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Post-traumatic growth in mental health recovery: qualitative study

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Manuscripts

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3 **Post-traumatic growth in mental health recovery: qualitative study**
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Abstract

Objectives

Post-traumatic growth, defined as positive psychological change experienced as a result of the struggle with challenging life circumstances, is under-researched in people with mental health problems. The aim of this study was to develop a conceptual framework for post-traumatic growth in the context of recovery for people with psychosis and other severe mental health problems.

Design

Qualitative cross-sectional semi-structured interviews about personal experiences of mental health recovery.

Setting

England.

Participants

Participants were adults aged over 18 and: (i) living with psychosis and not using mental health services (n=21); (ii) using mental health services and from black and minority ethnic communities (n=21); (iii) underserved, operationalised as lesbian, gay, bisexual and transgender community or complex needs or rural community (n=19); or (iv) employed in peer roles using their lived experience with others (n=16). The 77 participants comprised 42 (55%) female and 44 (57%) White British.

Results

Components of post-traumatic growth were present in 64 (83%) of recovery narratives. Six superordinate categories were identified, consistent with a view that post-traumatic growth involves learning about oneself (Self-discovery) leading to a new sense of who one is (Sense of self) and one's relationship with life (Life perspective). Observable positively-valued changes comprise a greater focus on self-management (Wellbeing)

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2
3 and more importance being attached to relationships (Relationships) and spiritual or
4 religious engagement (Spirituality). Categories are non-ordered and individuals may
5 start from any point in this process.
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9 10 *Conclusions*

11
12 Post-traumatic growth is often part of mental health recovery. Changes are compatible
13 with research about growth following trauma, but with more emphasis on self-
14 discovery, integration of illness-related experiences and active self-management of
15 wellbeing. Trauma-related growth may be a preferable term in a mental health context.
16
17 Trauma-informed mental health care could use the six identified categories as a basis
18 for developing new approaches to supporting recovery.
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28 *Key words*

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30 Post-traumatic growth, mental health, recovery
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35 *Trial registration*

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37 Conducted as part of the NIHR NEON Study (ISRCTN11152837).
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Article summary

Strengths and limitations of this study

- This study reports findings from a substantial qualitative investigation of post-traumatic growth in people with psychosis and other severe mental health problems
- The purposive sampling involved under-researched groups, including people with mental health problems who do not use mental health services or who are underserved by mental health services
- The involvement of eight analysts from varied backgrounds including several with lived experience of mental ill-health increases the credibility of the data analysis
- Participants were self-selecting so the views of people who do not associate with the term 'recovery' may be under-represented
- Interviewing paired family members and mental health workers would have provided new perspectives on the findings

Introduction

Post-traumatic growth is a relatively new area of research. The concept was introduced twenty years ago,¹ and is defined as perceptions of 'positive psychological change experienced as a result of the struggle with highly challenging life circumstances'.² Other terms for this phenomenon have also been used, such as benefit-finding,³ both a coping profile and a coping outcome,⁴ and positive illusions.⁵ This range of terms points to the complexity of the phenomenon, with different theorists emphasising change in identity and narrative (i.e. the sense of self),⁶ change in eudaimonic wellbeing (i.e. subjective quality of life),⁷ and change in social/psychological resources (i.e. broadening response repertoires).⁸ However, there is broad consensus over five post-traumatic growth domains: improved relations with others; identification of new possibilities for one's life; increased perception of personal strengths; spiritual growth; and enhanced appreciation of life.²

Post-traumatic growth is now a well-established concept in relation to 'event trauma', i.e. experience of a single traumatic event. Post-traumatic growth is widely reported in relation to event trauma and it is associated with mental health outcomes, such as depression. However, the direction of relationships between PTG and depression are not consistent across studies. For example, post-traumatic growth was found to moderate the negative association with quality of life found for both depression and post-traumatic stress in 58 Norwegian survivors interviewed two and six years after the 2004 Southeast Asia tsunami.⁹ Other studies have shown that post-traumatic growth is associated with a higher level of depression, such as a two-year follow-up study of 316 survivors of the L'Aquila earthquake in Italy.¹⁰ Similarly, higher post-traumatic growth was associated with lower post-traumatic stress disorder and higher

1
2
3 depression in 186 Iraqi students with an average of 13 war-related adversity
4 experiences.¹¹ There is some evidence of a curvilinear association between
5 depression and post-traumatic growth, for example two studies of assault survivors
6 (n=270 in total) found survivors with low or high post-traumatic growth reported more
7 symptoms of post-traumatic stress (both studies) and depression (one study) than
8 those with intermediate growth levels.¹² Longitudinal research is needed to fully
9 understand how reports of post-traumatic growth interact with depression in the
10 recovery from event trauma.
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24 Post-traumatic growth has relevance to health care, for example liver transplantation¹³
25 and stroke.¹⁴ There are several reasons why post-traumatic growth may also be
26 relevant to psychosis and other severe mental health problems.¹⁵ First, abuse
27 incidence is high. In particular, childhood adversity is strongly associated with
28 increased risk of psychosis. A meta-analysis of 18 case-control studies (n=2,048
29 psychosis, n=1,856 controls), 10 prospective studies (n=41,803) and 8 population-
30 based cross-sectional studies (n=35,546) found significant associations between
31 adversity and psychosis across all designs (OR2.78, 95%CI 5 2.34–3.31).¹⁶ Second,
32 comorbid depression, which is implicated in post-traumatic growth, is common. For
33 example, around 50% of people with a diagnosis of schizophrenia also experience
34 depression.¹⁷ Third, both the experience of psychosis itself and the consequent
35 experiences of societal discrimination and re-traumatisation caused by mental health
36 system responses^{18, 19} may generate trauma. Finally, some people with personal
37 experience of psychosis report post-traumatic growth.^{20, 21}
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3 There is strong evidence that positive changes can be experienced after first-episode
4 psychosis. A systematic review,²² published initially as a scoping review,²³ identified
5 40 studies involving 715 participants investigating the experience of positive change
6 after first episode psychosis. The review identified three levels of positive change.
7
8 Individual-level changes included new insights and self-understanding, new meaning
9 in life and changed values with a greater emphasis on the importance of others and
10 less on materialism and societal expectations. At the level of others, changes included
11 more importance attached to family and friends, more insight into who true friends
12 were, and a greater appreciation for the value of helping others. The third level of
13 change was spiritual, with increased levels of spirituality and religiosity, and more
14 positive religious experiences.
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31 There is only limited evidence about the frequency and types of post-traumatic growth
32 in people living long-term with psychosis and other severe mental illness
33 experiences.²⁴ A quantitative study of 121 people with severe mental illness using
34 community mental health rehabilitation centres in Israel found high levels of trauma,²⁵
35 and that meaning-making and coping self-efficacy mediated post-traumatic growth
36 experiences.²⁶ Three small (n=7,²⁷ n=7,²⁸ n=10²⁹) qualitative studies using
37 interpretative phenomenological analysis of semi-structured interviews all identify
38 themes of personal growth. Current evidence indicates that growth is integral to
39 recovery, and involves both restoration of existing aspects of identity and construction
40 of new aspects.³⁰
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56 The extent to which (a) the five growth processes identified from event trauma
57 research and (b) the more preliminary early psychosis-specific restorative and
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3 constructive identity processes are characterising the same changes is unknown.
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5 Integration of these two sources of evidence is needed, as is investigation of the
6
7 experiences of a broader range of people with long-term psychosis, including under-
8
9 researched groups. The aim of this study is to develop a conceptual framework for
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11 post-traumatic growth in the context of recovery for people with psychosis and other
12
13 severe mental health problems.
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19 **Methods**

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21 This research was undertaken as part of the NIHR Narrative Experiences Online
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23 (NEON) study (ISRCTN11152837, information at
24
25 <http://www.researchintorecovery.com/neon>) between March and August 2018. Ethical
26
27 Committee approval was obtained (Nottingham 2 REC 17/EM/0401). All participants
28
29 provided written informed consent.
30
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33

34 *Participants*

35
36 A purposive sample of under-researched populations took part. Inclusion criteria
37
38 common to all groups were: aged over 18; willing to discuss experiences; able to give
39
40 informed consent; and fluent in English.
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46
47 Group A (Outside the system) comprised people having had self-identified
48
49 experiences of psychosis and not using services. Psychosis experience prevalence
50
51 estimates in the general population range from 7%³¹ to 13%,³² yet lifetime rates of
52
53 psychosis, determined through contact with services, range from 0.2% (narrowly
54
55 defined criteria) to 0.7% (broadly defined).³³ The experience of the many individuals
56
57 who have psychosis without using services may therefore illuminate growth
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3 processes. Additional inclusion criteria for Group A were: self-identified lifetime
4 experience of psychosis; no use of secondary mental health services over the previous
5
6 five years.
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12 Group B (BAME) comprised people who identified as being from Black and Minority
13 Ethnic (BAME) populations. Ethnic minority groups often have problematic
14 relationships with services,³⁴ and research about recovery in these populations
15 identifies a strong emphasis on the post-traumatic growth concepts of
16 connectedness³⁵ and spirituality.³⁶ Additional inclusion criteria for Group B were:
17 currently using mental health services; Black, Asian and minority ethnic community
18 member.
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31 Group C (Under-served) comprised people who were not well engaged with mental
32 health services. This was operationalised for three under-served groups: people from
33 lesbian, gay, bisexual or trans (LGBT+) communities;³⁷ from rural communities;³⁸ or
34 with multiple complex health and social care needs.³⁹ Additional inclusion criteria for
35 Group C were: experience of mental health problems in previous 10 years; no or
36 mainly unsuccessful interactions with formal mental health services; member of
37 LGBT+ communities OR living in an area with less than 10,000 population OR
38 experience of at least two of homelessness, substance misuse issues or offending.
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51 Group D: (Peer) comprised people with experience of working in statutory or voluntary
52 roles for which lived experience is a requirement, e.g. peer support workers, trainers
53 or researchers. Addition inclusion criteria for Group D were: working in statutory or
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3 voluntary roles for which lived experience is an essential requirement; use their lived
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5 experience as a tool for engagement with other mental health service users.
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10 *Setting*

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12 Participants were recruited across England, with Groups A (Outside the system) and
13
14 B (BAME) primarily from London and Groups C (Under-served) and D (Peer) primarily
15
16 from the Midlands. Group A were recruited through primary care services support
17
18 groups, Hearing Voices Network, and online advertising. Group B were recruited
19
20 through community groups, a Recovery College and psychosis-specific secondary
21
22 mental health services. Group C were recruited through community networks,
23
24 voluntary sector organisations and secondary care mental health services. Group D
25
26 were recruited through community groups and secondary care mental health services.
27
28
29 Recruitment for all groups used snowball sampling.
30
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35 *Procedures*

36
37 A preliminary coding framework (Online Supplement 1) was developed in advance of
38
39 interviews, by merging existing post-traumatic growth dimensions identified in trauma
40
41 populations⁴⁰ and in previous studies of post-traumatic growth in psychosis.^{22, 23, 28}
42
43
44 The preliminary coding framework was intended to establish the link between existing
45
46 research and participant narratives, and comprised the code name, definition and
47
48 examples drawn from the source references. An 'Other' category was added to allow
49
50 the emergence of new themes.
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56 Interviews using a narrative approach were conducted by four researchers from
57
58 sociology, advocacy, public health and health psychology backgrounds. Each
59
60

1
2
3 participant took part in a 40-90 minute interview conducted in a health service or
4
5 community venue. The topic guide (shown in Online Supplement 2) asked the
6
7 participant to share their mental health and recovery experiences, as if it were a story,
8
9 with a beginning, a middle and an end, and to include some consideration of what
10
11 might happen in the future. Participants were remunerated (£20) for their time, and
12
13 given options to pause or discontinue if they became distressed. Interviews were
14
15 recorded, and pseudonymised transcripts were made after interviews. After the
16
17 interview the researcher wrote field notes, which were included in the analysis.
18
19 Interviews were conducted until theoretical saturation was achieved.
20
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26 *Analysis*

27
28 The four coders comprised three interviewers plus one non-interviewer with an
29
30 interdisciplinary background in sociology and mental health nursing. Thematic
31
32 analysis was undertaken using NVivo version 11.⁴¹ Coding was initially according to
33
34 the preliminary coding framework and informed by field notes, but coders remained
35
36 open to the identification of additional themes in the data. Coding involved
37
38 identification and allocation of text relating to the coding framework, enabling related
39
40 text to be grouped and compared, allowing identification of themes occurring within
41
42 and across sources. Regular discussions between analysts explored how themes of
43
44 post-traumatic growth were expressed and related to each other, allowing lower order
45
46 themes to be recognised.⁴² Each coder independently coded and compared the same
47
48 initial transcript. Remaining transcripts were then coded separately (25% per coder).
49
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56 The coding framework was then iteratively refined in meetings between the four
57
58 primary coders and a wider group of four other non-interviewer analysts with expertise
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3 in healthcare technologies, qualitative research, recovery research and clinical
4 psychology. Several of the interviewers, coders and analysts also had lived
5 experience of mental ill-health and recovery, to enhance the role of lived experience
6 in collection and analysis of data.⁴³ To enhance trustworthiness, an audit trail was
7 kept, and an interim coding framework is shown in Online Supplement 3. The
8 conceptual framework, i.e. the final coding framework, was agreed by all coders and
9 analysts.
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21 **Results**

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23 The sociodemographic and clinical characteristics of the 77 participants are shown in
24 Table 1.
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31 *Insert Table 1 here*
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34

35 Post-traumatic growth components were coded in 64 (83%) of the 77 transcripts. The
36 conceptual framework for post-traumatic growth in psychosis and other severe mental
37 health problems is summarised in Table 2 with a complete version including more
38 example coding in Online Supplement 4.
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49 *Insert Table 2 here*
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51 *Major themes*

