | | | | Y | | Y | | | |
| Mohamadi et al, 2019 | | | | | | | | | | | |
| Brotto et al, 2015 | Y | | Y | Y | Y | | | | | | |
| Guillet et al, 2019 | Y | | | | Y | | | | | | |
| Brotto et al, 2019 | | Y | | | Y | | | | | | |
| Zomorodi et al, 2015 | | | | | | | | | | | |

| Paper | Outcome | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | *Pain* | | | | | | | *Symptoms (non-pain)* | | *Fatigue-related* | |
| | Self-rated (any) | Acceptance | Self-efficacy | Hypervigilance | Catastrophising | Visceral sensitivity | Pain-related behavioural changes | Symptom severity | Disease activity | Fatigue | Activity levels |
| **MBA** | | | | | | | | | | | |
| Goren et al, 2021 | Y | | | | | | | | Y | | |
| Regev et al, 2023 | Y | | | | | | | | | | |
| Jedel et al, 2022 | | | | | | | | Y | | | |
| Bredero et al, 2022 | | | | | | | | | | Y | |
| Taghvaeimi et al, 2024 | | | | | | | | Y | | | |

| Paper | Outcome | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | *Psychological* | | | | | | *Intimacy* | | |
| | Mood | Anxiety | Illness perception | QoL | Stress | Psychological capital* | Sex-related distress | Sexual function | Pain during intercourse |
| **ACT** | | | | | | | | | |
| Hess et al, 2021 | | | | | | | | | Y |
| Maathz et al, 2023 | Y | Y | | Y | | | | | Y |
| Aghalar et al, 2020 | | | Y | | | | | | |
| Ito et al, 2020 | | | | Y | | | | | |
| Mirshirifa et al, 2019 | Y | | | | | Y | | | |
| Shahkarem et al, 2024 | Y | Y | | | | | | | |
| Shakerneja et al, 2021 | | | | | | | | | |
| Taghvaeimi et al, 2024 | Y | Y | | Y | | | | | |
| Wynne et al, 2019 | Y | | | Y | | | | | |

| Paper | Outcome | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | *Psychological* | | | | | | *Intimacy* | | |
| | Mood | Anxiety | Illness perception | QoL | Stress | Psychological capital* | Sex-related distress | Sexual function | Pain during intercourse |
| **MBA** | | | | | | | | | |
| Brotto et al, 2015 | Y | Y | | | | | Y | Y | |
| Guillet et al, 2019 | Y | Y | | | | | | | |
| Brotto et al, 2019 | | | | | | | Y | | Y |
| Forbes et al, 2020 | Y | | | Y | | | | | |
| Kanter et al, 2016 | | | | Y | | | | | |
| Ljotsson et al, 2010 | Y | | | Y | | | | | |
| Mohamadi et al, 2019 | | | | Y | Y | | | | |
| Zernicke et al, 2013 | Y | | | Y | Y | | | | |
| Zomorodi et al, 2014 | | | | | | | | | |
| Zomorodi et al, 2015 | | | | Y | | | | | |
| Bredero et al, 2022 | Y | Y | | Y | | | | | |
| Cebolla et al, 2021 | | Y | | Y | Y | | | | |

| **Paper** | **Outcome** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | *Psychological* | | | | | | *Intimacy* | | |
| | Mood | Anxiety | Illness perception | QoL | Stress | Psychological capital* | Sex-related distress | Sexual function | Pain during intercourse |
| **MBA** | | | | | | | | | |
| Neilson et al, 2016 | Y | Y | | Y | | | | | |
| Schoultz et al, 2015 | Y | | | Y | | | | | |
| Jedel et al, 2022 | Y | | | Y | | | | | |
| Taghvaeimi et al, 2024 | Y | Y | | Y | | | | | |
| Pourkazem et al, 2024** | | | | | | | | | |

*Defined as hope and optimism in paper

**Significant improvement in adaptive cognitive coping- no other study recorded so not on table.

Appendix 1E: Lay summary.

Chronic abdominal pain (CAPP) is a condition whereby people experience pain for more than 3 months in their abdomen, that cannot be explained by other conditions or by an injury. People with CAPP often experience distress, problems living their lives as they wish and a reduced quality of life. It can be difficult for doctors to diagnose CAPP, making it difficult for people to get the treatment they need. Guidelines currently suggest Cognitive Behavioural Therapy or medication to treat CAPP. This project searches the available published research on CAPP to see whether two other treatments, Acceptance and Commitment Therapy (ACT) and Mindfulness-Based Approaches (MBA), can also help people with CAPP. Looking at all the findings together, it wasn't possible to recommend whether ACT or MBA is best in treating CAPP. Future work in this area might explore whether different CAPP conditions are better treated with different interventions.

SIP

*Appendix 2A: Accessible summary*

- Dementia is when the brain stops working as well as it did. It can cause people to forget things or act differently.
    - Dementia affects lots of people with Down's Syndrome.
    - Testing for Dementia when a person is younger is called a baseline assessment. It can help get quicker support for people with Down's Syndrome.
- This project wanted to find out how a Learning Disability Team could offer baseline assessments for people with Down's Syndrome.
    - To do this the researchers looked at the evidence and referral data. They also talked to health professionals.
    - They found that health professionals want to offer baseline assessments to people with Down's Syndrome. However, there might be some challenges, such as having enough staff.
- The researchers made some recommendations. They said:
    - Baseline dementia assessments for people with Down's Syndrome are important.
    - The Learning Disability Team should offer baseline assessments.
    - Baseline assessments should only be done if the person and /or their carers want it.
    - Professionals should be trained to do baseline assessments.
    - The opinions of people with Down's Syndrome are important. Their views should influence how the assessments are done

*Appendix 2B: Further examples of themes from SIP focus group dialogue.*

| Theme | Sub-theme | Quote & participant number |
|---|---|---|
| **Theme 1: Blue sky thinking.**<br><br>(Identifying key considerations for a new pathway) | **The straw that might break the camel's back.**<br><br>(Pressures on clinical time). | "even if you had staff and even if you were fully staffed and quick to pick up, which we're not, we're all very stretched" – 10<br><br>"Dementia often isn't hitting the top of our risk list. So priority wise for us in psychology, it tends to be … Well, let's say the top, the top being high placement breakdown, police, involvement, suicidal…" – 10<br><br>"I think there is a real mismatch between the capacity of the team clinically to act quickly and dementia being a slow, steady, deteriorating process" – 10<br><br>"if you have a separate dementia assessment team… and you know, [that would be an] entirely different picture to our time scales, I would imagine" – 10<br><br>"So I guess in your diary you think it's so that would you prioritize the sort of the the actual dementia pathway or the more pressings or safeguarding needs that are at hand now?" – 11<br><br>"I'm thinking about where our health role lines up with our social care" – 11<br><br>"I think it's just a sign of the times of how stretched all of the care staff are and all of the organizations really" – 10<br><br>"they still were seeing people time and time again at one point they were doing yearly follow ups and then it became unmanageable. So now they're back to doing the baseline and then just seeing people when they start to get clinical signs of deterioration again because that's the only way they could do it" – 10<br><br>"It's just about making sure we have the systems in place, making sure we have the staffing, |

