**EDAPTS Appendix A**

**Survey Questions: Round 1**

**Question One**

Psychological therapy can be of benefit for a range of mental health conditions and we have evidence that different psychological therapies can help for different mental health conditions.

What we know less about is whether psychological therapy also causes harm or discomfort. We think it’s best to find out as much as possible to help people make the best decisions for themselves.

We are asking you for your opinions because you have professional or personal experience of psychological therapy. We know that it can be difficult to come up a list all at once, so after you give your first answer we will share some definitions and categories of adverse effects to help you come up with more.

There will be an opportunity to add to your list on each page.

**-What do you think are the adverse effects (or side effects) of psychological therapy? If you think there are no adverse effects, please tell us that in the box below. Please comment…**

**Question Two**

Adverse effects can be called many different things: Side effects

Unwanted events

Unintended consequences

Treatment-emergent reactions

Therapeutic risk

Necessary discomfort.

There are also many different definitions of Adverse effects:

‘unwanted because of their negative quality and because they are not intended by the treatment…not... the goal of treatment, and if there would be another therapy that works without this… it would be better.’ (Linden, 2013)

'harmful/uncomfortable/unpleasant events that occur during psychological therapy'

'get worse before get better'

We are interested in any effect that is unpleasant or negative. Some may be due to the type of therapy or therapist. Some may be necessary or important for treatment, for example, crying or exposure to anxiety. We realise that this may be a part of the process but still think it should be measured as an adverse effect. If you disagree, please let us know in the box below.

**-After reading these, have you thought of any more adverse effects?**

**Question Three**

Here are some areas where psychological therapy can have a positive effect.

Physical health

Relationships with partners, family or friends

Emotions

Behaviour

Daily Routine (such as sleeping, eating etc)

Work life

Sense of self

**-Do you think there are adverse effects in any of these areas?**

**Question Four**

**-When you think about what is difficult about psychological therapy, do you think of any more adverse effects**?

-End of Survey-

**EDAPTS Appendix B- Full list of potential adverse effects**

Table B: Full item list generated from Round 1 organised by theme; Exclusion/inclusion status and analysis comparing EBE and Professional ratings