52 *Self-discovery*

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3 The self-discovery theme involves a fuller and deeper understanding of oneself. This
4
5 involves the ability to access, accept and be mindful of difficult feelings:
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9

10 *...what was going on was an internal not an external thing. (B04)*
11
12
13

14 *...the key to everything isn't it, accessing your emotions, not running away from*
15
16 *them... (C19)*
17
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21 The resulting self-knowledge leads to greater authenticity and being less influenced
22
23 by the expectations of others
24
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27

28 *I feel like I know myself quite well, you know I can heal myself. (A08)*
29
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32

33 *When I discovered that freedom, that I didn't have to join the rat-race...that was*
34
35 *quite liberating... (B18)*
36
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39

40 Self-acceptance can arise from greater self-knowledge, by letting go of past difficulties
41
42 and developing self-compassion
43
44
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46

47 *It's all about self-accepting, getting to know me and it helped. (A17)*
48
49
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51 *The key word is accepting the situation that I was in, um, and being honest with*
52
53 *myself. (C03)*
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3 Alongside these processes, participants talked about the importance of taking, or
4 taking back, responsibility for one's own life
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10 *...that hit me like a, er, thunderbolt, knowing that, knowing I, that if I'm not going*
11 *to help myself, no one else will help me. And that was the beginning, really, of*
12 *my recovery. (B02)*
13
14
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18

19 *This was like taking a step back and looking at almost re-engineering life to*
20 *take into account self-care, self-preservation and also building myself up...*
21
22
23
24 (D08)
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27

28 *Sense of self*

29
30 The development of a more positive sense of self involved integration and valuing of
31 illness experiences. A repeated theme was pride in oneself as a person.
32
33
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35
36

37 *I believe in my self-worth these days...I must pat myself on the back. (A15)*
38
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41

42 *I think that's something I'm pretty proud of actually, that I just take people as*
43 *they are. (B21)*
44
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49 An important part of this pride was integrating experiences of mental ill-health so they
50 become an accepted part of one's sense of self.
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56 *You don't choose the issues that you've got but you can, you can make a choice*
57 *to change. (C04)*
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I am who I am because of what happened. (D04)

Some participants moved beyond accepting to positively valuing these experiences.

What they were calling symptoms that must be eradicated, were actually part of me and so I looked behind that and said that is where, that is where my creativity comes from. (A19)

I am still me but I am a different me and I am stronger. (D05)

Life perspective

Participants identified a new or renewed appreciation of, or gratitude about, aspects of life. For some this was a general sense of appreciation.

...I'm becoming one of those ridiculously ever hopeful, ever optimistic people who say there is hope, my life is a life that is about hope... (A08)

...I am alive, I appreciate that I am alive... (C19)

For others there was a new appreciation of support received from support groups, mental health services and workers.

...it [organisation] completely changed my view of life. (A11)

1
2
3 *Rehab and coming to <service name> changed my life, it's like <worker> got*
4
5 *me on a college course, it has been absolutely wonderful... (C18)*
6
7
8
9

10 The idea that suffering has been meaningful or worthwhile was expressed.
11
12
13

14 *Wow I see where I am and I go back to then and I just think 'you didn't go*
15
16 *through that in vain'. (A17)*
17
18
19

20 *...I suppose I am grateful, for want of another way of putting it, that I have lived*
21
22 *the life I have, I have had these experiences. (D04)*
23
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28 New connections with political consciousness or a survivor mission to ensure others
29 did not have similar bad experiences were identified by some participants, especially
30 in Group B.
31
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33
34

35 *...I could identify with more, kind of, politicised...the personal was political and*
36
37 *I was beginning to become aware of that on a deeper level. (B09)*
38
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41

42 *And then as I came back out it was just like no, I wanted to help...I've got stuff*
43
44 *I want to do, I want to help people... (B25)*
45
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51 *Wellbeing*

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53 The above psychological processes were complemented by a more active
54 engagement in managing wellbeing and lifestyle. A determination to stay well was
55 identified.
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...I swore from that day on, no man, money, love or beast would ever put me back into that situation again and I have stuck to it. (A15)

...I've been there, right there to the lowest of the low. And pulled myself back from it. And that's difficult to do. (C12)

This led to a greater engagement in wellbeing-related activities, including arts, music, sport, nature and learning

I think the art has given me great kind of, great kind of structure. (A01)

...I've just found learning to be so therapeutic and rewarding that I feel like I am at a point now where I can actually study and put my mind towards...doing something worthwhile. (B10)

Relationships

Many participants identified changes in relationships. For some this involved more actively choosing which relationships to continue, to re-start or to end

I got rid of this awful man in my life. (B06)

I needed to go back to a couple of my old primary school friends' houses and ask for their forgiveness for something. (B07)

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2
3 For others, the change was in the value placed on relationships with others.
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7
8 *...it's brought the incredible closeness with people with mental health with my,*
9
10 *with my immediate family and friends... (A03)*
11
12

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14 *It's been a process of learning that I needed, I need desperately, I desperately*
15 *needed family, you know, people I feel safe with, to be myself. (B09)*
16
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20
21 A greater ability to empathise with others was also identified.
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24

25
26 *So my purpose really is young people and even when I see the destruction that*
27 *young people are going through I never blame them, I said it stems from*
28 *somewhere... (A17)*
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35 *You have understanding, empathy...You really empathise. (B15)*
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40 All of these relationship processes informed a desire to give back, both by supporting
41 others in similar situations and by giving back to society. This code differs from the
42 survivor mission and mutuality sub-themes in its emphasis on giving as intrinsically
43 beneficial.
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50
51 *I just see myself as hopefully being a beacon to others who are, you know,*
52 *struggling, and others who are finding things difficult. (B02)*
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3 *I want to go on and help people if I can that have been through the same thing.*

4
5 (C18)
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10 *Spirituality*

11
12 Participants, especially in Group A, described a deeper engagement with spirituality,
13 religious and existential endeavours. For some, this was expressed as an enhanced
14 spiritual awareness.
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21 *Now I'm sort of growing older I know they're spirit animals, I still have them and*
22 *so it's the wolves that are the most powerful so I do feel protected by those.*

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26 (A18)
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30 *...as I went through that whole process it was like this massive opening, just*
31 *kind of spiritual opening again. (A10)*
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37 This was associated with new or renewed observable engagement in spiritual or
38 religious practices.
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44 *... I was sort of meditating and looking at the more spiritual aspects of my life*
45 *and...I was looking and seeking that help... (A08)*
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51 *...just pray, pray. (laughs) It works, do it, don't be scared. (C19)*
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55 **Discussion**

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3 Post-traumatic growth concepts were identified in 64 (83%) of the interviews with 77
4 diverse participants describing their mental health recovery. The six superordinate
5 categories are not ordered, but one narrative consistent with the results is that post-
6 traumatic growth involves learning about oneself (Self-discovery) leading to a new
7 sense of who one is (Sense of self) and one's relationship with life (Life perspective).
8 Observable positively-valued changes are a greater focus on self-management
9 (Wellbeing) and more importance being attached to relationships (Relationships) and
10 spiritual / religious engagement (Spirituality). Individuals may start from any point in
11 this narrative, so an alternative description would be that individuals experience a
12 change in their Life perspective, enabling an alternative Sense of self to be developed,
13 which facilitates new kinds of Self-Discovery. The conceptual framework is compatible
14 with the five growth processes identified in event trauma research, but participants
15 also experienced changes in (a) self-discovery, (b) sense of self, specifically including
16 integration of illness-related experiences into identity and (c) the importance they
17 attached to active self-management of well-being. Many participants were currently
18 struggling with adversity so the term 'post-traumatic' may need amending, perhaps to
19 'trauma-related'.
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44 The strengths of the study include the relatively large sample size for a qualitative
45 study, the purposive sampling of diverse and under-researched participant groups,
46 and the large analyst team (n=8) bringing multiple perspectives to enhance
47 trustworthiness of data analysis. Weaknesses include the limited geographical spread
48 mainly from two parts of England, an assumption that trauma was present and
49 therefore not coded for by analysts, and the absence of wider perspectives such as
50 paired family or mental health staff interviews. Identifying a change as positive was
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3 not always straightforward, so change experiences which in this study were not coded
4 as positive psychological change may merit further investigation. Examples which
5 were not coded as post traumatic growth include alternative methods of getting well,
6 escapism, knowing where to access support, cultural differences and environmental
7 factors. Recovering from 'trauma' was not the frame of reference used by many
8 participants in telling their stories, so this represents primarily a researcher framing of
9 experiences. Relatedly, the extent to which participants attributed changes to post-
10 traumatic growth, and the extent to which their formulations were derived from cultural
11 tropes, were not explored. An alternative analysis approach would have involved
12 inductive coding followed by comparison with existing research. Finally, the cross-
13 sectional coding inevitably abstracts from complex and contextualised stories, so may
14 not capture the ambivalent and conflicting perspectives common in narratives.
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33 This study provides further evidence that post-traumatic growth concepts are relevant
34 to many people living with psychosis and other severe mental health problems. The
35 concept of recovery in mental health has come to mean living as well as possible,
36 whether or not symptoms are present. Recovery thus differs from the traditional clinical
37 priorities of symptom remission and functional restoration,⁴⁴ and a systematic review
38 identified five recovery processes: Connectedness, Hope, Identity, Meaning and
39 Empowerment (CHIME Framework).³⁵ A mental health service orientation towards
40 supporting this understanding of recovery is recommended internationally,^{45, 46} and
41 central to national policy in many countries.⁴⁷⁻⁵⁰ A recovery orientation involves system
42 transformation⁵¹ requiring new clinical approaches including a greater emphasis on
43 supporting strengths,⁵²⁻⁵⁴ self-management,^{55, 56} hope,^{57, 58} and wellbeing,⁵⁹⁻⁶¹ more
44 use of new interventions such as positive psychology,^{62, 63} Recovery Colleges⁶⁴⁻⁶⁷ and
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3 peer support,^{68, 69} and a greater focus on human rights.^{70, 71} The current study supports
4 the case that trauma-informed approaches to mental health care should be added to
5 this list of recovery-supporting innovations.⁷²
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12 The conceptual framework provides a theoretical foundation for work to support post-
13 traumatic growth in mental health. Encouraging post-traumatic growth is an important
14 contribution to supporting recovery. For example, a study of post-traumatic growth and
15 recovery in 34 people experiencing first episode psychosis concluded that *'people with*
16 *early psychosis may benefit from disclosing their experiences of psychosis, including*
17 *those aspects that were traumatic, as this may support the processes of recovery and*
18 *post-traumatic growth'* (p.213).⁷³ A clinical implication is that it is important to reinforce
19 efforts by service users to find their own personally satisfactory meaning of their
20 experiences, rather than simply encouraging the adoption of a clinical explanatory
21 model. Similarly, supporting service users to engage in wellbeing self-management,
22 to actively choose relationships and to explore spiritual development should be a
23 significant clinical focus.
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42 The relationship between mental health recovery and post-traumatic growth is unclear,
43 as is the extent to which they are the same or overlapping but distinct phenomena.
44 Prospective longitudinal research is needed to investigate if there is a temporal
45 relationship between positive psychological change and development of an identity as
46 a 'person in recovery' for different clinical sub-populations, and how these change in
47 the context of crisis or relapse. The implications for mental health care processes also
48 need to be investigated, specifically identifying clinical sub-populations for whom a
49 post-traumatic growth approach is particularly indicated, and developing and
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3 evaluating manualised treatment approaches which support the identified positive
4 psychological changes. What is clear is that moving forward from severe mental health
5 problems is not simply a question of taking treatment as prescribed, but a far more
6 active process of engaging and re-engaging in the search for meaning for oneself,
7 learning to manage the demands of living well, and finding one's place in the world.
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Patient and Public Involvement statement

Patients were involved in acquisition of funding, both through a Lived Experience Advisory Panel informing the design and through involvement as applicants. Several interviewers and analysts had their own lived experience of mental ill-health and recovery, in addition to their professional training. The NEON Lived Experience Advisory Panel (LEAP) comprising ten members with lived experience of mental ill-health and recovery informed the ethics application, trained the interviewers, informed the topic guide and supported access to Group D. A LEAP member was involved in interpretation of the findings and as a co-author of this paper. The LEAP are leading the writing of a guide to sharing stories, which will be informed by this research.

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Competing interests statement

None declared

Author statement

MS and LB made a substantial contribution to the conception or design of the work. All authors contributed to the acquisition, analysis, or interpretation of data for the work. All authors were involved in drafting the work or revising it critically for important intellectual content, and gave final approval of the version to be published. All authors agree to be jointly accountable for all aspects of the work.

Data sharing statement

Data available from corresponding author.