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| | | making sure that everything is lined up together" – 9<br><br>"I'd love to be doing loads of preventative work, but if we looked at the needs of the population, is dementia the highest need or are there other things for us to be putting our time and energies into?" – 10<br><br>"… capacity, because we're drowning in work, we can't even keep up with things now the thought of adding in anything more, especially for people who are well" – 10<br><br>well, we could identify your need for help sooner with doing these baseline assessments, but you may not get it because yeah, there's not much out there. So how we to use our time in the team is also a question for me " – 10 |
| | **It takes a village.**<br><br>(Greater sharing of the load between professional groups) | "there's definitely more conversations taking place around, like sharing that, sharing, that kind of burdens the wrong word. But sharing that responsibility of doing that initial screening" – 1<br><br>"I think it does get highlighted that it doesn't have to be a nurse or a psychologist to complete that" – 8<br><br>"…challenge in certain in terms of resource, in terms of resource um nursing would not be able to facilitate anything beyond sort of oversight, really." – 8<br><br>"I would say the only way to facilitate kind of baseline screening is for us to do what I believe Surrey did, which is to specifically employ assistant psychologists to do that work." – 8<br><br>"I mean nursing would probably have some role in support, but the, the work, the assessment tools would probably have to come through specific workers specifically employed for the purpose" – 8<br><br>"it does a nice job, in my opinion, of sharing some of the responsibility out for the dementia assessment pathway. At the moment I think it can look quite sort of psychiatry, nursing, psychiatry, movement, psychology, psychiatry, nursing, heavy, but actually it's an opportunity |

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| | | for the rest of the MDT to get their hands kind of on the pathway and to feel a bit more confident and skilled up in it." – 11<br><br>"we kind of spoke to the team and said actually anybody could do this. The DSQIID is a questionnaire doesn't even need to be clinician… you could just give it out and could fill it in. But we think it's better to get the quality of data if you go through it with the person." – 10<br><br>"that gives people confidence as well." – 10<br><br>"with the database meeting that's been psychology and nursing that have kept that going" – 10<br><br>"who does those assessments whether it's every one you know what like we say at the moment it's mainly psychology or nursing" – 11<br><br>"It's gonna be a lot more coming to psychology. So again, I think resources will be a massive thing" – 10 |
| | **Singing from the same hymn sheet**<br><br>(Aiming for achieving clarity via documentation, logistics and decision making.) | "I think I quite like having something written down" – 10<br><br>"I think trying to explain that to some of the social workers and referrers is hard, but as soon as you introduce the actual assessment pathway and explain it step by step, I found those conversations easier." – 11<br><br>"[having a pathway written down] is containing." – 11<br><br>"[it] provide[s] structure not only for the clinicians that are actually going through this assessment for the wider team and having a better understanding on who is doing what and why they're doing it and when they're doing it" – 11<br><br>"quite containing and reassuring for us about saying, well, this is the path that we're taking" – 11 |

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| | | "I've not worked in this team before the pathway was in place, but it does seem to have a good structure and it does seem to work quite well in practice." – 9<br><br>"when someone starts new, it's very useful to see. Oh, OK, this is exactly what is happening and when once I've done the assessment, these are the results. Who do I go to, you don't have to, like, find everyone and ask what you can literally just sort of pathway and go. OK, that's person and that's the pathway we follow." – 13<br><br>"even the days of the meetings of sometimes dictated who can come" – 10<br><br>"do they all know about the pathway? I don't know how well known it is and when people are new to the team with their inductions, whether that's covered or not." – 11<br><br>"there was a time when it was much more like it's up on the wall in the meeting room... Now I feel like it's a little bit underground." – 10<br><br>"being able to share our pathway with like carers or referrers… were working with social workers who aren't necessarily sort of LD specialists anymore. They might be quite used to working with older adults where they go into adults services like a memory clinic" – 11 |
| | **Necessary foundations.**<br><br>(Current gaps in knowledge and opportunities to plug these gaps/skills development) | "I don't think everybody feels confident in using the DSQIID or asking the pertinent questions that would kind of trigger onward referral." – 1<br><br>"I don't think I've ever independently completed a DSQIID and I've always had support and I've, you know, I've been working in the team quite a while now" – 1<br><br>"I think there's a lot of people, particularly new start as in the same boat who may, who sort of know that they may have to do one at some point but don't necessarily know how to do it." – 8<br><br>"I guess it may not always occur to put two and two together and think and think dementia?" – 8 |

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| | | "we don't tend to get feedback on the diagnostic assessments or that side of things in my experience." – 8 |
| **The best laid plans…**<br><br>**(Considering the impact of current working styles on the existing & future dementia pathway).** | **Too many cooks**<br><br>(Imagining the impact of MDT style working on experiences of those experiencing the current pathway) | "… lots of professionals will get involved at the same time, which you know because the needs are there. But that can be a bit overwhelming or perceived to be overwhelming for carers." – 1<br><br>"It gets to a certain point and because the needs are such that we all kind of get involved at the same time, so it's almost nought to 60." – 1<br><br>"all of a sudden they've gone from perhaps just being open to maybe nursing and psychiatry to needing on, would referral to several members of the team" – 8<br><br>"I think is that potentially overwhelming for the person and or their carers to have all those internal referrals being made at once, I'm not sure there's much, I mean, I can only speak for my opinion, but I I don't see… there's not much getting around it" – 8<br><br>"Rather than having all those people open from the start, which I don't think would be clinically possible with caseloads and waiting lists." – 8<br><br>"So we try and sort of forewarn them as best as we can." – 8<br><br>"… we're very lucky and learning disabilities that we do think very holistically anyway" – 4<br><br>"it is an established area of clinical practise for us and I think people are genuinely quite appreciative of our input." – 8 |
| | **Prevention is the best cure?**<br><br>(Considering the current referral process) | "the flaw in our process is that it's reactive" – 8<br><br>"if the response is no, we're not gonna pick up this referral. There's always a reason why and you know, always the scope to come back in the future should things change" – 1 |

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| | | "and I have seen a few more of those [proactive referrals] sort of filtering through allocations" – 7<br><br>"the other thing that I think is going really well is and continues to go well, is the referrals within teams. I feel like they're really timely across the board" – 7<br><br>"Treatment is essentially starting too late. Um, so the benefit is that it can improve it. Early identification." – 8<br><br>"…clinical benefit in identifying people starting treatment sooner and that way as well. You can get sort of the equipment, any future planning needed done earlier." – 8<br><br>"we actually can start building relationships with people that little bit earlier and hopefully relieve some of those fears later on down the line.." – 1<br><br>"If they've got that sort of a named contact or whatever the case may be, post diagnostically, then it means that we can nip issues in the bud, support them, stay at in their own homes for longer." – 8<br><br>"we hope[d] that the pathway would speed us up. But I think from our experience … it can still take us a long time and we still have people who we've seen them many, many times. We're not sure where they've got dementia and they suddenly get very poorly very quickly with quite advanced dementia… there's been a few people or people who've passed away in hospital and there's kind of been known to us and then it probably turns out that they did have dementia" – 10<br><br>"I think somewhere along the way of our process, we're still missing people. I've not sort of got hard data to back that up. It's kind of just a sort of clinical sense." – 10<br><br>"no matter how early we try and get in, it almost isn't clear that they've got dementia until suddenly it's very, very, yeah, clear… my overall sense is we still may be a little bit too slow in picking up and identifying and diagnosing quickly enough." – 10 |