|  | **Round 2** | **Round 3** |
| --- | --- | --- |
|  |  | Included/ Excluded | Z score\* | P value | Rated more NB by | Z score | P value | Rated more NB by |
| **Therapy amplifies the problem** |  |  |  |  |  |  |  |
|  | Becoming more aware of own thoughts, behaviours, mood, problems | Excluded R3 | -1.20 | 0.23 |  | -1.60 | 0.11 |  |
|  | Becoming more judgmental of own thoughts, behaviours, mood, problems | Excluded R3 | -0.26 | 0.79 |  | 0.44 | 0.66 |  |
|  | **Painful realisations about own past/childhood/negative experiences/parenting** | **Included R2** | -1.54 | 0.12 |  |  |  |  |
|  | **Being retraumatised** | **Included R2** | 0.20 | 0.84 |  |  |  |  |
|  | **Pathologising own behaviour, for example, seeing own behaviour as abnormal** | **Supplementary** | 2.24 | 0.02\* | EBE | 1.11 | 0.27 |  |
|  | Feeling misunderstood or invalidated | Excluded R2 | 0.49 | 0.63 |  |  |  |  |
|  | **Therapy can highlight maintaining factors that cannot be changed (that is, factors that contribute to mental health difficulties)**  | **Included R2** | 0.05 | 0.96 |  |  |  |  |
|  | **No longer being able to avoid painful thoughts/beliefs about oneself** | **Included R2** | -0.78 | 0.43 |  |  |  |  |
|  | Accepting help makes mental health problems feel more real | Excluded R2 | 0.72 | 0.47 |  |  |  |  |
|  | Difficulties with trust are amplified in the therapy relationship | Excluded R2 | 1.54 | 0.12 |  |  |  |  |
|  | Fleeting suicidal impulses are given more meaning  | Excluded R2 | 0.92 | 0.36 |  |  |  |  |
| **Increased emotional lability (frequency or intensity)** |  |  |  |  |  |  |  |
|  | **anger**  | **Included R2** | -0.57 | 0.57 |  |  |  |  |
|  | **anxiety/fear/panic/ worry** | **Included R2** | -0.81 | 0.42 |  |  |  |  |
|  | bewilderment/confusion | Supplementary | 2.97 | 0.00\* | EBE | 2.84 | 0.00\* | EBE |
|  | **despair/feeling disheartened/demotivated/helpless/haplessness** | **Included R2** | 0.58 | 0.56 |  |  |  |  |
|  | **discomfort**  | **Included R2** | -1.81 | 0.07 |  |  |  |  |
|  | disempowerment | Excluded R2 | 1.94 | 0.05 |  |  |  |  |
|  | **distress** | **Included R2** | -1.12 | 0.26 |  |  |  |  |
|  | **feeling exposed/vulnerable** | **Included R2** | -0.57 | 0.57 |  |  |  |  |
|  | feeling 'foggy'- depersonalised/dereal | Excluded R3 | 1.15 | 0.25 |  | 0.32 | 0.75 |  |
|  | feeling judged/criticised/threatened | Excluded R2 | 1.22 | 0.22 |  |  |  |  |
|  | **feeling overwhelmed or unable to cope** | **Included R2** | -0.04 | 0.96 |  |  |  |  |
|  | feeling less kind and empathetic | Excluded R2 | 0.52 | 0.60 |  |  |  |  |
|  | frustration/disappointment | Excluded R3 | 0.74 | 0.46 |  | 1.19 | 0.24 |  |
|  | **guilt/shame** | **Included R2** | 0.35 | 0.73 |  |  |  |  |
|  | **hallucinations, flashbacks, psychosis, obsessions/compulsions** | **Included R2** | 1.99 | 0.05 |  |  |  |  |
|  | increased passivity/demotivation | Excluded R2 | 2.15 | 0.03\* | EBE |  |  |  |
|  | **hopelessness/feeling stuck** | **Included R3** | 2.20 | 0.03\* | EBE | 0.29 | 0.77 |  |
|  | loneliness/aloneness | Supplementary | 1.97 | 0.05 |  | 2.11 | 0.04\* | EBE |
|  | **stress** | **Included R2** | 0.49 | 0.62 |  |  |  |  |
|  | **tired/fatigue/exhaustion/emotionally drained** | **Included R2** | 0.41 | 0.68 |  |  |  |  |
|  | worthlessness | Supplementary | 0.56 | 0.58 |  | 2.18 | 0.03\* | EBE |
|  | **feeling upset/sadness/depression** | **Included R2** | -0.05 | 0.96 |  |  |  |  |
|  | **Experiencing a grief/loss reaction for life that could have been lived** | **Included R2** | -0.79 | 0.43 |  |  |  |  |
|  | **Anxiety during exposure tasks** | **Included R2** | -1.31 | 0.19 |  |  |  |  |
|  | Feeling like one is being manipulated in therapy | Excluded R2 | 3.35 | 0.00\* | EBE |  |  |  |
|  | Feeling like a failure | Excluded R2 | 0.76 | 0.45 |  |  |  |  |
|  | Being preoccupied with ideas from therapy | Supplementary | 1.30 | 0.19 |  | 2.48 | 0.01\* | EBE |
|  | **Feeling responsible if therapy doesn't help/feel pressured to 'use therapy properly'** | **Included R2** | 1.09 | 0.28 |  |  |  |  |
|  | **Going into therapy feeling good-then come out feeling low and upset** | **Included R2** | 0.04 | 0.97 |  |  |  |  |