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Table 1: Clinical and sociodemographic characteristics of participants (n=77)

| Characteristic | Total | Group A (Outside the system) | Group B (BAME) | Group C (Under- served) | Group D (Peer) |
|-------------------------------------|--------------|---|---------------------------|--|---------------------------|
| | n (%) | 77 (100) | 21 (27) | 21 (27) | 16 (21) |
| Gender n (%) | | | | | |
| Female | 42 (55) | 14 (67) | 11 (53) | 10 (42) | 9 (56) |
| Male | 30 (39) | 6 (29) | 9 (43) | 10 (47) | 6 (38) |
| Other / prefer not to say | 5 (6) | 1 (5) | 1 (5) | 1 (11) | 1 (6) |
| Ethnicity n (%) | | | | | |
| White British | 44 (57) | 12 (57) | 0 (0) | 11 (95) | 14 (88) |
| Black British | 5 (6) | 2 (10) | 3 (14) | 0 (0) | 0 (0) |
| Black African / Caribbean | 4 (5) | 1 (5) | 3 (14) | 0 (0) | 0 (0) |
| White Other | 5 (6) | 2 (10) | 1 (5) | 0 (0) | 2 (13) |
| White and Black African / Caribbean | 4 (5) | 0 (0) | 4 (19) | 0 (0) | 0 (0) |
| Asian / Mixed white Asian | 4 (5) | 0 (0) | 4 (19) | 0 (0) | 0 (0) |
| Other | 5 (6) | 2 (10) | 3 (14) | 0 (0) | 0 (0) |
| Prefer not to say | 6 (8) | 2 (10) | 3 (14) | 1 (5) | 0 (0) |
| Age (years) | | | | | |
| 18-25 | 4 (5) | 0 (0) | 0 (0) | 4 (16) | 1 (6) |
| 25-34 | 16 (21) | 3 (14) | 6 (29) | 4 (21) | 3 (19) |
| 35-44 | 16 (21) | 5 (24) | 4 (19) | 4 (21) | 3 (19) |
| 45-54 | 30 (39) | 8 (38) | 9 (43) | 4 (32) | 7 (43) |
| 55+ | 5 (6) | 4 (19) | 0 (0) | 1 (0) | 1 (6) |
| Prefer not to say | 6 (8) | 1 (5) | 2 (10) | 1 (11) | 1 (6) |
| Sexual orientation | | | | | |
| Heterosexual | 49 (64) | 15 (71) | 14 (67) | 10 (32) | 14 (88) |
| LGBT+ | 18 (23) | 3 (14) | 4 (19) | 4 (47) | 2 (13) |
| Prefer not to say | 10 (13) | 3 (14) | 3 (14) | 1 (21) | 0 (0) |
| Primary diagnosis | | | | | |
| Schizophrenia or other psychosis | 11 (14) | 5 (24) | 4 (19) | 1 (11) | 0 (0) |

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| Bipolar disorder / cyclothymia | 16 (21) | 8 (38) | 1 (5) | 4 (16) | 4 (25) |
| Mood disorder, e.g. anxiety, depression, dysthymia | 15 (19) | 1 (5) | 4 (19) | 4 (21) | 6 (38) |
| Other, e.g. ADHD, personality disorder, substance abuse, autism | 7 (9) | 0 (0) | 2 (10) | 4 (16) | 2 (13) |
| Prefer not to say | 28 (36) | 7 (33) | 10 (48) | 4 (37) | 4 (25) |

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Table 2: Final conceptual framework for post-traumatic growth in psychosis and other severe mental health conditions

| Type of growth | Definition of the positively perceived change |
|--------------------------------|---|
| 1. Self-discovery | Having a fuller and deeper understanding of oneself |
| 1.1 Emotional life | Discovering or re-discovering how to access, accept and be mindful of inner emotional life and difficult feelings |
| 1.2 Self-knowledge | Knowing oneself better, being more authentic and not being as shaped by the expectations of others |
| 1.3 Self-acceptance | Grieving and letting go of the past, and developing self-compassion |
| 1.4 Self-responsibility | Taking (back) responsibility for one's own life |
| 2. Sense of self | Development of a more positive sense of self, including integration and valuing of illness experiences |
| 2.1 Pride in self | Taking pride in oneself, including personal strengths and achievements |
| 2.2 Integration of experiences | Illness experiences become an accepted part of one's sense of self |
| 2.3 Valuing of experiences | Finding positives in the experience of illness |
| 3. Life perspective | New or renewed appreciation of or gratitude about aspects of life |
| 3.1 Appreciation of life | Appreciation for life and the importance of hopefulness |
| 3.2 Appreciation of support | Gratitude for support received from services |
| 3.3 Meaningful suffering | Gratitude that suffering was meaningful and not in vain |
| 3.4 Survivor mission | New growth of political consciousness or use of illness experiences to benefit others |
| 4. Wellbeing | More active engagement in, and management of, one's own wellbeing and lifestyle |
| 4.1 Motivation | Increased determined to stay well, self-manage and not return to a bad situation |
| 4.2 Being active | More engagement in the arts, music, sport, nature and learning |
| 5. Relationships | More actively choosing and valuing relationships with others |
| 5.1 Choosing relationships | Actively choosing relationships to continue, to re-start or to end |
| 5.2 Valuing relationships | Placing more value on relationships with others |
| 5.3 Empathy | Enhanced ability to empathise with others |
| 6 Spirituality | Deeper engagement with spirituality, religious and existential endeavours |
| 6.1 Spiritual awareness | Increased awareness of the presence of something greater than oneself making a positive contribution by providing meaning |
| 6.2 Spiritual engagement | New or renewed engagement with spiritual or religious practices, helping with meaning-making and providing comfort and security |

Online Supplement 1

Preliminary coding framework for post-traumatic growth in psychosis and other severe mental health conditions

| # | Code | Definition | Examples |
|----|----------------------|--|---|
| 1 | Strengths | New or improved use of personal strengths or resources | More resilience, confidence, self-efficacy, skills at navigating life challenges, inner strength, determination |
| 2 | Relationships | Improved relationships with others | Better connection with friends or family, new meaningful relationships |
| 3 | Purpose | New possibilities and purpose in life | Fresh directions, e.g. career, leisure pursuits; finding a place or role in society |
| 4 | Life appreciation | Greater or altered appreciation of life | Finding new meaning in experiences, seizing opportunities, finding new life purpose or direction |
| 5 | Spirituality | More engagement with spirituality or existential questions | New spiritual practice, (re-)connecting with an organised religion, deeper life meaning |
| 6 | Character | Developing positive character traits | More creativity, compassion for others |
| 7 | Lifestyle | Making positive lifestyle changes | Better sleep, more activity, healthier relationship with food / drink, developing new interests, choosing healthier relationships |
| 8 | Identity integration | Integration of experience of psychosis into identity | Psychosis experiences as shaping who the person is now, psychosis being part but not all of identity, more insight or clarity |
| 9 | Self-acceptance | More self-acceptance and awareness | More self-compassion, positive sense of self |
| 10 | Other | Other forms of post-traumatic growth not coded above | |

Online Supplement 2

NB The interview was in two parts. In Part 1 the participant was asked to tell their story of recovery. In Part 2, follow-up questions were asked about the impact of their stories on others. The topic guide for Part 1 did not change, and only data from Part 1 (i.e. the participant's open narrative) are reported in the current study.

Interview topic guide

START OF TOPIC GUIDE

Preparation

Before the participant arrives, allocate a unique identifier (UID) to the participant, and write it into a blank Informed Consent Form.

Introduction

- Introduce the interviewer facilitator
- Ensure the participant has read the information sheet and understands that participation is voluntary and that they are free to withdraw at any time
- Explain the aims and purpose of the activity and give a brief description of the interview structure. Tell the participant they can decide whether their story is used in the later part of the NEON study, emphasising that this may mean other people beyond the study team may see it.
- Provide an opportunity for participant to ask any questions, and then obtain written consent through the Informed Consent Form
- Describe digital recording of the interview. Clarify whether the participant wants to be video-recorded or audio-recorded.
- Turn on the recorder. Read out the UID so that it is recorded.

Questions

Part 1

Ask the participant to describe their own story of recovery. Do not use language (e.g. 'psychosis') which might be leading – refer to e.g. 'mental health difficulties'. Give them plenty of time, listen carefully. Reply if asked (e.g. "Is this okay?" – "Yes, you're doing great") and use minimal prompts if needed (e.g. "Do go on") but try to let the participant tell their story in their own words.

Part 2

Follow up with questions about the narrative, e.g.

1. Who have you shared your story with, and why?
2. What was the impact on the recipient and on you? If there was a particularly powerful part of their narrative, ask specifically about the impact of that part of their story.
4. Do you sometimes hold back some aspects of your story? If so, how do you decide what and when to hold back?

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3 3. Has anyone else shared a recovery narrative with you? What parts of someone
4 else's story made an impact? Why do you think that part made an impact?
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6 4. How has the way you have told your story changed over time? Why do you think
7 this is?
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10 *If the participant becomes distressed during the interview, ask if they would like to*
11 *take a break or stop. If the participant reveals information which is of concern and*
12 *may need reporting i.e. potential risks to another person or to themselves, or criminal*
13 *behaviour, then continue the interview if you feel comfortable to, but discuss these*
14 *with the PI at the earliest opportunity and where appropriate report accordingly.*
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17 **End of interview**

18 Explain the interview is now over and ask if the participant has any final questions.
19 Give information about timeline for the study and how publications can be accessed.
20 Thank the participant for their participation.
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24 **END OF TOPIC GUIDE**
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Online Supplement 3

Interim coding framework for post-traumatic growth in psychosis and other severe mental health conditions

| # | Code | Definition | Examples |
|----|----------------------|---|--|
| 1 | Strengths | New or improved recognition or use of personal strengths or resources | More resilience, confidence, self-efficacy, skills at navigating life challenges, inner strength, determination, positive character traits |
| 2 | Relationships | Improved relationships with others | Better connection with friends or family, new meaningful relationships, moving away from unhealthy relationships |
| 3 | Purposefulness | New possibilities and purpose in life | Fresh directions, e.g. career, leisure pursuits; finding a place or role in society, social or political activism. |
| 4 | Life appreciation | Greater or altered appreciation of or reflection on life | Fresh perspectives, new meaning-making framework. Finding new meaning in experiences, seizing opportunities, finding new life purpose or direction, new appreciation for informal or formal learning, new or different education or career development |
| 5 | Spirituality | More engagement with spirituality or existential questions | New spiritual practice, (re-)connecting with an organised religion, deeper life meaning |
| 6 | Self-discovery | Having a changed, fuller and deeper understanding of oneself and how to live in the world | More creativity, compassion for others, increased empathy for others, new skills |
| 7 | Lifestyle | Making positive lifestyle changes to maintain wellbeing and support self-care | Better sleep, more activity, healthier relationship with food / drink, developing new interests, choosing healthier relationships, changing social environment |
| 8 | Identity integration | Integration and sense-making of experience of mental health issues into identity | Mental health experiences as shaping who the person is now, psychosis or other mental health experiences being part but not all of identity, more insight or clarity, re-framing experiences, choosing other explanatory frameworks to make sense of experiences |
| 9 | Self-acceptance | More self-acceptance and self-compassion | More self-compassion, positive sense of self, less internalised stigma |
| 10 | Other | Other forms of post-traumatic growth not coded above | |

Online Supplement 4

Final conceptual framework for post-traumatic growth in psychosis and other severe mental health conditions

| Type of growth | Definition of the positively perceived change | Illustrative quotes |
|--------------------------|---|--|
| 1. Self-discovery | Having a fuller and deeper understanding of oneself | |
| 1.1 Emotional life | Discovering or re-discovering how to access, accept and be mindful of inner emotional life and difficult feelings | <p>But what I will say is that, er, I found that the, my, what was going on was an internal not an external thing. Because before that I, I've moved about nine times, I'd move, I'd just move somewhere else and thought it's going to be different now. At one point I moved to the States, you know? And I'd be in the same situation in the States that I'd be in England. (B04)</p> <p>There was just a point where I was just like I forgot how to feel, I forgot how to be hungry, I forgot how to feel tired, I forgot how to be exhausted, I forgot how to feel fear and then I realised oh my fuck I need to feel fear, you know, I need these things, these things are really fucking important, you know that a human being needs fear, we need tiredness, we need hunger...I moved to Hong Kong and it found me again and I realised it wasn't really my situation, it was me, it was something inside me that was drawing this energy towards me and there I, unless I changed the noise inside, the noise outside is never going to go away. (B25)</p> <p>And I think that is the key to everything isn't it, accessing your emotions, not running away from them, which a lot of people in mental suffering with mental health are trying to do because it is overwhelming and painful. So it is about yeah feeling and not feeling somebody else's or not, following somebody else and not being scared to be who you are and be different I think. (C19)</p> |

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| <p>1.2 Self-knowledge</p> | <p>Knowing oneself better, being more authentic and not being as shaped by the expectations of others</p> | <p>I feel like I know myself quite well, you know I can heal myself. And uh, these are things that people actually take for granted but took me a very long time to connect to how are you feeling you know and what do you want right now? (A08)</p> <p>I think you find out who you are and sort of how you have to live to keep yourself sane in a way. (A14)</p> <p>When I discovered that freedom, that I didn't have to join the rat-race of having a car, wife and three kids, you know, having a job, that was quite liberating... I was constrained by what people wanted me to do, instead of what I wanted to do. (B18)</p> <p>People or old friends that would say...you've got to stop being a bit like this, actually I would take that and think to myself am I? Am I a bit like that? And question what they've said and then if I thought well no actually I'm not like that anymore, you know, then I've turned around and said well actually, you know, that's wrong, you know, because that's, that's, that's not me and you can't tell me I am something if that's not what I am. You know, well you can but you know I'm not gonna listen to you. And uh you know by, by questioning uh what people was saying, uh sort of, uh, removed that vulnerability I think, and um, by removing vulnerability has allowed me to feel more in control of myself and um, who I am. (C03)</p> |
| <p>1.3 Self-acceptance</p> | <p>Grieving and letting go of the past, and developing self-compassion</p> | <p>I grieve all the hopes that are not there, you know things that haven't worked out, and I try to accept what is there and say well this is it, this is the thing that is real, maybe the other things were a little fantastical... And so I still talk to myself a lot but it's not now, it's, it's, it's me comforting myself and actually communicating with me, you know, just sort of, um it's that thing of having learned to love myself. (A08)</p> <p>I started going to loads of classical music concerts which I'd really shunned because I felt like I'd really failed as I'm not playing the violin anymore, I should be, I've really failed, I'm not good as the other people who have made it their profession. Suddenly I was like, God that doesn't matter, that is just so irrelevant, like classical music and music generally is so beautiful I just want to go and listen to it. (A10)</p> |