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| | | "the GP liaison part is always, UM, difficult, because we rely on external services. And UM, we don't necessarily have the, umm, ability or the OR linked into the systems that mean we can sort of expedite things ourselves. So if we're waiting on scans for waiting on Bloods, we don't necessarily get all those results in a timely fashion, and that just delays things further, unfortunately." – 9<br><br>"I do think there is a risk of us missing things as well" – 10<br><br>"it's all going on in the background, and service users probably don't necessarily appreciate the difference between being on a pathway and being seen by the LD team in a more general sense." – 9<br><br>"if we're getting people through and diagnosed and treated faster, that's better. Whether we are successfully doing that with the pathway, I don't know." – 9 |
| | **Systems working against us.**<br><br>(Issues with tech/note system: is it fit for purpose?) | "You know, it was most of them, but it was really interesting that we were looking and sometimes it was on the psychiatry letter, sometimes it wasn't, sometimes it was on a core assessment, sometimes it wasn't, sometimes it was on the referral tab" – 10<br><br>"we got a bit stuck because we were told we couldn't have a database for people Down syndrome because of kind of data and security issues at times" – 10<br><br>"sometimes our systems are working it against us" – 10<br><br>"Maybe if we go back to 15 years ago where we were doing things a little bit more on paper and with a very crude spreadsheet, we might actually been a little bit more up on who had Down's syndrome and who was presenting with risk. So it's slightly depressing that our systems that are meant to help us might be hindering." – 10<br><br>"so there is a learning disability section [on one system], but there's also just a disability section |

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| | | on [another system] and most commonly when we report document learning disability diagnosis on [the second system] it goes under the disability tab. But they're both sat there, capturing two different cohorts of about the same cohort." – 11<br><br>"when you pull off that disability data, it doesn't actually tell you what the disability is.It just says disability. OK, so that could be learning disability that could be autism, it could be all sorts of physical disabilities." – 10<br><br>"I mean that that feels entirely unfit for purpose in that case because by definition, all of our service users are going to be taking that box." – 9<br><br>"we can put diagnosis in and at one point we were told we needed to and the I CD10 coding, but then there was a debate about whether only doctors, medical doctors could do that or whether the psychologists could also do that. "– 10 |
| **Theme 3: Person centred care** | **Unheard voices**<br><br>(The voice of people with DS or carers of people with DS) | "I would question whether what's in place to support people, to self-report, where they can rather than relying on staff reports" – 6<br><br>"It's also quite a good way to see whether there's been a decline cognitive decline. Some of the dementia research in talking mats for people that have been using talking mats in dementia have said that's one of the outcomes that they've been able to recognise a decline" – 6<br><br>"whether there's anything that's translatable to asking the person, you know, how's it going with remembering things? How's it going with mobility or how's it going with just to get a sense where they might be struggling, which might indicate that that.. for further investigation for dementia or support." – 6<br><br>"are very much informant based, based on the perception of the people around [them]" – 8<br><br>"with the dld we try and include the person in answering some questions that they may be able to answer in order to get the direct picture" – 8 |

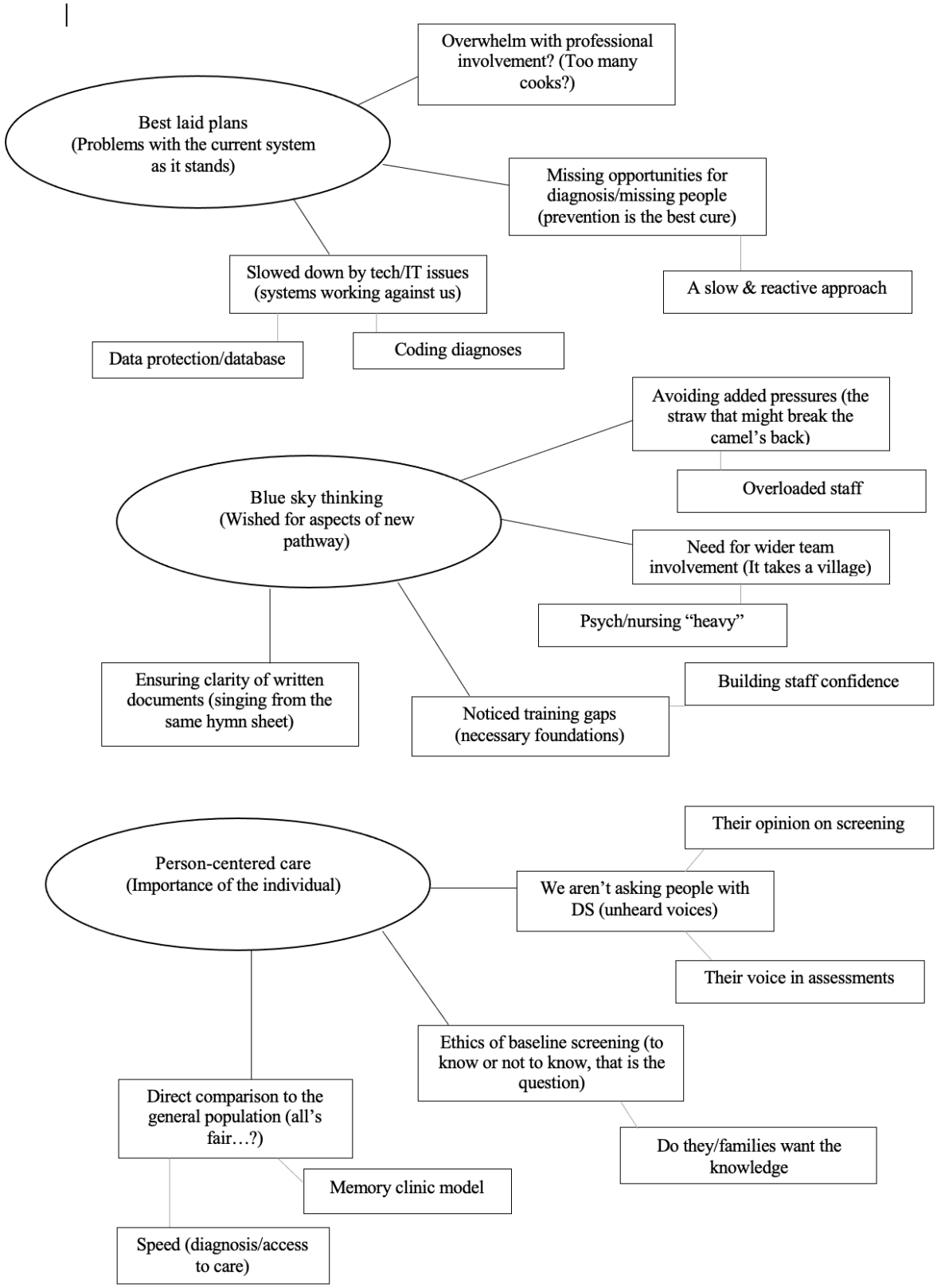
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| | | "I mean the only thing I can think of is probably asking the person directly. Do you have any concerns about your memory at all?" – 8<br><br>"… that would be when a simple checklist to with talking mats could really support the person to. And it doesn't say, you know, assessing them for dementia, you're just doing a talking mat around how they're getting on." – 6<br><br>" [could you use a method to say to them]…This is why we did this. This is what we were looking at. Could you do that really visually? Is that an option?" – 4<br><br>"I just. I just think it's really important in somewhere in all of this that we, the service users voice. There's there's some way of enabling that voice somewhere. I think I just think it's really important." – 6<br><br>"early identification would also be able to support that kind of conversations with the person that [CD] is advocating for it because there's say by the time typically they come to us for path for pathway at the moment it they've often declined to the point where they're kind of lacking the capacity to have those discussions."- 8<br><br>"I don't know what the Down syndrome community think about the early early screening. Just what their thoughts are around that, yeah." – 6<br><br>"I'm I guess if I had to guess, I'd imagine that like all populations, they probably have mixed views depending on who it is that's being discussed" – 8<br><br>"I'm just like really aware of we're in, in terms of Co production and we should be Co producing pathways and including the voice of people. I'm aware we're a group of clinicians here and there's no one actually from that Down syndrome community giving their voice cause they may have a completely different take" – 6<br><br>"we just haven't got their voice and I think that that's in coproduction is just like key key to pathways and things now really." – 6 |