|  | **Apprehension about therapy sessions** | **Included R2** | -1.94 | 0.05 |  |  |  |  |
|  | Crying more often | Excluded R3 | -1.24 | 0.22 |  | 0.07 | 0.94 |  |
|  | Feeling embarrassed about opening up to a stranger | Excluded R3 | -1.98 | 0.05\* | Prof | -1.42 | 0.15 |  |
|  | Therapy triggering a catatonic state  | Excluded R2 | 3.24 | 0.00\* | EBE |  |  |  |
| **Physical/Somatic** |  |  |  |  |  |  |  |
|  | **Increased nightmares** | **Included R2** | -0.19 | 0.85 |  |  |  |  |
|  | Insomnia | Excluded R3 | 1.01 | 0.31 |  | 1.51 | 0.13 |  |
|  | Weight gain/loss/change in appetite | Excluded R2 | 0.22 | 0.83 |  |  |  |  |
|  | Loss of sex drive | Excluded R2 | 0.07 | 0.94 |  |  |  |  |
|  | Concentration is affected due to thinking about therapy | Excluded R3 | 0.31 | 0.76 |  | 1.01 | 0.31 |  |
|  | Eczema has flared up  | Excluded R2 | 0.47 | 0.64 |  |  |  |  |
|  | IBS is worse | Excluded R2 | 0.33 | 0.74 |  |  |  |  |
|  | Increased headaches | Excluded R2 | 0.53 | 0.60 |  |  |  |  |
|  | Physical health conditions have been described as psychological  | Excluded R2 | 0.01 | 0.99 |  |  |  |  |
|  | Physical pain due to psychological pain | Excluded R2 | -0.12 | 0.91 |  |  |  |  |
|  | Physical pain from sitting for an hour | Excluded R2 | -0.81 | 0.42 |  |  |  |  |
|  | Somatic difficulties due to retraumatisation | Excluded R2 | 0.87 | 0.38 |  |  |  |  |
|  | Stress related increase in infections | Excluded R2 | 0.43 | 0.67 |  |  |  |  |
|  | Increased stomach aches | Excluded R2 | 0.84 | 0.40 |  |  |  |  |
| **Negative Coping Strategies** |  |  |  |  |  |  |  |
|  | Increased alcohol consumption | Supplementary | -0.31 | 0.76 |  | 2.00 | 0.05\* | EBE |
|  | Increased drug use | Excluded R2 | 0.20 | 0.84 |  |  |  |  |
|  | Smoking more | Excluded R2 | 0.24 | 0.81 |  |  |  |  |
|  | Over-eating | Excluded R3 | 0.18 | 0.86 |  | 1.86 | 0.06 |  |
|  | Excessive exercise | Excluded R2 | 0.12 | 0.91 |  |  |  |  |
|  | **Increased self-harm** | **Included R2** | -0.27 | 0.79 |  |  |  |  |
|  | **Increased suicidal ideation**  | **Included R2** | 0.25 | 0.80 |  |  |  |  |
|  | **Increased suicide attempt** | **Included R2** | 0.05 | 0.96 |  |  |  |  |
|  | **New safety behaviours develop (that is, behaviours to reduce anxiety in the short term)** | **Included R2** | -1.14 | 0.26 |  |  |  |  |
|  | Emergence of new 'rules about what I should do' based on what therapist said | Supplementary | -0.68 | 0.50 |  | 2.71 | 0.01\* | EBE |
| **Sense of Self** |  |  |  |  |  |  |  |
|  | Self-esteem or self-confidence has decreased | Excluded R3 | 0.65 | 0.52 |  | 1.66 | 0.10 |  |
|  | A reduced sense of self efficacy and/or feeling deskilled | Excluded R3 | 1.49 | 0.14 |  | 1.88 | 0.06 |  |
|  | **Own sense of self feels like it is determined by therapist's opinion** | **Included R3** | 2.64 | 0.01\* | EBE | 2.82 | 0.00\* | EBE |
|  | Feeling responsible or to blame for own mental health problems, for example, 'I'm depressed because I look at things negatively'  | Excluded R3 | 0.51 | 0.61 |  | 0.55 | 0.58 |  |
|  | Feeling incompetent for 'needing therapy' | Excluded R2 | 0.47 | 0.64 |  |  |  |  |
|  | Loss of faith | Excluded R2 | 0.04 | 0.97 |  |  |  |  |
|  | Feeling stigmatised by therapy process | Excluded R2 | -0.36 | 0.72 |  |  |  |  |
|  | Doubting own thoughts/feelings/responses | Supplementary | 0.60 | 0.55 |  | 2.38 | 0.02\* | EBE |
|  | Sense of self becomes fragmented- need to rebuild it in therapy | Excluded R3 | 0.63 | 0.53 |  | 0.80 | 0.42 |  |
|  | Becoming self-absorbed | Excluded R2 | 1.86 | 0.63 |  |  |  |  |
|  | Viewing oneself differently, and then feeling like one no longer fits in with own old life | Excluded R3 | -0.20 | 0.84 |  | 1.07 | 0.29 |  |
| **Therapy process** |  |  |  |  |  |  |
|  | Therapy leading to a realisation that one is no longer a strong person | Excluded R2 | -0.61 | 0.54 |  |  |  |  |
|  | Therapy relationship is not private which feels like confidentiality breach; for example, there are other strangers such as supervisors or other team members involved | Excluded R3 | 0.71 | 0.48 |  | -0.31 | 0.75 |  |
|  | Feeling inferior to the therapist | Excluded R2 | 0.41 | 0.68 |  |  |  |  |