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| | | <p>It's all about self-accepting, getting to know me and it helped. (A17)</p> <p>I feel like I'm at peace with a lot of the, erm, depression that I felt over things that have happened in the past. (B01)</p> <p>The key word is accepting the situation that I was in, um, and being honest with myself. (C03)</p> |
| 1.4 Self-responsibility | Taking (back) responsibility for one's own life | <p>Yeah, because in my own mindset and recovery...I had to become interested in the problem because prior to that my outlook on recovery in mental health was based on seeing a Consultant Psychiatrist and they will have the answer because that is the predominant feeling, patient/doctor relationship, you see a doctor, you trust what they say and then I had to become interested after I realised that the doctors can't fix me. So when I became interested I became open to learning. (A21)</p> <p>The one thing he did when he came, when he saw, he said, 'I'm not going to help you do one thing in this flat unless you start doing it for yourself. If you make a start yourself, I will help you. If you don't do anything, I'm gone. And that hit me like a, er, thunderbolt, knowing that, knowing I, that if I'm not going to help myself, no one else will help me. And that was the beginning, really, of my recovery. (B02)</p> <p>Everything I do is like an attempt to rebuild my life but it's taken a long time. (B05)</p> <p>Maybe sometimes we need to go through that process, in order to think, I don't need to go back there, to where I was ten years ago, thinking about that experience anymore. But you can think about it, but have a different sort of attitude to it. (B06)</p> <p>I tend to be living the moment, that's part of my new self, this post-near death experience self is to really be living in the moment as much as possible, not worry about the future or churn over the past. (D04)</p> <p>This was like taking a step back and looking at almost re-engineering life to take into account self-care, self-preservation and also building myself up rather than saying rotten</p> |

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| | | stuff about myself and focusing on what I couldn't do and what I should do and should be able to do and all of that. (D08) |
| 2. Sense of self | Development of a more positive sense of self, including integration and valuing of illness experiences | |
| 2.1 Pride in self | Taking pride in oneself, including personal strengths and achievements | <p>I feel quite proud of my stability. (A01)</p> <p>I'm proud of that and that makes me feel better and enables me to operate...I've worked on myself throughout my life and I'm quite proud of that. (A12)</p> <p>I believe in my self-worth these days...I must pat myself on the back. (A15)</p> <p>Doing well, embracing who you are, loving who you are. Because I went through a long period of neglecting myself, my identity, my race, my culture. (B08)</p> <p>I think that's something I'm pretty proud of actually, that I just take people as they are. (B21)</p> <p>So yeah, I'm proud of where I've come, do you know what I mean, how far I've come, and that's what help, holds me from stopping and falling apart completely when I think about my daughter, and I get real mad sometimes...That knowing what I've got, and how I've achieved, and I don't want to lose it, cos when she comes to find me I want her to see that I've got these things, and that I'm not a complete arsehole living in a hostel, know what I mean? (C10)</p> |
| 2.2 Integration of experiences | Illness experiences become an accepted part of one's sense of self | That stuff has happened in my life and that is just how it has turned out. Um yeah, that is unfortunate but it is not going to define everything about me. (A07) |

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| | | <p>If there was a big red button on the table and somebody said would you like to switch off your diagnosis I would say no because I have accepted it now. Although it was horrid, it was horrible, I can't take anything away from that, but I have accepted that it has become part of my personality and I am happy with that and that's me. (A21)</p> <p>I think for a long time I was just existing with the mental health, getting to know, getting to understand it...Because there's very much negativity around it and I felt ashamed. (B06)</p> <p>You don't choose the issues that you've got but you can, you can make a choice to change. (C04)</p> <p>I am who I am because of what happened. (D04)</p> <p>The more I was able to make sense through telling my story of what had happened to me, it then started to have a meaning. (D11)</p> |
| 2.3 Valuing of experiences | Finding positives in the experience of illness | <p>I've had all these amazing experiences and you are just saying it's illness, I just didn't believe it...I feel that it's important and the messages I've got from being in an alternative reality have been extremely important. (A10)</p> <p>What they were calling symptoms that must be eradicated, were actually part of me and so I looked behind that and said that is where, that is where my creativity comes from. This is where, this is how I am able to take a photograph, this is how I am able, when I am sitting at a piano to think of a tune. (A19)</p> <p>Whereas before I felt ashamed to have these mental health issues, I now feel really proud in a way because I know that I can use it for good and I can make a difference in my community. (B01)</p> <p>There is a liberation that comes through all of this, a personal kind of yeah, not sure it's full blown self-actualisation, but it's somewhere up close to the top of the pyramid. (D04)</p> <p>I am still me but I am a different me and I am stronger. (D05)</p> |

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| | | I kind of thought that that was the best I could ever hope for and that was fine because I kind of really internalized my label of I am an anorexic, I am a you know a broken person who needs a lot of support and actually it was seeing the people who were talking about their lived experience with lots and lots of confidence and taking lots of responsibility and um being empowered to, to self-manage and use their difficulties in a really positive way which kind of opened my eyes to like gosh maybe I am more than my label, maybe I am, maybe I could do more than just function or survive, maybe I could thrive. (D014) |
| 3. Life perspective | New or renewed appreciation of or gratitude about aspects of life | |
| 3.1 Appreciation of life | Appreciation for life and the importance of hopefulness | <p>I suppose I've become one of those ridiculously, someone I thought I'd never be, I'm becoming one of those ridiculously ever hopeful, ever optimistic people who say there is hope, my life is a life that is about hope, I hope. (A08)</p> <p>I have kind of realised that I am not in a position to dictate the terms of life: "it should be like this and I expect this and why is it not like this". Just, I am alive, I appreciate that I am alive and that I have got so many hours each day to gain something from, some joy or some inspiration or blessings and gifts everywhere that I can and the number one thing is to just keep going, I am a mother and I have to keep going. (C19)</p> |
| 3.2 Appreciation of support | Gratitude for support received from services | <p>So it [organisation] completely changed my view of life. And it's a, it's a roller coaster, it's not like every day's joyous, things would dip, challenges still come in but I deal with them completely differently. Yeah it's like I've found happiness that I never knew existed. (A11)</p> <p>Rehab and coming to <service name 1> changed my life, it's like <worker> got me on a college course, it has been absolutely wonderful, it really has, I did a theatre group ... and through the rehab I got told about [inaudible] and I came down here <service name 2> and this place is amazing, the things they do here for anybody involved in sex work is absolutely amazing. (C18)</p> |
| 3.3 Meaningful suffering | Gratitude that suffering was | Wow I see where I am and I go back to then and I just think 'you didn't go through that in vain'. (A17) |

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| | meaningful and not in vain | <p>So I think I'm, I suppose I am grateful, for want of another way of putting it, that I have lived the life I have, I have had these experiences. (D04)</p> <p>And it's okay, because I wouldn't be where I was, had I not had the experiences that I've had. I don't know what sort of person I'd be, but I certainly wouldn't be where I, doing what I'm doing now. (D12)</p> |
| 3.4 Survivor mission | New growth of political consciousness or use of illness experiences to benefit others | <p><Organisation> is about re-framing mental illness as a possible catalyst for possible transformation, so and the aim is to give hope to as many people as possible through the power of story-sharing, so I'm really grateful and passionate about this. (A11)</p> <p>I just see myself as hopefully being a beacon to others who are, you know, struggling, and others who are finding things difficult. And they can, you know, refer to me [inaudible] support person and they can look at me and think 'He can make it through all the things that happened to him, then I can make it too'. (B02)</p> <p>I think it's really important to give back to society. And I think that's what I'm doing through my work. This new chapter I'm going to start, with women now. (B06)</p> <p>And so, you know, I felt like I was becoming something. Erm, I could identify with more, kind of, politicised...the personal was political and I was beginning to become aware of that on a deeper level. So, I thought right, that's it and, I'm going to set up my own thing. (B09)</p> <p>And then as I came back out it was just like no, I wanted to help, I wanted to do something, I wanted to use this story, I wanted to actually like you know... I wanted, that's when I started studying psychology and then I applied to go study in <place>...what's helped me recover was I find life, you know, I've got stuff I want to do, I want to help people, I want to, I want to do psychology. (B25)</p> <p>I've been looking forward to sharing my experience because um, by people sharing theirs has really helped me and you know, and that makes it feel like talking about it is a</p> |

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| | | <p>really worthwhile thing to do, because its gonna allow somebody else to grow, or just take a little bit from it that you know, it might benefit them or it might not, maybe they need to hear a different story but, you know, somebody might, you know, might hear it and think well I'm really pleased that I've heard that because that's, that's gonna help me. (C03)</p> <p>I guess in my recovery I tried to be that person for other people, the thing that I didn't have. (C04)</p> <p>And my journey through prostitution, uh so I can talk to people about it now. And that's what I want to do, I want to go on and help people if I can that have been through the same thing. (C18)</p> |
| 4. Wellbeing | More active engagement in, and management of, one's own wellbeing and lifestyle | |
| 4.1 Motivation | Increased determined to stay well, self-manage and not return to a bad situation | <p>The violence started again and I had two broken jaws, a broken nose, scars on my head and scars on my body, but the biggest scar was in my heart and in my mind. I ended up... being put into a secure unit this time and I was meant to be there for three months. It ended up being two weeks, becoming a voluntary patient for a year. Touch wood and whistle, I swore from that day on, no man, money, love or beast would ever put me back into that situation again and I have stuck to it. (A15)</p> <p>I started to take my medication, I got rid of this awful man in my life who was my daughter's father. Which was very liberating and, suddenly had an epiphany through all the craziness and thought, I don't want this in my life anymore. If I get rid of certain things it will decrease some of the stress. (B06)</p> |

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| | | <p>I have been that low. And that ill, I have been there and I have seen the light and...I have come back from it. I have actually come out of it, I've been there, right there to the lowest of the low. And pulled myself back from it. And that's difficult to do. (C12)</p> <p>When I came out of hospital I was like "I can't go back there again so I've got to sort myself out and I've got to build a better relationship with me and the girls", you know, they'd been through so much. (D05)</p> <p>Rather than just aimlessly sort of treading water and doing things that I felt I was sort of having to do or other people were you know were saying I should do you know sort of planning about things that actually I enjoyed. (D13)</p> |
| 4.2 Being active | More engagement in the arts, music, sport, nature and learning | <p>I think the art has given me great kind of, great kind of structure. (A01)</p> <p>I didn't go into that dangerous space again but I did meet a lot of like-minded people and I played my violin a lot and I decided I wanted to do something with my violin...I would get like a kind of vision of what my purpose was, what my true purpose was in my life and, it was like you know, playing the violin, teaching the violin, it was, which I hadn't been doing because I was working in admin but it just felt really strongly, that is what, it wasn't to do with competition it just felt like, that's the right direction for me to go in and I need to go more and more in that direction, it felt like, like it was connecting me to my soul purpose somehow. (A10)</p> <p>I am someone that struggles with relaxing. So, um, gym, I find that I am someone who has to go to the gym, I have to exercise, um and as ridiculous as it sounds, eating as well. You know like I am someone that needs to treat myself good. In order to be good in myself. (A14)</p> <p>So that was quite liberating and I didn't think that it would help my mental health without even realising, but I think it did, I did become a bit obsessed with jogging because it was something, I guess, a bit of a break from my children and the monotony of life and the difficult relationship I was in, and the difficulties I had. (B06)</p> |

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| | | <p>And erm, and I believe that I need to give more time, a bit more time to, to interests. You know, like, er, I love nature. Absolutely adore nature, it's one of the places I've always felt safe, I could go and sleep in forests, more than I could go and sleep in someone's house. (B09)</p> <p>I've been reading quite a lot and educating myself on schizo-affective disorder, plus all the things I've learned about meditation and that kind of thing I practice daily, and I've just found learning to be so rewarding and things, learning through recovery college as well, even though they do suggest reading up on your condition and that kind of thing. So I've just found learning to be so therapeutic and rewarding that I feel like I am at a point now where I can actually study and put my mind towards...doing something worthwhile. (B10)</p> <p>I play a lot of music, music is like my, it's my salvation. (B25)</p> <p>I could see my body changing and I felt stronger and I felt better and I stopped drinking for a month and I just felt amazing! (D05)</p> <p>It was also about sort of about finding activities that I enjoyed much more, rather than just aimlessly sort of treading water and doing things that I felt I was sort of having to do or other people were you know were saying I should do, you know, sort of planning about things that actually I enjoyed... One of the things I did was I joined the choir and you know it's one of [inaudible] gospel choir in South London for about, ever since I got there really and it's a very, very supportive environment, so that's been really critical and I've been able to sort of go there when I've been in every kind of mood state possible. (D13)</p> |
| 5. Relationships | More actively choosing and valuing relationships with others | |

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| <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23</p> <p>5.1 Choosing relationships</p> | <p>Actively choosing relationships to continue, to re-start or to end</p> | <p>He (counsellor) used a waiter analogy where the waiter is trying to please the clients but then more and more people come in and he is still trying to please them all but the quality of the food comes down and then people start complaining and then it is mad, so basically just concentrate on what you can do and don't try to please everybody...I also now try to mix with people who are just happy and positive and try to stay away from people who aren't. (A09)</p> <p>But you need the right quality of people around you, network, for you to be able to stay in your mental health, going forward. (B02)</p> <p>I got rid of this awful man in my life. (B06)</p> <p>I needed to go back to a couple of my old primary school friends' houses and ask for their forgiveness for something. (B07)</p> <p>I'd also come to realise before then that the relationship I was in was not quite what it was as he told me lots of things that were untrue that I discovered so I ended that as well and that was having a clean slate but it took me a long time to get literally over it. (B17)</p> |
| <p>24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46</p> <p>5.2 Valuing relationships</p> | <p>Placing more value on relationships with others</p> | <p>My children they come at the weekend I give them 100%. I give them 100% because I want to be giving them 100%. (A01)</p> <p>But then in another sense it's brought the incredible closeness with people with mental health with my, with my immediate family and friends so it has different angles. (A03)</p> <p>It's been a process of learning that I needed, I need desperately, I desperately needed family, you know, people I feel safe with, to be myself. And I needed people to help me normalise my feelings rather than be freaked out and hiding and terrified of expressing. (B09)</p> <p>Now I do feel a lot more stable than I did back then, and then when I go to these kinds of experiences you know, I've started to like, connections have become my thing because connections are what saved me from like, connections with people, a spiritual connection</p> |