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|---|---|---|
| | | "it's very carer focused because in general I've not come across someone who's got a diagnosis of dementia, who's wound up with new diagnosis of dementia, that would be able to engage" – 8 |
| | **To know or not to know.**<br><br>(The ethics of choice and consent) | "But the tricky thing is it's about recognising when that discussion's appropriate to have because you wouldn't have it with even with [DS], you wouldn't necessarily have [that conversation] with a 20-year-old, for instance. If stuff's been brought up with the assessment, that's sort of lead in down that train of thought, then that would be fine, but otherwise I would question whether it's clinically appropriate to be asking that just as a generic question in an assessment that's… already quite long as is" – 8<br><br>"it would be whether whether that's appropriate to be asking just out of the blue when there's no concerns already" – 8<br><br>"sometimes parents don't want to future proof they kind of want to to think about here and now rather than future proofing everything" – 4<br><br>"having the early screening in some ways can help prepare them for that [knowing your child might get dementia]" – 4<br><br>"we may need to present it in a sensitive way is not an argument for not doing it just because one or two people may be scared of the process." – 8<br><br>"is it going to unduly worry people Down syndrome if we're talking about dementia and their age 30? So if is the service was to be offered, it would be there probably needs to be consideration on how we present it to the the service users." – 8<br><br>"[how to make sure we are] sensitively handling those discussions" – 4<br><br>"We used to have everybody with Down syndrome kept getting referred for dementia assessments when they were actually doing really well. And I think the service providers were |

| | | |
|---|---|---|
| | | really clued up that you might be more at risk, but they were sending people just when they were like 35/36 because they weren't doing so well or you know, they've got a little bit confused" – 10<br><br>"I don't think we'll solve all the other issues of the stickiness of identifying and getting people in, you know, getting the diagnosis confirmed." – 10<br><br>"We will inevitably also be picking up a lot more false negatives but hopefully if we have a robust enough system for dealing with a deterioration from that baseline, we should be able to sort of screen that out relatively quickly" – 9 |
| | **All's fair…?**<br><br>(Is it fair? Early identification/diagnosis in comparison to how mainstream services work) | "Part of the flaw in the current process is they will already have been a fair level of deterioration prior to us getting involved and I've not come across anyone who's got the level of insight that would that that would make that kind of education meaningful" – 8<br><br>"You can go through GP, go to memory clinic and then it's a fairly short process. I understand from my conversations with the memory clinic people, whereas ours tends to take maybe maybe 6 to 8 months" – 8<br><br>"…it gets a bit trickier to identify dementia in people who have already got pre-existing sort of profound, profound learning disability to begin with." – 8<br><br>"… people with an LD are routinely arsenal for annual health cheques and they used to going in and having those questions asked. We are advocating more and more for breast cancer screening. We're not telling them they're gonna have breast cancer, but we're asking them to get screened and I think we're moving towards an NHS that's trying to be proactive and it's around having those conversations and saying that" – 1<br><br>"but we're trying to get ahead like we would do with a breast cancer screening with the smear test, etcetera… Initially, would have been quite scary that people to think about cancers and stuff, but they've now become the norm for us to go and do those tests" – 1 |

| | | |
|---|---|---|
| | | “When you're born with a disability, you know people will tell you all the risks and all of the related concerns that might have come with having a disability because they want you to get access to treatment, don't they? But I don't know if anyone ever asks you, Ohh, you know, do you want to know that you've got an increased risk of diabetes or thyroid or whole issues are all those other things it's just kind of like the way our culture and society is aligned itself is that knowledge about medical risks is better so you can work on them… I don't know if anyone ever asked us at any point, did you want all of this medical knowledge? Did you want to know what the risks and the things that you should be doing that you actually don't want to do? ” – 10<br><br>We've also not got a clear way of explaining why we think it would be good to do baseline assessments and that's always been a bit tricky to us because we don't know whether people are Down syndrome would actually like to know that there are that increased risk of dementia and where the by offering them something that might help them get diagnosed earlier. We might also be affecting their entire adult lives and bringing a lot of worry and distress in” – 10<br><br>“I think again in just in terms of focus groups and sort of service user views, it's quite a big question to ask someone and to be able to have the capacity to understand the nuances of what are the benefits plus the medication as it stands at the moment doesn't, from my understanding, doesn't extend life necessarily, but it might keep the quality of life better for longer as that's still right though.” – 10<br><br>“Certainly we're not looking to stage where we have effective dementia, reversing drugs at the stage.” – 9 |

Appendix 2c: thematic map



The rationale behind the alignment of themes and subthemes in this project arose from careful consideration of the valuable points made by the team. The rational for each theme and the grouping of subthemes within it, are outlined here.

Theme 1: Blue sky thinking:

This theme relates to the general wishes and worries of the team. My interpretation during analysis related to the team raising ideas akin to a 'wish list' that they would want to implement in any future pathway, regardless of whether this was practical or present in the current pathway or service structure. Specifically, the team expressed wishes to form sound building blocks to support any change (as reflected in "singing from the same hymn sheet" and "necessary foundations") as they embraced the idea of shaping their own service as it moves through changes towards a different pathway for dementia in DS. This also encompasses "it takes a village" which related to staff comments around the inability for sub-speciailites to work through a dementia pathway alone, but rather requiring a collaborative and MDT-orientated approach to their work. They also voiced general worries about the service (as opposed to specific worries about the current pathway, which features below). These related to fears of being overwhelmed due to the significant case load already held by the service ("the straw that might break the camel's back").

Theme 2: Best laid plans:

This theme related to the more specific practical concerns that feature in already existing aspects of the service's reactive pathway approach to dementia in DS (rather than 'wish list' ideas for a future pathway, this related to me more to 'correcting' problems that already exist). Some of these arose from staff having previously received service user/carer feedback identifying that large numbers of staff got involved very suddenly when they/their family member was referred for a dementia assessment that then led to a diagnosis ("too many cooks") and a desire to address this specific concern about the current pathway. This theme also identified electronic record and database issues ("systems working against us") that the team flagged as requiring change before new pathways might be implemented in a practical sense (e.g., how best to code diagnoses on the electronic record system to ensure they are flagged for screening, and which professional groups are able to log these diagnoses), The subtheme of "prevention is the best cure" also arose here, from a feeling within the team that the current pathway does not meet the guidelines and recommendations set out for supporting the DS population, and a professional discomfort with that. To me during my analysis of the focus group feedback, these concerns were specific to the pathway, rather than a more general 'wishful thinking' as reflected in the Blue Sky Thinking theme.