|  | Feeling like the therapist makes judgements before having had a chance to explain oneself fully | Excluded R2 | 1.28 | 0.20 |  |  |  |  |
|  | Feeling under pressure to recall bad memories/emotions/give the right answers/improve | Supplementary | 0.55 | 0.58 |  | 2.46 | 0.01\* | EBE |
|  | **Feeling over reliant/dependent on therapist** | **Included R2** | 0.16 | 0.87 |  |  |  |  |
|  | Fearing that there may be consequences for child protection/benefits | Excluded R3 | -0.65 | 0.52 |  | 0.89 | 0.37 |  |
|  | Feeling unable to disagree/criticise the process as this will be perceived as denial | Supplementary | 1.86 | 0.06 |  | 2.57 | 0.01\* | EBE |
|  | Diagnosis/misdiagnosis can affect own sense of self and may become a self-fulfilling prophecy | Supplementary | 1.60 | 0.11 |  | 2.22 | 0.03\* | EBE |
|  | Concerned about wasting therapist's time | Excluded R2 | -1.02 | 0.31 |  |  |  |  |
|  | **Feeling confused about the process, for example, unsure about how and when it will end** | **Included R2** | 1.18 | 0.24 |  |  |  |  |
|  | Therapy can feel therapist centred, instead of patient centred | Excluded R2 | 2.22 | 0.03\* | EBE |  |  |  |
|  | Feeling cheated and/or used in private practice | Excluded R2 | 2.54 | 0.01\* | EBE |  |  |  |
|  | Therapist's dogma/standards may be forced upon the client | Excluded R2 | 1.29 | 0.20 |  |  |  |  |
|  | Feeling vulnerable to negative things therapist says about oneself/one's past/family | Supplementary | 0.25 | 0.80 |  | 2.44 | 0.02\* | EBE |
|  | Feeling guilty because the therapy relationship is one sided; it's difficult to get used to | Excluded R2 | -0.67 | 0.50 |  |  |  |  |
|  | Feeling like the therapist is 'digging around for trauma' when there is none | Excluded R2 | 0.68 | 0.50 |  |  |  |  |
|  | Being unsure of the clinical reasoning behind the therapist's questions | Excluded R2 | 0.42 | 0.67 |  |  |  |  |
|  | Practical barriers, such as childcare etc. can affect attendance, therapist might think this is a sign that one doesn't want therapy | Excluded R2 | -0.26 | 0.79 |  |  |  |  |
|  | Finding it difficult to maintain own boundaries- the therapist has the power | Excluded R3 | 0.10 | 0.92 |  | 1.17 | 0.24 |  |
|  | Being offered rehabilitation/superficial support, not recovery | Excluded R2 | 1.16 | 0.24 |  |  |  |  |
|  | Own narrative is restricted by therapist/therapy style | Excluded R2 | 1.11 | 0.27 |  |  |  |  |
|  | **Therapy involves creating a bond that will be severed; fear of being left again/abandoned** | **Included R2** | -0.66 | 0.51 |  |  |  |  |
|  | **Experiencing a sense of loss when the therapist is away or when therapy ends- and having no one to talk to about this loss** | **Included R2** | -1.02 | 0.31 |  |  |  |  |
|  | Feeling like one is not being listened to; if therapist won't listen then who will? | Excluded R2 | 0.79 | 0.43 |  |  |  |  |
|  | Repeating things over and over in session; this can make unhelpful beliefs stronger | Excluded R2 | 1.11 | 0.27 |  |  |  |  |
|  | Being unsure about appropriate boundaries, for example, can I send a Christmas card? | Excluded R2 | -0.92 | 0.36 |  |  |  |  |
|  | Feeling infantalised or patronised in session | Excluded R2 | 1.95 | 0.05 |  |  |  |  |
|  | The therapy sessions are so far apart there's no momentum- feels like starting over every time | Excluded R2 | 1.23 | 0.22 |  |  |  |  |
|  | Difficult relationship dynamics are re-enacted in the therapy relationship | Included R2 | -0.61 | 0.54 |  |  |  |  |
|  | Therapy has articulated problems but did not provide tools to cope/change things | Excluded R3 | 2.24 | 0.03\* | EBE | 1.55 | 0.12 |  |
|  | Worrying about therapist's opinion | Excluded R3 | -1.50 | 0.13 |  | 0.94 | 0.35 |  |
|  | False sense of success when therapy ended- still struggling with difficulties | Excluded R3 | 0.61 | 0.54 |  | 1.45 | 0.15 |  |
| **Practical** |  |  |  |  |  |  |  |
|  | **Therapy requires huge effort at a time of vulnerability** | **Included R2** | -0.78 | 0.43 |  |  |  |  |
|  | **Feeling vulnerable; in session, all day after therapy and between sessions** | **Included R2** | -0.06 | 0.95 |  |  |  |  |