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| | | <p>and this connection between people, there's interconnection between people is essentially what saves people...That power of coming together is so powerful, that is worth fighting for, worth dying for, it's worth me giving my time for. (B25)</p> <p>Having the friendship, the respect that built up over that in learning from each other, you know educated, talented, intelligent people. (C04)</p> |
| 5.3 Empathy | Enhanced ability to empathise with others | <p>I can empathise and I do empathise and I use empathy in my work a lot. (A12)</p> <p>So my purpose really is young people and even when I see the destruction that young people are going through I never blame them, I said it stems from somewhere...I knew what I went through as a young girl. I could have been a prostitute, I could have been on drugs, I didn't. Do you see what I'm saying? So therefore it's deep. (A17)</p> <p>You have understanding, empathy...You really empathise. (B15)</p> |
| 6. Spirituality | Deeper engagement with spirituality, religious and existential endeavours | |
| 6.1 Spiritual awareness | Increased awareness of the presence of something greater than oneself making a positive contribution by providing meaning | <p>Although the experiences were horrendous, and they were horrendous, there's no other way of describing the agony, it has been necessary because I couldn't do it on my own, so it still feels, and maybe this is just you know the spiritual aspect of my life but it still feels as though I do have like something watches over me and is helping me um and I survived. (A08)</p> <p>I kind of relived stuff and at the same time just physically I wanted to let go of loads of things, I just kind of clutter cleared my whole house, really cleaned it, I got rid of loads of bits and pieces that I didn't need any more and as I went through that whole process it was like this massive opening, just kind of spiritual opening again...I felt very very free, I felt like I was being guided with everything, I felt very, very spiritual. Um lots of things happened that were very healing I suppose, played a lot of music...when I relived it and</p> |

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| | | <p>the emotion that was associated my voice really did, like it changed, it kind of opened out and it became much more free and liberated and um at the same time I felt like I went into a completely different reality, it was really incredible, it was like intensely spiritual and a feeling that everything was connected and it was though lots of chakras opened or something happened in my body and my mind. (A10)</p> <p>Now I'm sort of growing older I know they're spirit animals, I still have them and so it's the wolves that are the most powerful so I do feel protected by those. Um and the other one is [inaudible] spiritual as well I always used to feel some [inaudible] egocentric, sort of like, wounds, [inaudible] kind of reaching out to people because I've always felt like I'm [inaudible] ever since I was really little which has why I have gone into mental health, to help people. (A18)</p> <p>But I think the longer deal is this, this, internal shift, they call it a psychic shift, an internal psychic shift, which is more about that spiritual experience and I don't know anything else that, that would work with me, do you know what I mean. And so, erm, since about 2009, that's what I've been kind of exploring in a, in a sort of ad hoc way. (B04)</p> <p>But when you kind of realise that there is something bigger than you, you start to realise don't hurt yourself, have more respect for yourself, and you also don't harm others in a sense, not but everything falls into place. The world has meaning, has greater meaning. (C19)</p> |
| 6.2 Spiritual engagement | New or renewed engagement with spiritual or religious practices, helping with meaning-making and providing comfort and security | <p>Like wow so I ran over to them and they kind of just guided me so I was just being guided by all of the spirits and stuff and they guided me up the hill into the woods. (A02)</p> <p>...was actually, uh, around all of this I was sort of meditating and looking at the more spiritual aspects of my life and you know, just looking for, I was looking and seeking that help and I was, I was meditating. It, it, it brought a lot of pain but I was looking at that. (A08)</p> |

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| | | <p>I became very um sort of what's the word, like spiritual as well. I found the church very comforting and kind of a place I would be, to trust and yeah, it just gave a sense of security for some reason. (A14)</p> <p>So, you know, if it wasn't, if it wasn't for yoga, my Buddhist practice and community, who get, who don't, who, who see that there's something valuable from raw emotion, that there's energy in raw emotion...My understanding of Buddhism had, had grown. Erm, I'd been introduced to it, to the practice of chanting [inaudible], to reveal your own courage and compassion and wisdom and create, create more humane connections with people. And, I thought it was amazing energy to, to nourish, 'cos it wasn't based on any gods or idols or who was, you know, who was, who was cool and who wasn't. It's universal. It's a universal truth....the long and short of it, Buddhist practice helped [laughs]. More harmonious with myself and other people. (B09).</p> <p>Every morning I put my hand on my heart and I pray and I meditate and I go into that space where it's myself...Now I feel like now I do feel a lot more stable than I did back then and then when I go to these kinds of experiences you know, I've started to like connections have become my thing because connections are what saved me from like, connections with people, a spiritual connection and this connection between people, there's interconnection between people is essentially what saves people. (B25)</p> <p>I was still a Quaker at this point so that was really helpful, so I would go each week to have silent worship and that was really good, I saw it as an opportunity to kind of pause and have my brain calm down and yeah that was really lovely. (C15)</p> <p>...think also a lot, mental health is to do with emotion, for me I can only find the emotional vocabulary within church. And many things that we are struggling with are deep spiritual psychic rooms and you can't find that power and that passion in a, in anything other than a spiritual context... So for me recovery is about spirituality, it is about God, that is me and that's what works for me, it might not be the same for everyone...just pray, pray. (laughs) It works, do it, don't be scared. (C19)</p> |
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SRQR Checklist

| No. | Topic | Item | Location in text |
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| | Title and abstract | | |
| S1 | Title | Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | Title |
| S2 | Abstract | Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | Abstract |
| | Introduction | | |
| S3 | Problem formulation | Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | Introduction |
| S4 | Purpose or research question | Purpose of the study and specific objectives or questions | Introduction last paragraph |
| | Methods | | |
| S5 | Qualitative approach and research paradigm | Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended | Methods Procedures paragraph 2 |
| S6 | Researcher characteristics and reflexivity | Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | Methods Procedures and Methods Analysis |
| S7 | Context | Setting/site and salient | Methods Setting |

| | | contextual factors | |
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| S8 | Sampling strategy | How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale | Methods Setting |
| S9 | Ethical issues pertaining to human subjects | Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | Methods paragraph 1 |
| S10 | Data collection methods | Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings | Methods Procedures and Online Supplement 2 |
| S11 | Data collection instruments and technologies | Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | Online Supplement 2 |
| S12 | Units of study | Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | Table 1 |
| S13 | Data processing | Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts | Methods Procedures last paragraph |
| S14 | Data analysis | Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale | Methods Analysis and Online Supplement 1 and 3 |

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| S15 | Techniques to enhance trustworthiness | Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale | Methods Analysis |
| | Results/findings | | |
| S16 | Synthesis and interpretation | Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | Results Major themes |
| S17 | Links to empirical data | Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | Results Category descriptions and Online Supplement 4 |
| | Discussion | | |
| S18 | Integration with prior work, implications, transferability, and contribution(s) to the field | Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | Discussion |
| S19 | Limitations | Trustworthiness and limitations of findings | Discussion paragraph 2 |
| | Other | | |
| S20 | Conflicts of interest | Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | Competing Interests statement |
| S21 | Funding | Sources of funding and other support; role of funders in data collection, interpretation, and reporting | Funding statement |

BMJ Open

Post-traumatic growth in mental health recovery: qualitative study of narratives

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| | |

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Manuscripts

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3 **Post-traumatic growth in mental health recovery: qualitative study of narratives**
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Abstract

Objectives

Post-traumatic growth, defined as positive psychological change experienced as a result of the struggle with challenging life circumstances, is under-researched in people with mental health problems. The aim of this study was to develop a conceptual framework for post-traumatic growth in the context of recovery for people with psychosis and other severe mental health problems.

Design

Qualitative thematic analysis of cross-sectional semi-structured interviews about personal experiences of mental health recovery.

Setting

England.

Participants

Participants were adults aged over 18 and: (i) living with psychosis and not using mental health services (n=21); (ii) using mental health services and from black and minority ethnic communities (n=21); (iii) underserved, operationalised as lesbian, gay, bisexual and transgender community or complex needs or rural community (n=19); or (iv) employed in peer roles using their lived experience with others (n=16). The 77 participants comprised 42 (55%) female and 44 (57%) White British.

Results

Components of post-traumatic growth were present in 64 (83%) of recovery narratives. Six superordinate categories were identified, consistent with a view that post-traumatic growth involves learning about oneself (Self-discovery) leading to a new sense of who one is (Sense of self) and appreciation of life (Life perspective). Observable positively-valued changes comprise a greater focus on self-management (Wellbeing) and more

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3 importance being attached to relationships (Relationships) and spiritual or religious
4 engagement (Spirituality). Categories are non-ordered and individuals may start from
5 any point in this process.
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9 10 *Conclusions*

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12 Post-traumatic growth is often part of mental health recovery. Changes are compatible
13 with research about growth following trauma, but with more emphasis on self-
14 discovery, integration of illness-related experiences and active self-management of
15 wellbeing. Trauma-related growth may be a preferable term for participants who
16 identify as having experienced trauma. Trauma-informed mental health care could use
17 the six identified categories as a basis for new approaches to supporting recovery.
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28 29 *Key words*

30 Post-traumatic growth, mental health, recovery
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35 36 *Trial registration*

37 Conducted as part of the NIHR NEON Study (ISRCTN11152837).
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Article summary

Strengths and limitations of this study

- This study reports findings from a substantial qualitative investigation of post-traumatic growth in people with psychosis and other severe mental health problems
- The purposive sampling involved under-researched groups, including people with mental health problems who do not use mental health services or who are underserved by mental health services
- The involvement of eight analysts from varied backgrounds including several with lived experience of mental ill-health increases the credibility of the data analysis
- Participants were self-selecting so the views of people who do not associate with the term 'recovery' may be under-represented
- Participants were not asked specifically about trauma experiences

Introduction

Post-traumatic growth is a relatively new area of research. The concept was introduced twenty years ago,¹ and is defined as perceptions of 'positive psychological change experienced as a result of the struggle with highly challenging life circumstances'.² Other terms for this phenomenon have also been used, such as benefit-finding,³ both a coping profile and a coping outcome,⁴ and positive illusions.⁵ This range of terms points to the complexity of the phenomenon, with different theorists emphasising change in identity and narrative (i.e. the sense of self),⁶ change in eudaimonic wellbeing (i.e. subjective quality of life),⁷ and change in social/psychological resources (i.e. broadening response repertoires).⁸ However, there is broad consensus over five post-traumatic growth domains: improved relations with others; identification of new possibilities for one's life; increased perception of personal strengths; spiritual growth; and enhanced appreciation of life.²

Post-traumatic growth is now a well-established concept in relation to 'event trauma', i.e. experience of a single traumatic event. Post-traumatic growth is widely reported in relation to event trauma and it is associated with mental health outcomes, such as depression. However, the direction of relationships between PTG and depression are not consistent across studies. For example, post-traumatic growth was found to moderate the negative association with quality of life found for both depression and post-traumatic stress in 58 Norwegian survivors interviewed two and six years after the 2004 Southeast Asia tsunami.⁹ Other studies have shown that post-traumatic growth is associated with a higher level of depression, such as a two-year follow-up study of 316 survivors of the L'Aquila earthquake in Italy.¹⁰ Similarly, higher post-traumatic growth was associated with lower post-traumatic stress disorder and higher

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3 depression in 186 Iraqi students with an average of 13 war-related adversity
4 experiences.¹¹ There is some evidence of a curvilinear association between
5 depression and post-traumatic growth, for example two studies of assault survivors
6 (n=270 in total) found survivors with low or high post-traumatic growth reported more
7 symptoms of post-traumatic stress (both studies) and depression (one study) than
8 those with intermediate growth levels.¹² Longitudinal research is needed to fully
9 understand how reports of post-traumatic growth interact with depression in the
10 recovery from event trauma.
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24 Post-traumatic growth has relevance to health care, for example liver transplantation¹³
25 and stroke.¹⁴ There are several reasons why post-traumatic growth may also be
26 relevant to psychosis and other severe mental health problems.¹⁵ First, abuse
27 incidence is high. In particular, childhood adversity is strongly associated with
28 increased risk of psychosis. A meta-analysis of 18 case-control studies (n=2,048
29 psychosis, n=1,856 controls), 10 prospective studies (n=41,803) and 8 population-
30 based cross-sectional studies (n=35,546) found significant associations between
31 adversity and psychosis across all designs (OR2.78, 95%CI 2.34–3.31).¹⁶ Second,
32 comorbid depression, which is implicated in post-traumatic growth, is common. For
33 example, around 50% of people with a diagnosis of schizophrenia also experience
34 depression.¹⁷ Third, both the experience of psychosis itself and the consequent
35 experiences of societal discrimination and re-traumatisation caused by mental health
36 system responses^{18,19} may generate trauma. Finally, some people with personal
37 experience of psychosis report post-traumatic growth.^{20,21}
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3 There is strong evidence that positive changes can be experienced after first-episode
4 psychosis. A systematic review,²² published initially as a scoping review,²³ identified
5 40 studies involving 715 participants investigating the experience of positive change
6 after first episode psychosis. The review identified three levels of positive change. The
7 individual-level change theme was developed by combining three sub-themes: insight
8 and clarity (e.g. reassessing one's life, realising who one's friends are, less emphasis
9 on materialism and societal expectations); personality, outlook and skills (e.g. more
10 authenticity, better able to handle stress, learning time management); and health,
11 lifestyle and interests (e.g. simpler life, new possibilities, better sleep habits). The
12 interpersonal-level change theme was developed by combining two sub-themes:
13 relationships with family and friends (improvements in communication, spending more
14 time together, letting go of unhealthy relationships) and place or role in society
15 (desiring to give back, challenging stigma in society). The religious or spiritual-level
16 theme examples were praying more, increased engagement in religious institutions
17 and positive religious experiences.
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40 There is only limited evidence about the frequency and types of post-traumatic growth
41 in people living long-term with psychosis and other severe mental illness
42 experiences.²⁴ A quantitative study of 121 people with severe mental illness using
43 community mental health rehabilitation centres in Israel found high levels of trauma,²⁵
44 and that meaning-making and coping self-efficacy mediated post-traumatic growth
45 experiences.²⁶ Three small (n=7,²⁷ n=7,²⁸ n=10²⁹) qualitative studies using
46 interpretative phenomenological analysis of semi-structured interviews all identified
47 themes of personal growth.
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3 The concept of recovery in mental health has come to mean living as well as possible,
4 whether or not symptoms are present. Recovery thus differs from the traditional clinical
5 priorities of symptom remission and functional restoration,³⁰ and a systematic review
6 identified five recovery processes: Connectedness, Hope, Identity, Meaning and
7 Empowerment (CHIME Framework).³¹ Current evidence indicates that growth is
8 integral to recovery, and involves both restoration of existing aspects of identity and
9 construction of new aspects.³²

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12 The extent to which (a) the five growth processes identified from event trauma
13 research and (b) the more preliminary early psychosis-specific restorative and
14 constructive identity processes are characterising the same changes is unknown.
15 Integration of these two sources of evidence is needed, as is investigation of the
16 experiences of a broader range of people with long-term psychosis, including under-
17 researched groups. The aim of this study is to develop a conceptual framework for
18 post-traumatic growth in the context of recovery for people with psychosis and other
19 severe mental health problems.