Theme 3: Person-centred care:

During analysis, this theme arose via comments relating to the ethics of screening approaches in DS. The subtheme of "to know or not to know" arose from questions about the ethics of introducing the knowledge that those with DS that they are likely to develop dementia as they age. This was countered by the "All's fair..?" subtheme, which compared learning disability provision to that of the general population. Health screening is common in the general population, and much is made of informed consent and individuals being well-informed of their risks for various conditions and the impact on health behaviour choices. As a result, these two subthemes naturally linked for me within the Person-centred care theme. A frequent and recurrent thought from the team was around how important it will be to include individuals with DS in conversations around pathway changes, care provision. This related to the ethics of choices services make around these, leading to the subtheme "Unheard voices". Many reasons for the lack of input from individuals living with DS may be identified, but the team often found ways to possibly navigate around these or at least highlighted the importance of finding a way to allow meaningful input from these stakeholders. During analysis this subtheme aligned for me with consideration of ethics around screening and the inability to ethically exclude people with DS from these conversations.

Appendix 2D: Reflective statement

Reflection

As above, reflexivity is a core aspect of good qualitative research. Reflexivity was aimed for in this work via identification of identities and biases in the main researcher (FP). Having a placement in this service will have influenced connection with staff members and possibly identification with their concerns and needs beyond that of an external researcher, whilst family experiences of dementia may have influenced identification with the idea of improving access to diagnosis. Additionally, research supervision by a clinician working in general population older adults may have influenced the main researcher's aims for the project in the sense of comparison to general services and may have minimised understanding of the uniqueness of learning disability teams. The core point of reflexivity in this project was conversation between RV and FP about the identification of codes and themes, and the creation of a thematic map.

Appendix 2E: Response from service

*Response from service*

Response provided by member of psychology team with leadership responsibilities in the current dementia pathway: “I think the recommendations are appropriate and reflect the key findings. I appreciate the inclusion of the comments about the team’s capacity to undertake the baseline assessments. Positively, the work has already informed several internal conversations between psychology and nursing, and as such our nursing team have been able to put together a draft proposal for a phased rollout of these assessments. Additionally, we are actioning the recommendation around accurately recording Down’s Syndrome diagnoses; this was raised at the wider team business meeting and individual clinicians have been asked to review the current diagnoses for anyone they are care coordinating, making sure this is documented on our central patient record system. Finally, I am keen to think more in our MDT Dementia Working Group about how we achieve meaningful co-production with service users, their families and wider stakeholders; you are right to bring this to our attention as an important matter.”

TDRP

*Appendix 3a: participant information sheet and consent form.*

**Exploring the roles of adverse childhood experiences, negative self-beliefs and self-compassion in body mass index (BMI).**
**CUREC Approval Reference: R92324/RE001**

**General Information**

The aim of this research is to investigate the relationship between adverse childhood experiences, negative beliefs about the self, levels of self-compassion and BMI in the general population through a series of online questionnaires.

We appreciate your interest in participating in this online series of questionnaires. You have been invited to participate as you are female and aged 18 years and over. Please read through this information before agreeing to participate (if you wish to) by ticking the 'yes' box below.

You may ask any questions before deciding to take part by contacting the researcher (details below). The student researcher is Fiona Patrick, who is attached to the Institute of Clinical Psychology Training and Research which is an NHS training programme validated by the University of Oxford. This research is being completed under the supervision of Dr Myra Cooper.

If you choose to take part in this study, you will be asked to answer a series of questionnaires focused on presence of certain experiences in childhood (no details required, yes/no answer), self-compassion, beliefs about the self, anxiety and mood. You will also be asked your height, weight, age and ethnicity. This should take about 15 minutes. No background knowledge is required. The data will be analysed to understand whether beliefs about the self are different depending on BMI and whether they play a role in any relationship between adverse experiences in childhood and BMI.

**Do I have to take part?**

No. Please note that participation is voluntary. If you do decide to take part, you may withdraw at any point for any reason before submitting your answers by pressing the 'Exit' button/ closing the browser.
All questions are compulsory, but we have included a 'Prefer not to say' option for each set of questions should you prefer not to answer a particular question.

**How will my data be used?**

We will not collect any data that could directly identify you.
We will take all reasonable measures to ensure that data remain confidential.
The responses you provide will be stored in a password-protected electronic file on University of Oxford secure servers and may be used in academic publications, conference presentations and the student's thesis. Research data will be stored for 3 years after publication or public release of the work of the research.

**Who will have access to my data?**

The researchers named here, and their collaborator Dr Esme Banting will have access to the data. All data is anonymised. The results will be written up for a Doctorate in Clinical Psychology degree.

**Who has reviewed this research?**

This research has been reviewed by, and received ethics clearance through, a subcommittee of the University of Oxford Central University Research Ethics Committee R92324/RE001

**Who do I contact if I have a concern or I wish to complain?**

If you have a concern about any aspect of this research, please speak to Fiona Patrick (Fiona.patrick@hmc.ox.ac.uk) or their supervisor (myra.cooper@hmc.ox.ac.uk) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

**Please note that you may only participate in this survey if you are 18 years of age or over. If you have read the information above and agree to participate with the understanding that the data you submit will be processed accordingly, please tick the boxes below to start.**

☐ I am 18 years of age or over

☐ I have read the information sheet and consent to take part in this study.

*Appendix 3B: assumptions for all data analysis*

All the proposed analysis assumes normal distribution to the data. The distribution statistics are shown in the table below.

| | Skew (SE) | S-W (df), p | Kurtosis (SE) |
|---|---|---|---|
| | | Normal BMI | |
| Age | 1.49 (.219) | .82 (122), p < .001 | 1.46 (.435) |
| ACEs | 1.67 (.219) | .75 (122), p <.001 | 2.26 (.435) |
| GAD-7 | 1.07 (.219) | .89 (122), p <.001 | .61 (.435) |
| PHQ-8 | 1.48 (.219) | .83 (122), p < .001 | 1.86 (.435) |
| SCSFQ | .30 (.219) | .98 (122), p = .104 | -.12 (.435) |
| NSB self-loathing | 2.76 (.219) | .58 (122), p < .001 | 7.80 (.435) |
| NSB unassertive | .21 (.219) | .98 (122), p = .085 | -.68 (.435) |
| NSB high standards for self | -.70 (.219) | .96 (122), p = .002 | .49 (.435) |
| NSB demanding | .41 (.219) | .96 (122), p =.002 | -.68 (.435) |
| NSB abandoned/isolated | 1.13 (.219) | .86 (122), p <.001 | .38 (.435) |
| NSB total score | .69 (.219) | .97 (122), p = .008 | 1.07 (.435) |
| | | Overweight/obese BMI | |
| | Skew (SE) | S-W (df, p) | Kurtosis (SE) |
| Age | .86 (.240) | .88 (100), p < .001 | -.48 (.476) |
| ACEs | 1.21 (.240) | .82 (100), p < .001 | .94 (.476) |
| GAD-7 | 1.05 (.240) | .92 (100), p < .001 | .97 (.476) |
| PHQ-8 | 1.06 (.240) | .92 (100), p < .001 | 1.37 (.476) |
| SCSFQ | .42 (.240) | .97 (100), p = .081 | -.32 (.476) |
| NSB self-loathing | 2.45 (.240) | .67 (100), p < .001 | 7.81 (.476) |
| NSB unassertive | -.09 (.240) | .98 (100), p = .082 | -.85 (.476) |
| NSB high standards for self | -.34 (.240) | .98 (100), p = .33 | -.09 (.476) |
| NSB demanding | .27 (.240) | .97 (100), p = .02 | -.69 (.476) |
| NSB abandoned/isolated | .83 (.240) | .92 (100), p < .001 | .37 (.476) |
| NSB total score | .37 (.240) | .97 (100), p = .02 | -.49 (.476) |

ACEs: Adverse Childhood Experiences; BMI: Body Mass Index; GAD-7: Generalized Anxiety Disorder-7; PHQ-8: Patient Health Questionnaire-8; SCSFQ: Self-compassion Short Form Questionnaire; NSB: Negative self-beliefs; SE: Standard Error; K-S: Kolmogorov-Smirnov; S-W: Shapiro-Wilks; df: degrees of freedom.