|  | Asking for time off work can trigger difficulties and lead to stigma | Excluded R3 | -0.07 | 0.94 |  | -0.80 | 0.42 |  |
|  | Changes made as a result of therapy can cause conflict at work, for example, expressing negative emotions | Excluded R3 | -0.52 | 0.61 |  | 1.62 | 0.11 |  |
|  | Deterioration in social life | Excluded R2 | 0.94 | 0.35 |  |  |  |  |
|  | Deterioration in occupational functioning/work life | Excluded R2 | 0.33 | 0.74 |  |  |  |  |
|  | Therapy involves an 'opportunity cost'; my attention, energy, time and money could be spent elsewhere  | Excluded R2 | 0.31 | 0.75 |  |  |  |  |
|  | Therapy is at an inconvenient location | Excluded R2 | 0.30 | 0.77 |  |  |  |  |
|  | Time is required; for sessions, to recover, to do homework etc. | Excluded R3 | -1.50 | 0.13 |  | 1.89 | 0.06 |  |
|  | One's capacity to cope with day to day activities is reduced | Excluded R3 | 0.20 | 0.84 |  | 0.94 | 0.35 |  |
|  | Needing to reduce medication to take part in therapy- could lead to less coping in daily life | Excluded R2 | 2.01 | 0.04\* | EBE |  |  |  |
| **Relationships** |  |  |  |  |  |  |  |
|  | **Relationships change as gaining new insight into negative relationships** | **Included R2** | -0.15 | 0.88 |  |  |  |  |
|  | **Relationships change as own behaviour changed, for example, became more assertive** | **Included R2** | -0.72 | 0.47 |  |  |  |  |
|  | Therapy feels like a barrier- other relationships feel devalued in comparison | Excluded R2 | 0.75 | 0.45 |  |  |  |  |
|  | Loved ones might not be able to provide support or might withdraw their support as they know one is in therapy | Excluded R2 | 0.16 | 0.87 |  |  |  |  |
|  | Withdrawal of intimacy from loved ones because of preoccupation with therapy | Excluded R2 | 0.07 | 0.95 |  |  |  |  |
|  | Loved ones may feel betrayed, isolated, disempowered, defensive | Excluded R2 | 0.85 | 0.40 |  |  |  |  |
|  | **One's interactions with people are affected if they were discussed in therapy, for example, feeling anger about past events** | **Included R2** | 1.05 | 0.29 |  |  |  |  |
|  | Throwaway comments made by therapist can become a self-fulfilling prophesy, for example, comments about attachment style | Excluded R2 | 0.80 | 0.42 |  |  |  |  |
|  | Therapy affects how one interacts with people- for example stop opening up to people, or saying everything without filter like in therapy | Excluded R2 | 0.77 | 0.44 |  |  |  |  |
| **Consequences and/or risks** |  |  |  |  |  |  |  |
|  | Could be diverted away from other possible treatments | Excluded R2 | 2.08 | 0.04\* | EBE |  |  |  |
|  | Therapy failure may lead to a label of 'treatment resistant' | Excluded R3 | 1.17 | 0.24 |  | 2.13 | 0.03\* | EBE |
|  | Information about therapy is shared in medical notes  | Excluded R3 | -1.32 | 0.19 |  | 1.91 | 0.06 |  |
|  | May be misdiagnosed | Excluded R3 | 1.79 | 0.07 |  | 1.58 | 0.12 |  |
|  | May misuse what was learned in therapy to inappropriate situations | Excluded R2 | 0.55 | 0.58 |  |  |  |  |
|  | At risk of institutional abuse | Excluded R2 | 0.44 | 0.66 |  |  |  |  |
|  | At risk of experiencing a misuse of power, whether deliberate or accidental | Excluded R2 | 0.63 | 0.53 |  |  |  |  |
|  | At risk of financial exploitation | Excluded R2 | 2.84 | 0.00\* | EBE |  |  |  |
|  | Feeling that therapists are agents of the state and will not critique social injustice | Excluded R2 | 0.20 | 0.84 |  |  |  |  |
|  | At risk of being bullied by therapist | Excluded R2 | 0.54 | 0.59 |  |  |  |  |
|  | At risk of gas lighting (being made to doubt own sanity) by therapist | Excluded R2 | 0.95 | 0.34 |  |  |  |  |
|  | At risk of being abused by therapist; emotionally, physically, sexually | Excluded R2 | 0.59 | 0.55 |  |  |  |  |
|  | At risk of psychiatric abuse if detained | Excluded R2 | -0.43 | 0.67 |  |  |  |  |
|  | Feel caught between psychiatry and psychology and that own voice is never heard | Excluded R2 | 1.04 | 0.30 |  |  |  |  |
|  | Feel that therapy can distract from wider issues in society | Excluded R2 | 0.26 | 0.80 |  |  |  |  |
|  | ***\*Likert scale [1-5: essential, very important, important, of little importance or not important at all].*** |