20 21 22 **Methods**

23 This research was undertaken as part of the NIHR Narrative Experiences Online
24 (NEON) study (ISRCTN11152837, information at
25 <http://www.researchintorecovery.com/neon>) between March and August 2018. Ethical
26 Committee approval was obtained (Nottingham 2 REC 17/EM/0401). All participants
27 provided written informed consent.

28 29 30 *Participants*

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3 A purposive sample of under-researched populations took part. Inclusion criteria
4 common to all groups were: aged over 18; willing to discuss experiences; able to give
5 informed consent; and fluent in English.
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12 Group A (Outside the system) comprised people having had self-identified
13 experiences of psychosis of sufficient frequency or duration that they identify as
14 someone with experience of psychosis, and not using services. Psychosis experience
15 prevalence estimates in the general population range from 7%³³ to 13%,³⁴ yet lifetime
16 rates of psychosis, determined through contact with services, range from 0.2%
17 (narrowly defined criteria) to 0.7% (broadly defined).³⁵ The experience of the many
18 individuals who have psychosis without using services may therefore illuminate growth
19 processes. Additional inclusion criteria for Group A were: self-identified lifetime
20 experience of psychosis; no use of secondary mental health services over the previous
21 five years.
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38 Group B (BAME) comprised people who identified as being from Black and Minority
39 Ethnic (BAME) populations. Ethnic minority groups often have problematic
40 relationships with services,³⁶ and research about recovery in these populations
41 identifies a strong emphasis on the post-traumatic growth concepts of
42 connectedness³¹ and spirituality.³⁷ Additional inclusion criteria for Group B were:
43 currently using mental health services; Black, Asian and minority ethnic community
44 member.
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56 Group C (Under-served) comprised people who were not well engaged with mental
57 health services. This was operationalised for three under-served groups: people from
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3 lesbian, gay, bisexual or trans (LGBT+) communities;³⁸ from rural communities;³⁹ or
4 with multiple complex health and social care needs.⁴⁰ Additional inclusion criteria for
5 Group C were: experience of mental health problems in previous 10 years; no or
6 mainly unsuccessful interactions with formal mental health services; member of
7 LGBT+ communities OR living in an electoral district area with less than 10,000
8 population OR experience of at least two of homelessness, substance misuse issues
9 or offending.

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21 Group D: (Peer) comprised people with experience of working in statutory or voluntary
22 roles for which lived experience is a requirement, e.g. peer support workers, trainers
23 or researchers. Additional inclusion criteria for Group D were: working in statutory or
24 voluntary roles for which lived experience is an essential requirement; use their lived
25 experience as a tool for engagement with other mental health service users.

26 27 28 29 30 31 32 33 34 35 *Setting*

36
37 Participants were recruited across England, with Groups A (Outside the system) and
38 B (BAME) primarily from London and Groups C (Under-served) and D (Peer) primarily
39 from the Midlands. Guidelines for recruitment are shown in Online Supplement 1.
40 Group A were recruited through primary care services support groups, Hearing Voices
41 Network, and online advertising. Group B were recruited through community groups,
42 a Recovery College and psychosis-specific secondary mental health services. Group
43 C were recruited through community networks, voluntary sector organisations and
44 secondary care mental health services. Group D were recruited through community
45 groups and secondary care mental health services. Recruitment for all groups used
46 snowball sampling.

Procedures

A preliminary coding framework (Online Supplement 2) was developed in advance of interviews, by collating existing post-traumatic growth dimensions identified in trauma populations⁴¹ and in previous studies of post-traumatic growth in psychosis.^{22,23,28} Duplicates were removed, dimension names were made consistent, and then thematic grouping of the dimensions was used to develop the preliminary coding framework, which was intended to establish the link between existing research and participant narratives, and comprised the code name, definition and examples drawn from the source references. An 'Other' category was added to allow the emergence of new themes.

Each participant took part in a 40-90 minute interview conducted in a health service or community venue. Interviews using a narrative approach were conducted by four researchers from sociology, advocacy, public health and health psychology backgrounds. The topic guide (shown in Online Supplement 3) asked the participant to share their mental health and recovery experiences, as if it were a story, with a beginning, a middle and an end, and to include some consideration of what might happen in the future. Participants were remunerated (£20) for their time, and given options to pause or discontinue if they became distressed. Interviews were recorded, and pseudonymised transcripts were made after interviews. After the interview the researcher wrote field notes, which were included in the analysis.

Analysis

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2
3 The four coders comprised three interviewers plus one non-interviewer with an
4 interdisciplinary background in sociology and mental health nursing. Thematic
5 analysis was undertaken using NVivo version 11.⁴² The study had a predetermined
6 focus on developing a conceptual framework starting from a synthesis of empirical
7 evidence derived from event trauma research as described above, which was then
8 developed through analysis of interview data. An approach akin to framework
9 analysis was adopted⁴³. Framework analysis involves applying *a priori* codes and
10 categories to qualitative data to explore specific questions of interest to the research
11 aims, with attention also paid to inductive analysis of data relating to topics which
12 were not anticipated in advance, and to responsive revision of the coding frame as
13 analysis progresses and in the light of regular discussion within the research team.
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30 Coding was initially according to the preliminary coding framework and informed by
31 emergent understandings captured by field notes, but coders remained open to the
32 identification of additional themes in the data. Coding involved identification and
33 allocation of text relating to the coding framework, enabling related text to be grouped
34 and compared, allowing identification of themes occurring within and across sources.
35 Regular discussions between analysts explored how themes of post-traumatic growth
36 were expressed and related to each other, allowing lower order themes to be
37 recognised.⁴⁴ Each coder independently coded and compared the same initial
38 transcript. Remaining transcripts were then coded separately (25% per coder).
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54 The coding framework was then iteratively refined in meetings between the four
55 primary coders and a wider group of four other non-interviewer analysts with expertise
56 in healthcare technologies, qualitative research, recovery research and clinical
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1
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3 psychology. Several of the interviewers, coders and analysts also had lived
4 experience of mental ill-health and recovery, to enhance the role of lived experience
5 in collection and analysis of data.⁴⁵ To enhance trustworthiness, an audit trail was
6 kept, and an interim coding framework is shown in Online Supplement 4. The
7 conceptual framework, i.e. the final coding framework, was agreed by all coders and
8 analysts.
9

19 **Results**

20 The sociodemographic and clinical characteristics of the 77 participants are shown in
21 Table 1.
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28 *Insert Table 1 here*

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33 Post-traumatic growth components were coded in 64 (83%) of the 77 transcripts. The
34 conceptual framework for post-traumatic growth in psychosis and other severe mental
35 health problems is summarised in Table 2 with a complete version including more
36 example coding in Online Supplement 5.
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44 *Insert Table 2 here*

48 *Major themes*

51 *Theme 1: Self-discovery*

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54 The self-discovery theme involves a fuller and deeper understanding of oneself. This
55 involves the ability to access, accept and be mindful of difficult feelings:
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5 ...what was going on was an internal not an external thing. (B04)
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10 ...the key to everything isn't it, accessing your emotions, not running away from
11 them... (C19)
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16
17 The resulting self-knowledge leads to greater authenticity and being less influenced
18 by the expectations of others
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23
24 *I feel like I know myself quite well, you know I can heal myself.* (A08)
25
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27

28 *When I discovered that freedom, that I didn't have to join the rat-race...that was*
29 *quite liberating...* (B18)
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35 Self-acceptance can arise from greater self-knowledge, by letting go of past difficulties
36 and developing self-compassion
37
38
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41

42 *It's all about self-accepting, getting to know me and it helped.* (A17)
43
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46
47 *The key word is accepting the situation that I was in, um, and being honest with*
48 *myself.* (C03)
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54 Alongside these processes, participants talked about the importance of taking, or
55 taking back, responsibility for one's own life
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3 *...that hit me like a, er, thunderbolt, knowing that, knowing I, that if I'm not going*
4 *to help myself, no one else will help me. And that was the beginning, really, of*
5 *my recovery. (B02)*
6
7
8
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10
11
12 *This was like taking a step back and looking at almost re-engineering life to*
13 *take into account self-care, self-preservation and also building myself up...*
14
15
16
17 (D08)
18
19

20 21 *Theme 2: Sense of self*

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23
24 The development of a more positive sense of self involved integration and valuing of
25 illness experiences. A repeated theme was pride in oneself as a person.
26
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31 *I believe in my self-worth these days...I must pat myself on the back. (A15)*
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35 *I think that's something I'm pretty proud of actually, that I just take people as*
36 *they are. (B21)*
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42 An important part of this pride was integrating experiences of mental ill-health so they
43 become an accepted part of one's sense of self.
44
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49 *You don't choose the issues that you've got but you can, you can make a choice*
50 *to change. (C04)*
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56 *I am who I am because of what happened. (D04)*
57
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3 Some participants moved beyond accepting to positively valuing these experiences.
4
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6

7
8 *What they were calling symptoms that must be eradicated, were actually part*
9
10 *of me and so I looked behind that and said that is where, that is where my*
11
12 *creativity comes from. (A19)*
13
14

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16
17 *I am still me but I am a different me and I am stronger. (D05)*
18
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21 *Theme 3: Life perspective*

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23
24 Participants identified a new or renewed appreciation of, or gratitude about, aspects
25
26 of life. For some this was a general sense of appreciation.
27
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31 *...I'm becoming one of those ridiculously ever hopeful, ever optimistic people*
32
33 *who say there is hope, my life is a life that is about hope... (A08)*
34
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38 *...I am alive, I appreciate that I am alive... (C19)*
39
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41

42 For others there was a new appreciation of support received from support groups,
43
44 mental health services and workers.
45
46
47

48
49 *...it [organisation] completely changed my view of life. (A11)*
50
51
52

53
54 *Rehab and coming to <service name> changed my life, it's like <worker> got*
55
56 *me on a college course, it has been absolutely wonderful... (C18)*
57
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1
2
3 The idea that suffering has been meaningful or worthwhile was expressed.
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6
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8 *Wow I see where I am and I go back to then and I just think 'you didn't go*
9 *through that in vain'. (A17)*
10
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12
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14 *...I suppose I am grateful, for want of another way of putting it, that I have lived*
15 *the life I have, I have had these experiences. (D04)*
16
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21 New connections with political consciousness or a survivor mission to ensure others
22 did not have similar bad experiences were identified by some participants, especially
23 in Group B.
24
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30 *...I could identify with more, kind of, politicised...the personal was political and*
31 *I was beginning to become aware of that on a deeper level. (B09)*
32
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36

37 *And then as I came back out it was just like no, I wanted to help...I've got stuff*
38 *I want to do, I want to help people... (B25)*
39
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44 *Theme 4: Wellbeing*

45 The above psychological processes were complemented by a more active
46 engagement in managing wellbeing and lifestyle. A determination to stay well was
47 identified.
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54 *...I swore from that day on, no man, money, love or beast would ever put me*
55 *back into that situation again and I have stuck to it. (A15)*
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...I've been there, right there to the lowest of the low. And pulled myself back from it. And that's difficult to do. (C12)

This led to a greater engagement in wellbeing-related activities, including arts, music, sport, nature and learning

I think the art has given me great kind of, great kind of structure. (A01)

...I've just found learning to be so therapeutic and rewarding that I feel like I am at a point now where I can actually study and put my mind towards...doing something worthwhile. (B10)

Theme 5: Relationships

Many participants identified changes in relationships. For some this involved more actively choosing which relationships to continue, to re-start or to end

I got rid of this awful man in my life. (B06)

I needed to go back to a couple of my old primary school friends' houses and ask for their forgiveness for something. (B07)

For others, the change was in the value placed on relationships with others.