*Independent samples t-test*

Group comparisons with independent samples t-tests relies on assumptions of 1) measurement using interval scale, 2) normal distribution of data, 3) adequate sample size and 4) that variance is homogeneous. The assumption of normality of data distribution was violated in the variables intended for group comparison (see above). Evidence suggests than in this scenario, Mann-Whitney U tests are more robust and reliable, leading to their use in this analysis. Mann-Whitney U tests assume data is independent and unpaired, which is true in this sample.

*One-way ANCOVA, exploratory hypothesis follows on from primary hypothesis.*

Assumptions for ANCOVA include: 1) continuous nature of dependent and covariate variables; 2) categorical nature of independent variable; 3) independence of observations; 4) no significant outliers; 5) normally distributes residuals; 6) homogeneity of variances; 7) linear relationship between covariate and dependent variable in each group; 8) homoscedasticity. Assumptions 1-3 were met: independence of observations was demonstrated with Durbin-Watson, which gave an outcome of 2.001. Outliers were identified through use of Grubbs test which gave a significant p-value on 4 stepwise iterations, requiring rejection of the hypothesis that there were no significant outliers. The 4 outliers were removed (all outliers were overweight/obese BMI, ranging from 40.4- 49.7). The final iteration of Grubbs test was non-significant, indicating no further outliers ($G = 3.195$, $U = 0.956$, $p = 0.146$). As such, $n = 96$ for the overweight/obese group in the ANCOVA analysis.

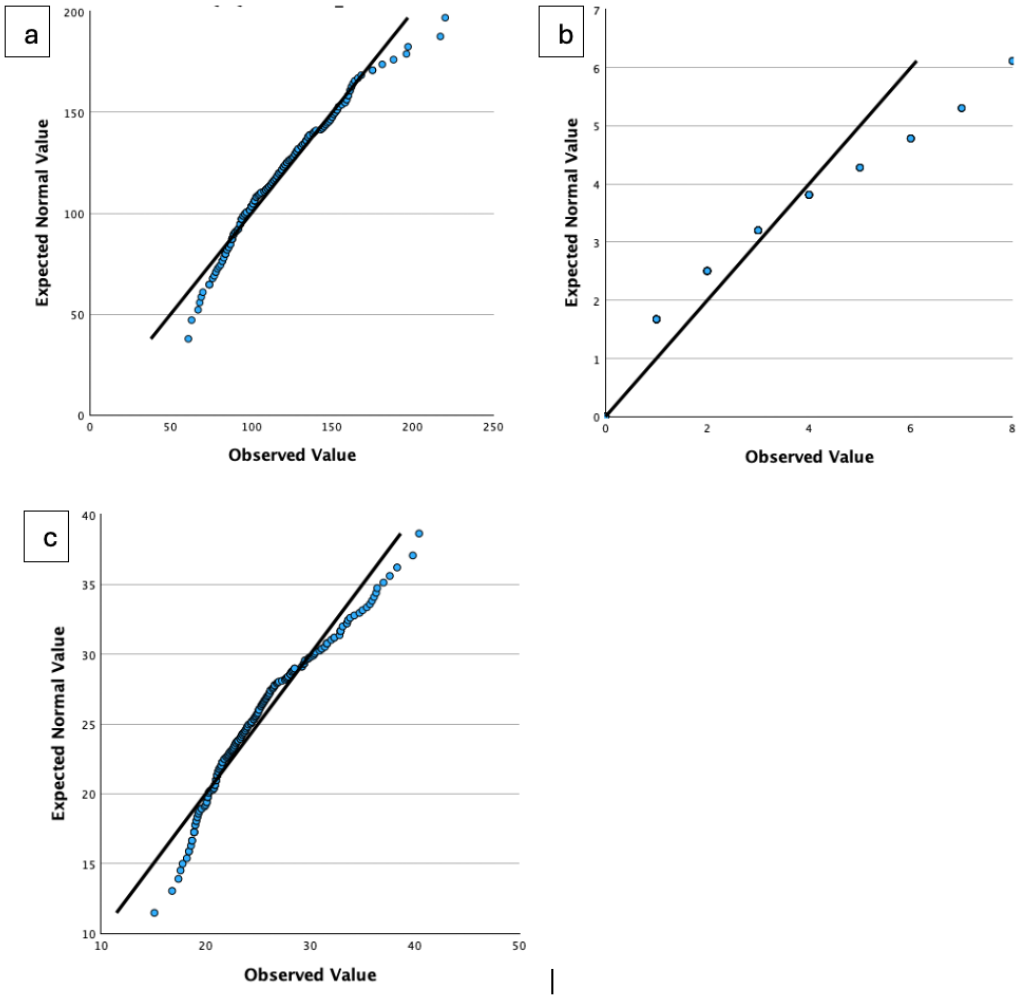
Though the assumption of normality was violated (see above), homogeneity of variances was present as demonstrated by non-significant Levene's Test for Equality of Error Variances (all $p>.05$). There is evidence that ANCOVA remains robust if normality is not present, if homogeneity of variance is met (Olejnik & Algina, 1984). Linearity of the relationship between covariates and outcome were visualised with scatterplots. Homoscedasticity was shown through plotting of residuals and visually checked.

*Linear regressions, secondary hypotheses.*

Assumptions for a linear regression are 1) linearity, 2) independence of residuals, 3) homoscedasticity, 4) normality of residuals, 5) absence of outliers and 6) absence of perfect

collinearity (IBM, 2023). Linearity was demonstrated by partial regression plots, and a plot of standardised residuals against the predicted values. Residuals were shown to be normally distributed, by visual inspection of Q-Q plots (Q-Q plots of BMI, ACEs and NSB total are shown, though all variables and covariates were tested and shown to meet this assumption; figure below). Outliers were removed as in the ANCOVA analysis above. Multicollinearity indicated tolerance value of 1 or greater, suggesting multicollinearity was not violated.

Q-Q plots: a) NSB total score, b) ACEs and c) BMI



*Appendix 3C: power calculations for a) group comparisons and b) linear regressions*

a)




b)



*3D: Correlations*

| | BMI | NSB self-loathing | NSB unassertive | NSB high standards for self | NSB demanding | NSB abandoned/ isolated |
|---|---|---|---|---|---|---|
| ACEs | .001 | .300** | .193* | .147* | .212** | ..660** |
| BMI | - | -.133 | -.060 | -.107 | .067 | -.083 |
| NSB self-loathing | - | - | .251** | -.020 | .414** | .456** |
| NSB unassertive | - | - | - | .014 | .378** | .298** |
| NSB high standards-for-self | - | - | - | - | .013 | .076 |
| NSB demanding | - | - | - | - | - | .478** |

*Significant a p <.05

**Significant at p<.005

BMI: Body Mass Index; ACEs: Adverse Childhood Experiences; NSB: Negative self-beliefs.

NB: Outliers are removed from this analysis (appendix 3B).