**EDAPTS Appendix C**

**Table C1; Characteristics of experience of psychological therapy; Round 1, by group**

|   | Experts by Experience | *Professional’s personal therapy* | Professionals delivering therapy |
| --- | --- | --- | --- |
|   | n=51 | *n=31* | n=51 |
| **Type of therapy** |   |   |  |  |   |   |
| Counselling | 37 | 73% | *20* | *65%* | 12 | 24% |
| Cognitive Behaviour Therapy (CBT) | 36 | 71% | *12* | *39%* | 43 | 84% |
| Psychodynamic or psychoanalytic therapy | 17 | 33% | *12* | *39%* | 8 | 16% |
| Don’t know | 11 | 22% | *1* | *3%* | 0 | 0% |
| Mindfulness &Mindfulness-Based Cognitive Therapy | 10 | 20% | *3* | *10%* | 17 | 33% |
| Interpersonal Psychotherapy (IPT) | 9 | 18% | *4* | *13%* | 3 | 6% |
| Dialectical Behaviour Therapy (DBT) | 5 | 10% | *0* | *0%* | 9 | 18% |
| Solution focused therapy | 5 | 10% | *1* | *3%* | 8 | 16% |
| Cognitive Analytic Therapy (CAT) | 5 | 10% | *3* | *10%* | 6 | 12% |
| Acceptance Commitment Therapy (ACT) | 3 | 6% | *2* | *6%* | 16 | 31% |
| Mentalization Based Therapy | 2 | 4% | *1* | *3%* | 4 | 8% |
| EMDR | 1 | 2% | *3* | *10%* | 0 | 0% |
| Transactional Analysis | 0 | 0% | *3* | *10%* | 0 | 0% |
| Other: (see line below) | 10 | 20% | *5* | *16%* | 10 | 20% |
| Other: Compassionate Focused Therapy, Group Therapy, Humanistic/Integrative, Emotion Focused Therapy, Neurofeedback, Family Therapy/Systemic, Schema Therapy, Narrative, Metacognitive, Transpersonal |
| **Qualification of Therapist**  |   |
| Clinical Psychologist | 29 | 57% | *13* | *42%* | 18 | 35% |
| Counsellor | 29 | 57% | *16* | *52%* | 3 | 6% |
| Psychiatrist | 14 | 27% | *1* | *3%* | 1 | 2% |
| IAPT Professional | 13 | 25% | *0* | *0%* | 3 | 6% |
| Nurse | 11 | 22% | *6* | *19%* | 1 | 2% |
| Counselling Psychologist | 10 | 20% | *3* | *10%* | 0 | 0% |
| Psychotherapist | 7 | 14% | *1* | *3%* | 1 | 2% |
| Don’t know | 5 | 10% | *1* | *3%* | 0 | 0% |
| Social Worker | 4 | 8% | *0* | *0%* | 0 | 0% |
| Psychoanalyst/Psychodynamic | 3 | 6% | *2* | *6%* | 0 | 0% |
| Clinical Associate Applied Psychologist (CAAP) | 1 | 2% | *0* | *0%* | 7 | 14% |
| Trainee Clinical Psychologist | 0 | 0% | *0* | *0%* | 12 | 24% |
| Other: (see line below) | 5 | 10% | *4* | *13%* | 8 | 16% |
| Other: BACP registered therapist, Occupational Therapist, Student psychotherapist, Art therapist, CBT therapist, Trainee Counselling Psychologist, Hypnotherapist, CAT therapist, Transactional analysis therapist, Prefer not to say |
| **Mental health difficulty therapy was for**  |
| Depression | 37 | 73% | *15* | *48%* | 48 | 94% |
| Generalised Anxiety Disorder | 19 | 37% | *8* | *26%* | 44 | 86% |
| Trauma | 17 | 33% | *7* | *23%* | 41 | 80% |
| Self-Harm and Suicidal Behaviour | 16 | 31% | *6* | *19%* | 38 | 75% |
| Social Anxiety/Social Phobia | 15 | 29% | *2* | *6%* | 46 | 90% |
| Eating Disorders | 11 | 22% | *2* | *6%* | 19 | 37% |
| Panic Disorder With/Without Agoraphobia | 8 | 16% | *0* | *0%* | 34 | 67% |
| Psychosis (including Schizophrenia) | 7 | 14% | *0* | *0%* | 20 | 39% |
| Borderline Personality Disorder | 6 | 12% | *1* | *3%* | 28 | 55% |
| Bipolar Disorder | 6 | 12% | *1* | *3%* | 22 | 43% |
| Obsessive Compulsive Disorder | 5 | 10% | *1* | *3%* | 41 | 80% |
| Don’t know | 3 | 6% | *1* | *3%* | 0 | 0% |
| Alcohol Problems | 2 | 4% | *1* | *3%* | 18 | 35% |
| Personal Development | 0 | 0% | *6* | *19%* | 0 | 0% |
| Substance Use | 1 | 2% | *0* | *0%* | 18 | 35% |
| Non-psychotic perinatal affective disorders | 0 | 0% | *0* | *0%* | 7 | 14% |
| Other: (see line below) | 9 | 18% | *6* | *19%* | 4 | 8% |
| Other: Dissociative Identity Disorder, Other Personality disorders, Emetophobia, OCPD, Perfectionism, ADHD, PTSD, Attachment problem, Neurodevelopmental disorder, Bereavement counselling, Couples counselling, Life event adjustment, Reject diagnostic categories. |
| **Satisfaction with Therapy**  |
| Very Satisfied | 10 | 20% | *5* | *16%* | 9 | 18% |
| Somewhat Satisfied | 19 | 37% | *17* | *55%* | 36 | 71% |
| Neither Satisfied nor Dissatisfied | 4 | 8% | *3* | *10%* | 1 | 2% |
| Somewhat Dissatisfied | 6 | 12% | *3* | *10%* | 5 | 10% |
| Very Dissatisfied | 11 | 22% | *3* | *10%* | 0 | 0% |
| **Satisfaction with information received about Therapy** |  |   |   |
| Very Satisfied | 7 | 14% | *5* | *16%* |  |   |
| Somewhat Satisfied | 15 | 29% | *13* | *42%* |  |   |
| Neither Satisfied nor Dissatisfied | 5 | 10% | *6* | *19%* |  |   |
| Somewhat Dissatisfied | 8 | 16% | *5* | *16%* |  |   |
| Very Dissatisfied | 16 | 31% | *2* | *6%* |  |   |