1
2
3 *...it's brought the incredible closeness with people with mental health with my,*
4 *with my immediate family and friends... (A03)*
5
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10 *It's been a process of learning that I needed, I need desperately, I desperately*
11 *needed family, you know, people I feel safe with, to be myself. (B09)*
12
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17 A greater ability to empathise with others was also identified.
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21 *So my purpose really is young people and even when I see the destruction that*
22 *young people are going through I never blame them, I said it stems from*
23 *somewhere... (A17)*
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30 *You have understanding, empathy...You really empathise. (B15)*
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35 All of these relationship processes informed a desire to give back, both by supporting
36 others in similar situations and by giving back to society. This code differs from the
37 survivor mission and mutuality sub-themes in its emphasis on giving as intrinsically
38 beneficial.
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46 *I just see myself as hopefully being a beacon to others who are, you know,*
47 *struggling, and others who are finding things difficult. (B02)*
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52 *I want to go on and help people if I can that have been through the same thing.*
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56 (C18)
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Theme 6: Spirituality

Participants, especially in Group A, described a deeper engagement with spirituality, religious and existential endeavours. For some, this was expressed as an enhanced spiritual awareness.

Now I'm sort of growing older I know they're spirit animals, I still have them and so it's the wolves that are the most powerful so I do feel protected by those.
(A18)

...as I went through that whole process it was like this massive opening, just kind of spiritual opening again. (A10)

This was associated with new or renewed observable engagement in spiritual or religious practices.

... I was sort of meditating and looking at the more spiritual aspects of my life and...I was looking and seeking that help... (A08)

...just pray, pray. (laughs) It works, do it, don't be scared. (C19)

Discussion

Post-traumatic growth concepts were identified in 64 (83%) of the interviews with 77 diverse participants describing their mental health recovery, and no participants rejected the idea of post-traumatic growth. The six superordinate categories are not ordered, but one narrative consistent with the results is that post-traumatic growth

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3 involves learning about oneself (Self-discovery) leading to a new sense of who one is
4 (Sense of self) and one's appreciation of life (Life perspective). Observable positively-
5
6 valued changes are a greater focus on self-management (Wellbeing) and more
7
8 importance being attached to relationships (Relationships) and spiritual / religious
9
10 engagement (Spirituality). Individuals may start from any point in this narrative, so an
11
12 alternative description would be that individuals experience a change in their Life
13
14 perspective, enabling an alternative Sense of self to be developed, which facilitates
15
16 new kinds of Self-Discovery. The conceptual framework is compatible with the five
17
18 growth processes identified in event trauma research, but participants also
19
20 experienced changes in (a) self-discovery, (b) sense of self, specifically including
21
22 integration of illness-related experiences into identity and (c) the importance they
23
24 attached to active self-management of well-being. Many participants were currently
25
26 struggling with adversity so the term 'post-traumatic' may need amending, perhaps to
27
28 'trauma-related' for those who view their experiences as related to trauma.
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38 The strengths of the study include the relatively large sample size for a qualitative
39
40 study, the purposive sampling of diverse and under-researched participant groups,
41
42 and the large analyst team (n=8) bringing multiple perspectives to enhance
43
44 trustworthiness of data analysis. Weaknesses include the limited geographical spread
45
46 mainly from two parts of England, the absence of member-checking, not collecting
47
48 data on historical mental health service use by Group A participants, and an
49
50 assumption that trauma was present and therefore not asked about in interview
51
52 (allowing assessment of the extent to which participants framed their experiences as
53
54 'trauma'). Identifying a change as positive was not always straightforward, so change
55
56 experiences which in this study were not coded as positive psychological change may
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3 merit further investigation. These were not dissenting voices or competing accounts,
4
5 but statements about types of change which were not judged by analysts to be post-
6
7 traumatic growth. Examples which were not coded as post traumatic growth include
8
9 alternative methods of getting well, escapism, knowing where to access support,
10
11 cultural differences and environmental factors. Recovering from 'trauma' was not the
12
13 language or frame of reference used by many participants in telling their stories, so
14
15 this represents a researcher framing of experiences. However, many of the changes
16
17 identified by participants were clearly describing growth arising directly out of their
18
19 experiences. Relatedly, the extent to which participants attributed changes to post-
20
21 traumatic growth, and the extent to which their formulations were derived from cultural
22
23 understandings, were not explored. Our data are consistent with a view that the
24
25 development of trauma-informed mental health services, with consequent changes in
26
27 language and constructs used to describe experiences, will lead to an increase in
28
29 individuals using post-traumatic growth concepts in their own recovery narratives. An
30
31 alternative analysis approach would have involved wholly inductive coding followed by
32
33 comparison with existing research. This would be more applicable to an interview
34
35 study using a topic guide to assess previous experiences of trauma and identifying
36
37 specifically post-traumatic growth experiences, rather than the current topic guide
38
39 which was focussed on recovery narratives and did not specifically ask about previous
40
41 trauma experiences. The wide diagnostic spread of participants and high proportion
42
43 (36%) who preferred not to give a diagnosis could be seen as a limitation. The
44
45 standard health research approach would be to use a standardised assessment to
46
47 confirm research diagnosis, but recovery research tends to have a more trans-
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49 diagnostic focus. Finally, the cross-sectional coding inevitably abstracts from complex
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3 and contextualised stories, so may not capture the ambivalent and conflicting
4 perspectives common in narratives.
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10 This study provides further evidence that post-traumatic growth concepts may be
11 relevant to many people living with psychosis and other severe mental health
12 problems, including previously under-research groups. A mental health service
13 orientation towards supporting recovery is recommended internationally,^{46,47} and
14 central to national policy in many countries.⁴⁸⁻⁵¹ A recovery orientation involves system
15 transformation⁵² requiring new clinical approaches including a greater emphasis on
16 supporting strengths,⁵³⁻⁵⁵ self-management,^{56,57} hope,^{58,59} and wellbeing,⁶⁰⁻⁶² more
17 use of new interventions such as positive psychology,^{63,64} Recovery Colleges⁶⁵⁻⁶⁸ and
18 peer support,^{69,70} and a greater focus on human rights.^{71,72} The current study supports
19 the case that trauma-informed approaches to mental health care should be added to
20 this list of recovery-supporting innovations.⁷³
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38 The conceptual framework provides a theoretical foundation for work to support post-
39 traumatic growth in mental health. Encouraging post-traumatic growth is an important
40 contribution to supporting recovery. For example, a study of post-traumatic growth and
41 recovery in 34 people experiencing first episode psychosis concluded that '*people with*
42 *early psychosis may benefit from disclosing their experiences of psychosis, including*
43 *those aspects that were traumatic, as this may support the processes of recovery and*
44 *post-traumatic growth*' (p.213).⁷⁴ A clinical implication is that it is important to reinforce
45 efforts by service users to find their own personally satisfactory meaning of their
46 experiences, rather than simply encouraging the adoption of a clinical explanatory
47 model. Similarly, supporting service users to engage in wellbeing self-management,
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3 to actively choose relationships and to explore spiritual development should be a
4 significant clinical focus.
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10 The relationship between mental health recovery and post-traumatic growth is unclear,
11 as is the extent to which they are the same or overlapping but distinct phenomena.
12 Prospective longitudinal research is needed to investigate if there is a temporal
13 relationship between positive psychological change and development of an identity as
14 a 'person in recovery' for different clinical sub-populations, and how these change in
15 the context of crisis or relapse. The implications for mental health care processes also
16 need to be investigated, specifically identifying clinical sub-populations for whom a
17 post-traumatic growth approach is particularly indicated, and developing and
18 evaluating manualised treatment approaches which support the identified positive
19 psychological changes. What is clear is that moving forward from severe mental health
20 problems is not simply a question of taking treatment as prescribed, but a far more
21 active process of engaging and re-engaging in the search for meaning for oneself,
22 learning to manage the demands of living well, and finding one's place in the world.
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Patient and Public Involvement statement

Patients were involved in acquisition of funding, both through a Lived Experience Advisory Panel informing the design and through involvement as applicants. Several interviewers and analysts had their own lived experience of mental ill-health and recovery, in addition to their professional training. The NEON Lived Experience Advisory Panel (LEAP) comprising ten members with lived experience of mental ill-health and recovery informed the ethics application, trained the interviewers, informed the topic guide and supported access to Group D. A LEAP member was involved in interpretation of the findings and as a co-author of this paper. The LEAP are leading the writing of a guide to sharing stories, which will be informed by this research.

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None declared

Author statement

MS and LB made a substantial contribution to the conception or design of the work. MS, SRE, LB, JLB, DF, AH, GT, RM, KP, SP, AR, DR and ED contributed to the acquisition, analysis, or interpretation of data for the work. MS, SRE, LB, JLB, DF, AH, GT, RM, KP, SP, AR, DR and ED were involved in drafting the work or revising it critically for important intellectual content, and gave final approval of the version to be published. MS, SRE, LB, JLB, DF, AH, GT, RM, KP, SP, AR, DR and ED agree to be jointly accountable for all aspects of the work.

Data sharing statement

All data are included.

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Table 1: Clinical and sociodemographic characteristics of participants (n=77)

| Characteristic | Total | Group A (Outside the system) | Group B (BAME) | Group C (Under- served) | Group D (Peer) |
|-------------------------------------|--------------|---|---------------------------|--|---------------------------|
| n (%) | 77 (100) | 21 (27) | 21 (27) | 19 (25) | 16 (21) |
| Gender n (%) | | | | | |
| Female | 42 (55) | 14 (67) | 11 (53) | 10 (42) | 9 (56) |
| Male | 30 (39) | 6 (29) | 9 (43) | 10 (47) | 6 (38) |
| Other / prefer not to say | 5 (6) | 1 (5) | 1 (5) | 1 (11) | 1 (6) |
| Ethnicity n (%) | | | | | |
| White British | 44 (57) | 12 (57) | 0 (0) | 12 (95) | 14 (88) |
| Black British | 5 (6) | 2 (10) | 3 (14) | 0 (0) | 0 (0) |
| Black African / Caribbean | 4 (5) | 1 (5) | 3 (14) | 0 (0) | 0 (0) |
| White Other | 5 (6) | 2 (10) | 1 (5) | 0 (0) | 2 (13) |
| White and Black African / Caribbean | 4 (5) | 0 (0) | 4 (19) | 0 (0) | 0 (0) |
| Asian / Mixed white Asian | 4 (5) | 0 (0) | 4 (19) | 0 (0) | 0 (0) |
| Other | 5 (6) | 2 (10) | 3 (14) | 0 (0) | 0 (0) |
| Prefer not to say | 6 (8) | 2 (10) | 3 (14) | 1 (5) | 0 (0) |
| Age (years) | | | | | |
| 18-25 | 4 (5) | 0 (0) | 0 (0) | 4 (16) | 1 (6) |
| 25-34 | 16 (21) | 3 (14) | 6 (29) | 4 (21) | 3 (19) |
| 35-44 | 16 (21) | 5 (24) | 4 (19) | 4 (21) | 3 (19) |
| 45-54 | 30 (39) | 8 (38) | 9 (43) | 4 (32) | 7 (43) |
| 55+ | 5 (6) | 4 (19) | 0 (0) | 1 (0) | 1 (6) |
| Prefer not to say | 6 (8) | 1 (5) | 2 (10) | 1 (11) | 1 (6) |
| Sexual orientation | | | | | |
| Heterosexual | 49 (64) | 15 (71) | 14 (67) | 10 (32) | 14 (88) |
| LGBT+ | 18 (23) | 3 (14) | 4 (19) | 4 (47) | 2 (13) |
| Prefer not to say | 10 (13) | 3 (14) | 3 (14) | 1 (21) | 0 (0) |
| Primary diagnosis | | | | | |
| Schizophrenia or other psychosis | 11 (14) | 5 (24) | 4 (19) | 1 (11) | 0 (0) |

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| 3 | Bipolar disorder / cyclothymia | 16 (21) | 8 (38) | 1 (5) | 4 (25) |
| 4 | Mood disorder, e.g. anxiety, | 15 (19) | 1 (5) | 4 (19) | 6 (38) |
| 5 | depression, dysthymia | | | | |
| 6 | Other, e.g. ADHD, personality | 7 (9) | 0 (0) | 2 (10) | 2 (13) |
| 7 | disorder, substance abuse, autism | | | | |
| 8 | Prefer not to say | 28 (36) | 7 (33) | 10 (48) | 4 (25) |
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Table 2: Final conceptual framework for post-traumatic growth in psychosis and other severe mental health conditions

| Type of growth | Definition of the positively perceived change |
|--------------------------------|---|
| 1. Self-discovery | Having a fuller and deeper understanding of oneself |
| 1.1 Emotional life | Discovering or re-discovering how to access, accept and be mindful of inner emotional life and difficult feelings |
| 1.2 Self-knowledge | Knowing oneself better, being more authentic and not being as shaped by the expectations of others |
| 1.3 Self-acceptance | Grieving and letting go of the past, and developing self-compassion |
| 1.4 Self-responsibility | Taking (back) responsibility for one's own life |
| 2. Sense of self | Development of a more positive sense of self, including integration and valuing of illness experiences |
| 2.1 Pride in self | Taking pride in oneself, including personal strengths and achievements |
| 2.2 Integration of experiences | Illness experiences become an accepted part of one's sense of self |
| 2.3 Valuing of experiences | Finding positives in the experience of illness |
| 3. Life perspective | New or renewed appreciation of or gratitude about aspects of life |
| 3.1 Appreciation of life | Appreciation for life and the importance of hopefulness |
| 3.2 Appreciation of support | Gratitude for support received from services |
| 3.3 Meaningful suffering | Gratitude that suffering was meaningful and not in vain |
| 3.4 Survivor mission | New growth of political consciousness or use of illness experiences to benefit others |
| 4. Wellbeing | More active engagement in, and management of, one's own wellbeing and lifestyle |
| 4.1 Motivation | Increased determination to stay well, self-manage and not return to a bad situation |
| 4.2 Being active | More engagement in the arts, music, sport, nature and learning |
| 5. Relationships | More actively choosing and valuing relationships with others |
| 5.1 Choosing relationships | Actively choosing relationships to continue, to re-start or to end |
| 5.2 Valuing relationships | Placing more value on relationships with others |
| 5.3 Empathy | Enhanced ability to empathise with others |
| 6 Spirituality | Deeper engagement with spirituality, religious and existential endeavours |
| 6.1 Spiritual awareness | Increased awareness of the presence of something greater than oneself making a positive contribution by providing meaning |
| 6.2 Spiritual engagement | New or renewed engagement with spiritual or religious practices, helping with meaning-making and providing comfort and security |

Online Supplement 1

Guidelines for promotional material

All promotional material produced to support recruitment in NEON Phase 1, for both activities 1 and 2, will incorporate the following:

1. A summary of the objectives of the project as a whole, e.g.

“The NEON Study looks at whether experiencing online stories of personal recovery (‘recovery narratives’) told by peers improves quality of life for people with psychosis.”