*Appendix 3E: Lay summary.*

Being overweight or obese is linked to a greater chance of experiencing both physical and mental health problems. Guidelines suggest that psychological treatments can be used to help people who are overweight or obese, along with medications and diet/exercise groups. However, the guidelines don't suggest a specific psychology treatment for this. This project looked at whether one particular model of why people might be overweight/obese and why they might stay overweight/obese, might be useful. The project recruited 222 women online, who answered questionnaires about their mood, childhood experiences, thoughts about themselves and how self-compassionate (kind to themselves) they were. They also reported their height and weight, so their BMI could be calculated. The results showed that people in the overweight/obese BMI group scored higher on self-loathing questions, and also had lower mood, than those in the "normal' BMI group. The results did not support using the model explored in this project, and instead suggested that other models or ways of thinking about being obese/overweight may be more useful. Future work could use this information to identify how best to help people who are overweight/obese, if they want support.

Submission guidelines

*Appendix 4A: Submission guidelines for Cognitive Behavioural Therapy, planned journal for systematic review of the literature*

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

*Article Types*

The following word limits are considered general recommendation. However, longer articles of particular interest for the journal can be permitted on a case-by-case basis. Please advise the editor upon submission.

**Research Article**

- Should be written with the following elements in the following order: title page (including acknowledgements as well as funding and grant-awarding bodies); abstract; keywords; main text introduction, materials and methods, results, discussion; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 8000 words (or 15000 words for qualitative studies), exclusive of:
    - Tables
    - References
    - Figure or table captions
- Should contain an unstructured abstract of 200 words.
- Should contain no more than 6 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

- **Theoretical articles** are also accepted and should be no more than 12000 words, exclusive of tables, references, figures or table captions. Theoretical articles do not have to include empirical data, but discuss a theoretically important topic that fits the scope of the journal. These articles should be submitted under the article type Research Article with a note to indicate they are Theoretical Articles.

**Review Article**

- Should be written with the following elements in the following order: see Research Article
- Should be no more than 12000 words, exclusive of:
    - Tables
    - References
    - Figure or table captions
- Should contain an unstructured abstract of 200 words.
- Should contain no more than 6 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

**Case Study**

- Should be written with the following elements in the following order: see Research Article
- Should be no more than 4000 words, exclusive of:
    - Tables
    - References

    - Figure or table captions
- Should contain an unstructured abstract of 200 words.
- Should contain no more than 6 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

**Brief Report**

- Should be written with the following elements in the following order: see Research Article
- Should be no more than 4000 words, exclusive of:
    - Tables
    - References
- Should contain an unstructured abstract of 200 words.

*Format-Free Submission*

Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), PDF, or LaTeX files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, and references. Further details may be requested upon acceptance.
- References can be in any style or format, so long as a consistent scholarly citation format is applied. For manuscripts submitted in LaTeX format a .bib reference file must be included. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. All bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.
- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

*Taylor & Francis Editing Services*

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

*Checklist: What to Include*

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) requirements for authorship is included as an author of your paper. Please ensure all listed authors meet the Taylor & Francis authorship criteria. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of

the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

2. **Graphical abstract** (optional). This is an image to give readers a clear idea of the content of your article. For the optimal online display, your image should be supplied in landscape format with a 2:1 aspect ratio (2 length x 1 height). Graphical abstracts will often be displayed online at a width of 525px, therefore please ensure your image is legible at this size. Save the graphical abstract as a .jpg, .png, or .tiff. Please do not embed it in the manuscript file but save it as a separate file, labelled GraphicalAbstract1.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   *For single agency grants*
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   *For multiple agency grants*
   This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
5. **Disclosure statement.** This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare*. Further guidance on what is a conflict of interest and how to disclose it.
6. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
7. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
8. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
9. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.
10. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
11. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
12. **Units.** Please use SI units (non-italicized).

*Appendix 4B: Submission guidelines for British Journal of Learning disabilities for future publication of SIP*

## 1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publicataion elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

New submissions should be made via the Research Exchange submission portal https://wiley.atyponrex.com/journal/BLD. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging on to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our FAQs or contact submissionhelp@wiley.com.

If you cannot submit online, please contact the Editorial Office by email: BLDedoffice@wiley.com

**Free format submission**

The *British Journal of Learning Disabilities* now offers Free Format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files—whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.
- An ORCID ID, freely available at https://orcid.org. *(Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)*
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)*
    - Statements relating to our ethics and integrity policies, which may include any of the following *(Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication)*:
        - data availability statement
        - funding statement
        - conflict of interest disclosure
        - ethics approval statement
        - patient consent statement
        - permission to reproduce material from other sources
        - clinical trial registration

**Important: the journal operates a double-blind peer review policy. Please anonymize your manuscript and supply a separate title page file.**

To submit, login at https://wiley.atyponrex.com/journal/BLD and create a new submission. Follow the submission steps as required and submit the manuscript.

**Data protection**

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at https://authorservices.wiley.com/statements/data-protection-policy.html.

**Preprint policy**

Wiley believes that journals publishing for communities with established pre-print servers should allow authors to submit manuscripts which have already been made available on a non-commercial preprint server. Allowing submission does not, of course, guarantee that an article will be sent out for review. It simply reflects our belief that journals should not rule out reviewing a paper simply because it has already been available on a non-commercial server. Please see below for the specific policy language.

However, Wiley also knows that the use of preprint servers is not universally accepted and that individual journals and/or societies may approach submission of preprints differently.

*This journal will consider for review articles previously available as preprints on non-commercial servers such as ArXiv, bioRxiv, psyArXiv, SocArXiv, engrXiv, etc. Authors may also post the submitted version of a manuscript to non-commercial servers at any time. Authors are requested to update any pre-publication versions with a link to the final published article.*

## 2. AIMS AND SCOPE

The *British Journal of Learning Disabilities* is an interdisciplinary international peer-reviewed journal that draws contributions from a wide community of international researchers. It encompasses contemporary debate/s and developments in research, policy and practice that are relevant to the field of learning disabilities. Learning disabilities here refers to intellectual (global) disabilities and not to specific learning disabilities like dyslexia. The scope includes:

- activism and advocacy
- communication, interaction and relationships
- community lives and quality of life
- education and employment
- families and advocacy
- health and wellbeing
- policy, law and rights
- profound and multiple learning disabilities/additional needs
- research methods and inclusive research
- social care and professional roles.

The journal publishes original papers, commissioned keynote reviews on major topics, and book/resource reviews with some Special Issues giving comprehensive coverage to specific subject areas. The editor welcomes suggestions of topics for future Special Issues.

The journal supports dialogue with people with learning disabilities. *In Response* pieces provide feedback on the issues arising in the journal papers and their relevance for the lives of people with learning disabilities and those supporting them.

The international audience for *British Journal of Learning Disabilities* includes academics, professionals, practitioners, families and people with a personal and professional interest in learning disability. Authors are expected to consider this wide readership, to communicate in an accessible manner, and to exhibit knowledge of previously-published articles when submitting their work for consideration for publication. Careful attention to respectful terminology and ethical treatment is essential. You can see the journal's position on ethics here.

The *British Journal of Learning Disabilities* is the official journal of the British Institute of Learning Disabilities. The opinions expressed in articles, whether editorials or otherwise, do not necessarily represent the official view of the British Institute of Learning Disabilities and the Institute accepts no responsibility for the quality of goods or services advertised.

## 3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

- All Manuscripts submitted to *British Journal of Learning Disabilities* should include: Accessible Summary, Keywords, Abstract, Main Text (divide by appropriate sub headings) and References.
- Manuscripts should not be more than 7,000 words in length including references.

## 4. PREPARING THE SUBMISSION

### Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures.