**\*** “Other” represents categories where there were 2 or fewer participants in each group.

**EDAPTS Appendix D**

**Sample quotes from comments in Round 2 and Round 3**

|  |
| --- |
| ***Validity of Concept*** |
| “By all means inform people that therapy can open the door to all these situations as part of a consent process for treatment but to say that these experiences are adverse is to miss the point of therapy completely.”- Expert by Experience“My problem with all of above is that I read them as risk factors only if working with a poor-quality therapist. With a good well-trained therapist, they are adverse effects that may be experienced but should both be shared immediately and satisfactorily dealt with. So they may occur as the natural impact of the therapy but if they persist or become pathological then THAT is the problem not the adverse effects themselves.” -Expert by Experience“This is tricky! I think the basics should be clearly set […] but this need not be listed as an adverse effect as such, just made very clear from the start and not left ambiguous at all. […] A lot of adverse effects occur when things have already gone wrong and trust is broken so that is why certain things need to be made very clear early on and it is important the patient has a safety and support network in place BEFORE starting therapy- like the therapist already has.” -Expert by Experience “Impossible to distinguish these 'potential effects' from the symptoms that might drive one to seek therapy anyway. Therapy might intensify all of these feelings, but that need not be harmful, if the feelings are properly heard and understood by the therapist.” -Expert by Experience“Many of the issues listed here are likely to occur in therapy, but they should not be considered adverse effects, indeed if they did not occur it is hardly likely that therapy would be beneficial.” - Professional“I think it's important to stress that these are POTENTIAL adverse effects, and that they may not apply to all people, and that the experience of therapy is extremely individual. I am a little concerned about a nocebo effect, I guess.” -Both professional and personal experience |
| ***Inappropriateness of Rating System*** |
| “I found it difficult to rate these symptoms in terms of how important they are to be recognised- all of them are important if a patient is experiencing them, however I am not sure that some of them are experienced by many patients, such as bewilderment or catatonia. Some of the symptoms would be extremely concerning if they are regularly found to be experienced by patients, and would indicate significant problems in the quality of the therapy being provided, such as being invalidated or judged.” -Professional“I think it's difficult to rate these in terms of 'importance', rather, my responses are more reflective of the extent to which I agree these may be adverse effects of psychological therapy. Some of these things are just facts that are good to know about, much of these statements are not outwith the realms of possibility (e.g. abuse by therapist) but realistically I don't feel they are adverse effects, like you might have a side effect list on medication.” - Both professional and personal experience“Some 'Of little importance' selections based on imagining low probability of event, and weighing that up against adverse consequence of suggesting fear-inducing consequence where the event is unlikely.” -Professional  |
| ***Concern about use of a list*** |
| “Some of these feelings/consequences are not things that 'should' occur in therapy- it is more a sign of something gone wrong and I would think/hope are extremely rare (many I have had no experience of whatsoever). To tell people some of these things are possible consequences of therapy would be very alarming and in my opinion, would not be a realistic outcome of therapy.” -Expert by Experience“There are some enormously important considerations here, but I'm not clear what would be done with them. To have these on some kind of list, and to be giving that list to an anxious and vulnerable person, would – I believe – be wildly unhelpful. However, for therapists to be aware of these potential outcomes, and to be encouraged to bear them in mind and explore them: \*that\* would be brilliant.” -Professional“The items on this list seem to me more like ‘let your doctor know if any of these occur’.” -Expert by Experience |

**EDAPTS Appendix E**

**Post hoc analyses**

**E1: Gender**

There were no male expert by experience responders in Round 2, and so an exploratory analysis of gender difference in the “both” group was carried out to review whether male (n=7) and female (n=7) responders rated items similarly or differently in Round 2. This analysis is not intended to account for the lack of a male voice in the experts by experience group, rather provide some context of the potential differences between male and female responders. Differences (with a p value <.05) were identified foR20 of 147 items (14%) items- see table F1 for a list of items. Where there was a statistically significant difference, male responders were more conservative about what to include, with lower ratings of importance compared to female responders on all but one item; “Feeling like one is being manipulated in therapy”. The samples however are small and the results of this analysis are likely underpowered.

**Table E1; Items with statistically significant different rating by gender**

|  |  | **Round 2** |
| --- | --- | --- |
|  | Included/ Excluded | Z score | P value | Rated as more NB by |
| Therapy can highlight maintaining factors that cannot be changed (that is, factors that contribute to mental health difficulties)  | Included R2 | 2.08 | 0.04 | female |
| Increased frequency or intensity; distress | Included R2 | 2.97 | 0.00 | female |
| Anxiety during exposure tasks | Included R2 | 2.41 | 0.02 | female |
| Feeling like one is being manipulated in therapy | Excluded R2 | -2.42 | 0.02 | male |
| Therapy leading to a realisation that one is no longer a strong person | Excluded R2 | 1.96 | 0.05 | female |
| Fearing that there may be consequences for child protection/benefits | Excluded R3 | 2.12 | 0.03 | female |
| Practical barriers, such as childcare etc. can affect attendance, therapist might think this is a sign that one doesn't want therapy | Excluded R2 | 2.69 | 0.01 | female |
| Finding it difficult to maintain own boundaries- the therapist has the power | Excluded R3 | 2.35 | 0.02 | female |
| Therapy involves creating a bond that will be severed; fear of being left again/abandoned | Included R2 | 2.26 | 0.02 | female |
| Therapy has articulated problems but did not provide tools to cope/change things | Excluded R3 | 2.04 | 0.04 | female |
| Worrying about therapist's opinion | Excluded R3 | 2.71 | 0.01 | female |
| False sense of success when therapy ended- still struggling with difficulties | Excluded R3 | 2.66 | 0.01 | female |
| Therapy requires huge effort at a time of vulnerability | Included R2 | 2.77 | 0.01 | female |
| Feeling vulnerable; in session, all day after therapy and between sessions | Included R2 | 2.06 | 0.04 | female |
| Changes made as a result of therapy can cause conflict at work, for example, expressing negative emotions | Excluded R3 | 3.11 | 0.00 | female |
| Therapy is at an inconvenient location | Excluded R2 | 1.99 | 0.05 | female |
| Time is required; for sessions, to recover, to do homework etc. | Excluded R3 | 2.06 | 0.04 | female |
| Relationships change as gaining new insight into negative relationships | Included R2 | 2.73 | 0.01 | female |
| Relationships change as own behaviour changed, for example, became more assertive | Included R2 | 2.71 | 0.01 | female |
| One's interactions with people are affected if they were discussed in therapy, for example, feeling anger about past events | Included R2 | 3.03 | 0.00 | female |