### Title page

The title page should contain:
i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
ii. A short running title of less than 40 characters;
iii. The full names of the authors;
iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
v. Acknowledgments.

### Abstract and Accessible Summary

Papers should include a structured abstract (maximum 200 words) incorporating the following headings: Background, Methods, Findings, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. As well as an abstract, authors must include an easy-to-read summary of their papers. This was introduced in 2005, and was done so in the spirit of making research findings more accessible to people with learning disabilities.

The editorial board also believe that this will make 'scanning' the Journal contents easier for all readers. Authors are required to:

- Summarise the content of their paper using bullet points (4 or 5 at most),
- Express their ideas in this summary using straightforward language, and
- State simply why the research is important, and should matter to people with learning disabilities.

**Authorship**

Please refer to the journal's authorship policy the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

**Acknowledgments**

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

**Conflict of Interest Statement**

Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

**Main Text File**

As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors.

Manuscripts can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx).

Your main document file should include:

- A short informative title containing the major key words. The title should not contain abbreviations
- The full names of the authors with institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- Acknowledgments;
- Abstract structured (Background, Methods, Findings, Conclusions)
- Keywords;
- Main body;
- References;
- Tables (each table complete with title and footnotes);
- Figures: Figure legends must be added beneath each individual image during upload AND as a complete list in the text.

***Tables***

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

***Figure Legends***

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

***Figures***

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

**Color Figures.** Figures submitted in color may be reproduced in colour free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white.

***Data Citation***

In recognition of the significance of data as an output of research effort, Wiley has endorsed the FORCE11 Data Citation Principles and is implementing a mandatory data citation policy. Wiley journals require data to be cited in the same way as article, book, and web citations and authors are required to include data citations as part of their reference list. Data citation is appropriate for data held within institutional, subject focused, or more general data repositories. It is not intended to take the place of community standards such as in-line citation of GenBank accession codes. When citing or making claims based on data, authors must refer to the data at the relevant place in the manuscript text and in addition provide a formal citation in the reference list. We recommend the format proposed by the Joint Declaration of Data Citation Principles:

[dataset] Authors; Year; Dataset title; Data repository or archive; Version (if any); Persistent identifier (e.g. DOI)

**References**

This journal uses the *Publication Manual of the American Psychological Association* (6th edition) reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

*Appendix 4C: Submission guidelines for Health Psychology Open for future publication of TDRP*

This Journal is a member of the Committee on Publication Ethics (COPE)

This Journal recommends that authors follow the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals formulated by the International Committee of Medical Journal Editors (ICMJE).

**Article types**

(a) Reports of empirical studies likely to further our understanding of health psychology
(b) Critical reviews of the literature
(c) Theoretical contributions and commentaries
(d) Intervention studies
(e) Brief reports

**Registered Reports, Pre-Data or Post-Data:** There are two types of Registered Reports:

- Registered Reports – Pre-Data, i.e., before any data have been gathered
- Registered Reports – Post-Data, i.e., before already existing data have been examined and analysed.

These submissions are reviewed in two stages. In Stage 1, a study proposal is considered for publication prior to data collection and/or analysis. Stage 1 submissions should include a complete Introduction, Methods, and Proposed Analyses. High-quality proposals will be accepted in principle before data collection and/or data analysis commences. Once the study is completed, the author will finish the article including Results and Discussion sections (Stage 2). Publication of the Stage 2 submission is guaranteed as long as the approved Stage 1 protocol is followed and the conclusions are appropriate. Full details can be found here. The Journal's manuscript requirements should be adhered to for the stage 2 submission.

**Authorship**

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors,. This includes paid or unpaid medical/commercial writers ('ghost writers').

The list of authors should include all those who can legitimately claim authorship. This is all those who:

- Made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data,
- Drafted the article or revised it critically for important intellectual content,
- Approved the version to be published,
- Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Authors should meet the conditions of all of the points above. When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

If medical/commercial writers are to be involved in the preparation of manuscripts then they must co-author with a clinician (or other medical professional) and their name and full affiliation must appear on the article.

The work of any medical/commercial writer must not be passed off as that of a clinician or other medical professional.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section.

Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

Please note that AI chatbots, for example ChatGPT, should not be listed as authors. For more information see the policy on Use of ChatGPT and generative AI tools.

**Acknowledgements**

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

***Third party submissions***
Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

  Where appropriate, Sage reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

***Writing assistance***

Individuals who provided writing assistance, e.g. from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgements section. Authors must disclose any writing assistance – including the individual's name, company and level of input – and identify the entity that paid for this assistance.

It is not necessary to disclose use of language polishing services.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

**Funding**

Health Psychology Open requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the *Funding Acknowledgements* page on the Sage Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

**Declaration of conflicting interests**

It is the policy of Health Psychology Open to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript and on the title page, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'.

For guidance on conflict of interest statements, please see the ICMJE recommendations.

Please see the ICMJE Form for Disclosure of Potential Conflicts of Interest for more information about what items should be referenced in a Conflict of Interest statement.

**Research ethics and patient consent**

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

**Research data**

The journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the Sage Research Data policy pages.

Subject to appropriate ethical and legal considerations, authors are encouraged to:

- share your research data in a relevant public data repository
- include a data availability statement linking to your data. If it is not possible to share your data, we encourage you to consider using the statement to explain why it cannot be shared.
- cite this data in your research

**Preparing your manuscript**

**Word processing formats**

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

**Artwork, figures and other graphics**

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit Sage's Manuscript Submission Guidelines

Figures supplied in color will appear in color online.

**Abstract**: The abstract should accurately and concisely reflect the content of the article, and should be limited to 150 words. Please avoid reference citations and undefined abbreviations in the abstract.

**Word length of manuscripts**

Articles of any word length will be considered. Tables and Figures count nominally as 500 words each in lieu of text. Supplemental files will be published online together with the paper, subject to peer review.

**Units of measurement**

Units of measurement should be expressed in SI and metric units; older conventional units may be added in parentheses.

**Nomenclature**

Use the generic or chemical name of any drug, in lower case; the specific trade name (capitalized) may be given in parentheses after the first text reference.

**Standard abbreviations and symbols**

Standard Abbreviations and symbols should be used, then defined in full in the first instance unless they are standard units of measurement. Avoid any use of abbreviations in the article title and abstract.

**Supplemental material**

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files

*Appendix 5A: CUREC ethics approval for TDRP*

**MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE**
Research Services, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB
Tel: +44(0)1865 616575
ethics@medsci.ox.ac.uk

**CONFIDENTIAL**

Dr Myra Cooper & Fiona Patrick
Oxford Institute for Clinical Psychology Training & Research
Isis Education Centre
Warneford Hospital
Oxford

19 April 2024

Dear Dr Cooper and Fiona,

**Research Ethics Approval - CUREC 1**

**Ethics Approval Reference: R92324/RE001**

**Study title: Exploring the roles of adverse childhood experiences, negative self-beliefs and reduced self-compassion in body mass index (BMI) in women**

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) in accordance with the University's procedures for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted from **19th April 2024** until **18th October 2025.**

Insurance-provided indemnity arrangements are in place for the duration of the approval stated above. It is your responsibility to ensure that you request an extension to the end date for indemnity to remain in place should you continue the research beyond the dates covered.

**Amendments**

Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form.

Yours Sincerely

DocuSigned by:
Leah Butts
9F14889D2BC549A...

Mrs Leah Butts
Research Ethics Administrator

*for*
Dr Helen Barnby-Porritt
Research Ethics Manager