**E2; Participant status**

The pre-registered protocol (registered on Open Science Framework; <https://osf.io/tyxk2/>) specified a Wilcoxon rank-sum test foR2 independent groups. The high proportion of participants that identified as having both personal and professional experience was not anticipated. There is little evidence to identify whether personal experience or professional training has more influence on opinions about therapy and it was decided to categorise those with experiences of both in the professional group for the primary analysis. Given the lack of empirical support for this decision, an exploratory analysis was carried out to investigate the impact of considering the ‘both’ category as a third independent group. A Kruskal Wallis test was chosen in place of Wilcoxon rank-sum test to identify any differences in ratings between the 3 distinct participant groups. Where a statistically significant difference of p>.05 was found, the Dunn test was used post hoc to identify where this difference lay.

Differences were identified for 11 of the 147 (7%) items in Round 2, and 8 of the 41 (20%) items included in Round 3 (see table F2 for details). This represents less difference between the 3 groups compared with the dichotomous expert by experience/professional analysis, which identified differences for 10% and 32% of items respectively. As seen in table F2, the rating by the ‘both’ group was between the professional only and expert by experience groups for 13 items, indicating that the opinions of people in the both category tended to be less conservative than the professional only group, but more conservative than the expert by experience group. Differences were identified for 4 items which were not rated differently in the original analysis; 3 were rated as more important by the both group; “increased anxiety/fear/panic/worry”, “increased distress”, and “increased guilt/shame”. The 4th item, ‘becoming self-absorbed’, was rated as most important by the expert by experience group. As in the original analysis, the expert by experience group were more likely to rate items as more important, and the professionals did not rate any items as more important, compared to the other groups.

**Table E2; Items with statistically significant different rating by group status**

|  |  |  | Difference (p> 0.05) |  |
| --- | --- | --- | --- | --- |
|  |  | Included/ Excluded | Prof v EBE | Prof v Both  | EBE v Both  | Order of rating from most NB to least |
| **Round 2** |  |  |  |  |  |
|  | Pathologising own behaviour, for example, seeing own behaviour as abnormal | Excluded R3 | yes | - | - | EBE- Both- Prof |
|  | anxiety/fear/panic/ worry | Included R2 | - | yes | yes | Both - EBE -Prof |
|  | bewilderment/confusion | Excluded R3 | yes | - | yes | EBE - Both -Prof |
|  | bewilderment/confusion- *also Round 3* | ... | yes | - | yes | EBE - Both -Prof |
|  | Distress | Included R2 | - | yes | yes | Both - EBE -Prof |
|  | guilt/shame | Included R2 | yes | yes | - | Both - EBE -Prof |
|  | Feeling like one is being manipulated in therapy | Excluded R2 | yes | - | yes | EBE- Both-Prof |
|  | Therapy triggering a catatonic state  | Excluded R2 | yes | - | yes | EBE- Prof- Both |
|  | Own sense of self feels like it is determined by therapist's opinion | Included R3 | yes | - | - | EBE- Both-Prof |
|  | Own sense of self feels like it is determined by therapist's opinion- *also Round 3* | … | yes | - | yes | EBE- Prof- Both |
|  | Becoming self-absorbed | Excluded R2 | yes | - | - | EBE- Both-Prof |
|  | Feeling cheated and/or used in private practice | Excluded R2 | yes | - | yes | EBE- Both-Prof |
|  | At risk of financial exploitation | Excluded R2 | yes | - | - | EBE- Both-Prof |
| **Round 3** |  |  |  |  |  |
|  | Being preoccupied with ideas from therapy- Round 2 | Excluded R3 | yes | - | - | EBE- Both-Prof  |
|  | Emergence of new 'rules about what I should do' based on what therapist said | Excluded R3 | yes | - | yes | EBE- Both-Prof |
|  | Doubting own thoughts/feelings/responses | Excluded R3 | yes | yes | - | EBE- Both-Prof |
|  | Feeling under pressure to recall bad memories/emotions/give the right answers/improve | Excluded R3 | yes | - | yes | EBE-Prof- Both |
|  | Feeling unable to disagree/criticise the process as this will be perceived as denial | Excluded R3 | yes | yes | - | EBE- Both-Prof |
|  | Feeling vulnerable to negative things therapist says about oneself/one's past/family | Excluded R3 | yes | - | yes | EBE- Both-Prof |
|  | Round 2; EBE (n=31), Both (n= 17), Professional (n=14)Round 3; EBE (n=27), Both (n= 19), Professional (n=17) |