2. A summary of the objectives of phase 1, e.g.

“The aim of phase one is to develop a theoretical understanding of how recovery narratives (personal stories of mental health problems and recovery) can be of benefit to other people with mental health problems.”

3. A summary of the group which the promotional material is aiming to recruit, e.g.

“We are seeking to recruit 30 participants who are working in statutory or voluntary roles where having lived experience of mental health problems is a requirements, and where sharing personal experiences is a normal part of the work of the role”

4. A summary of what participation would require, e.g.

“Each participant would engage in a single one-hour interview, where they will be asked to talk about their experience of recovery”.

5. The corporate identity of Nottinghamshire Healthcare NHS Foundation Trust (NHCT), as the project sponsor (e.g. see header of this document)

6. If this piece of recruitment is located in a site other than NHCT, then the corporate identity of the site where it is being conducted.

This will be either South London and Maudsley NHS Foundation Trust (SLAM) or East London NHS Foundation Trust (ELFT).

7. A mechanism to allow people to find out more information, e.g.

- An email address or telephone number
- An information page on the project website

8. Information about the funder and mechanism, e.g.

“This project has been funded by the National Institute of Health Research, as a Programme Grant for Applied Research (PGfAR)”

9. Information about approvals that have been received, e.g.

“This study has been reviewed and given favourable opinion by INSERT REC INFO and CONTACT INFO. The project has also been reviewed by the Health Research Authority, and by the Research and Innovation Team at Nottingham Healthcare NHS Foundation Trust, who are sponsoring the project.”

Online Supplement 2

Preliminary coding framework for post-traumatic growth in psychosis and other severe mental health conditions

| # | Code | Definition | Examples |
|----|----------------------|--|---|
| 1 | Strengths | New or improved use of personal strengths or resources | More resilience, confidence, self-efficacy, skills at navigating life challenges, inner strength, determination |
| 2 | Relationships | Improved relationships with others | Better connection with friends or family, new meaningful relationships |
| 3 | Purpose | New possibilities and purpose in life | Fresh directions, e.g. career, leisure pursuits; finding a place or role in society |
| 4 | Life appreciation | Greater or altered appreciation of life | Finding new meaning in experiences, seizing opportunities, finding new life purpose or direction |
| 5 | Spirituality | More engagement with spirituality or existential questions | New spiritual practice, (re-)connecting with an organised religion, deeper life meaning |
| 6 | Character | Developing positive character traits | More creativity, compassion for others |
| 7 | Lifestyle | Making positive lifestyle changes | Better sleep, more activity, healthier relationship with food / drink, developing new interests, choosing healthier relationships |
| 8 | Identity integration | Integration of experience of psychosis into identity | Psychosis experiences as shaping who the person is now, psychosis being part but not all of identity, more insight or clarity |
| 9 | Self-acceptance | More self-acceptance and awareness | More self-compassion, positive sense of self |
| 10 | Other | Other forms of post-traumatic growth not coded above | |

Online Supplement 3

NB The interview was in two parts. In Part 1 the participant was asked to tell their story of recovery. In Part 2, follow-up questions were asked about the impact of their stories on others. The topic guide for Part 1 did not change, and only data from Part 1 (i.e. the participant's open narrative) are reported in the current study.

Interview topic guide

START OF TOPIC GUIDE

Preparation

Before the participant arrives, allocate a unique identifier (UID) to the participant, and write it into a blank Informed Consent Form.

Introduction

- Introduce the interviewer facilitator
- Ensure the participant has read the information sheet and understands that participation is voluntary and that they are free to withdraw at any time
- Explain the aims and purpose of the activity and give a brief description of the interview structure. Tell the participant they can decide whether their story is used in the later part of the NEON study, emphasising that this may mean other people beyond the study team may see it.
- Provide an opportunity for participant to ask any questions, and then obtain written consent through the Informed Consent Form
- Describe digital recording of the interview. Clarify whether the participant wants to be video-recorded or audio-recorded.
- Turn on the recorder. Read out the UID so that it is recorded.

Questions

Part 1

Ask the participant to describe their own story of recovery. Do not use language (e.g. 'psychosis') which might be leading – refer to e.g. 'mental health difficulties'. Give them plenty of time, listen carefully. Reply if asked (e.g. "Is this okay?" – "Yes, you're doing great") and use minimal prompts if needed (e.g. "Do go on") but try to let the participant tell their story in their own words.

Part 2

Follow up with questions about the narrative, e.g.

1. Who have you shared your story with, and why?
2. What was the impact on the recipient and on you? If there was a particularly powerful part of their narrative, ask specifically about the impact of that part of their story.
4. Do you sometimes hold back some aspects of your story? If so, how do you decide what and when to hold back?

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3 3. Has anyone else shared a recovery narrative with you? What parts of someone
4 else's story made an impact? Why do you think that part made an impact?
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6 4. How has the way you have told your story changed over time? Why do you think
7 this is?
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10 *If the participant becomes distressed during the interview, ask if they would like to*
11 *take a break or stop. If the participant reveals information which is of concern and*
12 *may need reporting i.e. potential risks to another person or to themselves, or criminal*
13 *behaviour, then continue the interview if you feel comfortable to, but discuss these*
14 *with the PI at the earliest opportunity and where appropriate report accordingly.*
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17 **End of interview**

18 Explain the interview is now over and ask if the participant has any final questions.
19 Give information about timeline for the study and how publications can be accessed.
20 Thank the participant for their participation.
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24 **END OF TOPIC GUIDE**
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Online Supplement 4

Interim coding framework for post-traumatic growth in psychosis and other severe mental health conditions

| # | Code | Definition | Examples |
|----|----------------------|---|--|
| 1 | Strengths | New or improved recognition or use of personal strengths or resources | More resilience, confidence, self-efficacy, skills at navigating life challenges, inner strength, determination, positive character traits |
| 2 | Relationships | Improved relationships with others | Better connection with friends or family, new meaningful relationships, moving away from unhealthy relationships |
| 3 | Purposefulness | New possibilities and purpose in life | Fresh directions, e.g. career, leisure pursuits; finding a place or role in society, social or political activism. |
| 4 | Life appreciation | Greater or altered appreciation of or reflection on life | Fresh perspectives, new meaning-making framework. Finding new meaning in experiences, seizing opportunities, finding new life purpose or direction, new appreciation for informal or formal learning, new or different education or career development |
| 5 | Spirituality | More engagement with spirituality or existential questions | New spiritual practice, (re-)connecting with an organised religion, deeper life meaning |
| 6 | Self-discovery | Having a changed, fuller and deeper understanding of oneself and how to live in the world | More creativity, compassion for others, increased empathy for others, new skills |
| 7 | Lifestyle | Making positive lifestyle changes to maintain wellbeing and support self-care | Better sleep, more activity, healthier relationship with food / drink, developing new interests, choosing healthier relationships, changing social environment |
| 8 | Identity integration | Integration and sense-making of experience of mental health issues into identity | Mental health experiences as shaping who the person is now, psychosis or other mental health experiences being part but not all of identity, more insight or clarity, re-framing experiences, choosing other explanatory frameworks to make sense of experiences |
| 9 | Self-acceptance | More self-acceptance and self-compassion | More self-compassion, positive sense of self, less internalised stigma |
| 10 | Other | Other forms of post-traumatic growth not coded above | |

Online Supplement 5

Final conceptual framework for post-traumatic growth in psychosis and other severe mental health conditions

| Type of growth | Definition of the positively perceived change | Illustrative quotes |
|--------------------------|---|--|
| 1. Self-discovery | Having a fuller and deeper understanding of oneself | |
| 1.1 Emotional life | Discovering or re-discovering how to access, accept and be mindful of inner emotional life and difficult feelings | <p>But what I will say is that, er, I found that the, my, what was going on was an internal not an external thing. Because before that I, I've moved about nine times, I'd move, I'd just move somewhere else and thought it's going to be different now. At one point I moved to the States, you know? And I'd be in the same situation in the States that I'd be in England. (B04)</p> <p>There was just a point where I was just like I forgot how to feel, I forgot how to be hungry, I forgot how to feel tired, I forgot how to be exhausted, I forgot how to feel fear and then I realised oh my fuck I need to feel fear, you know, I need these things, these things are really fucking important, you know that a human being needs fear, we need tiredness, we need hunger...I moved to Hong Kong and it found me again and I realised it wasn't really my situation, it was me, it was something inside me that was drawing this energy towards me and there I, unless I changed the noise inside, the noise outside is never going to go away. (B25)</p> <p>And I think that is the key to everything isn't it, accessing your emotions, not running away from them, which a lot of people in mental suffering with mental health are trying to do because it is overwhelming and painful. So it is about yeah feeling and not feeling somebody else's or not, following somebody else and not being scared to be who you are and be different I think. (C19)</p> |
| 1.2 Self- | Knowing oneself | I feel like I know myself quite well, you know I can heal myself. And uh, these are things |

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| <p>knowledge</p> | <p>better, being more authentic and not being as shaped by the expectations of others</p> | <p>that people actually take for granted but took me a very long time to connect to how are you feeling you know and what do you want right now? (A08)</p> <p>I think you find out who you are and sort of how you have to live to keep yourself sane in a way. (A14)</p> <p>When I discovered that freedom, that I didn't have to join the rat-race of having a car, wife and three kids, you know, having a job, that was quite liberating... I was constrained by what people wanted me to do, instead of what I wanted to do. (B18)</p> <p>People or old friends that would say...you've got to stop being a bit like this, actually I would take that and think to myself am I? Am I a bit like that? And question what they've said and then if I thought well no actually I'm not like that anymore, you know, then I've turned around and said well actually, you know, that's wrong, you know, because that's, that's, that's not me and you can't tell me I am something if that's not what I am. You know, well you can but you know I'm not gonna listen to you. And uh you know by, by questioning uh what people was saying, uh sort of, uh, removed that vulnerability I think, and um, by removing vulnerability has allowed me to feel more in control of myself and um, who I am. (C03)</p> |
| <p>1.3 Self-acceptance</p> | <p>Grieving and letting go of the past, and developing self-compassion</p> | <p>I grieve all the hopes that are not there, you know things that haven't worked out, and I try to accept what is there and say well this is it, this is the thing that is real, maybe the other things were a little fantastical... And so I still talk to myself a lot but it's not now, it's, it's, it's me comforting myself and actually communicating with me, you know, just sort of, um it's that thing of having learned to love myself. (A08)</p> <p>I started going to loads of classical music concerts which I'd really shunned because I felt like I'd really failed as I'm not playing the violin anymore, I should be, I've really failed, I'm not good as the other people who have made it their profession. Suddenly I was like, God that doesn't matter, that is just so irrelevant, like classical music and music generally is so beautiful I just want to go and listen to it. (A10)</p> <p>It's all about self-accepting, getting to know me and it helped. (A17)</p> |

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| | | <p>I feel like I'm at peace with a lot of the, erm, depression that I felt over things that have happened in the past. (B01)</p> <p>The key word is accepting the situation that I was in, um, and being honest with myself. (C03)</p> |
| <p>1.4 Self-responsibility</p> | <p>Taking (back) responsibility for one's own life</p> | <p>Yeah, because in my own mindset and recovery...I had to become interested in the problem because prior to that my outlook on recovery in mental health was based on seeing a Consultant Psychiatrist and they will have the answer because that is the predominant feeling, patient/doctor relationship, you see a doctor, you trust what they say and then I had to become interested after I realised that the doctors can't fix me. So when I became interested I became open to learning. (A01)</p> <p>The one thing he did when he came, when he saw, he said, 'I'm not going to help you do one thing in this flat unless you start doing it for yourself. If you make a start yourself, I will help you. If you don't do anything, I'm gone. And that hit me like a, er, thunderbolt, knowing that, knowing I, that if I'm not going to help myself, no one else will help me. And that was the beginning, really, of my recovery. (B02)</p> <p>Everything I do is like an attempt to rebuild my life but it's taken a long time. (B05)</p> <p>Maybe sometimes we need to go through that process, in order to think, I don't need to go back there, to where I was ten years ago, thinking about that experience anymore. But you can think about it, but have a different sort of attitude to it. (B06)</p> <p>I tend to be living the moment, that's part of my new self, this post-near death experience self is to really be living in the moment as much as possible, not worry about the future or churn over the past. (D04)</p> <p>This was like taking a step back and looking at almost re-engineering life to take into account self-care, self-preservation and also building myself up rather than saying rotten stuff about myself and focusing on what I couldn't do and what I should do and should be</p> |

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| | | able to do and all of that. (D08) |
| 2. Sense of self | Development of a more positive sense of self, including integration and valuing of illness experiences | |
| 2.1 Pride in self | Taking pride in oneself, including personal strengths and achievements | <p>I feel quite proud of my stability. (A01)</p> <p>I'm proud of that and that makes me feel better and enables me to operate...I've worked on myself throughout my life and I'm quite proud of that. (A12)</p> <p>I believe in my self-worth these days...I must pat myself on the back. (A15)</p> <p>Doing well, embracing who you are, loving who you are. Because I went through a long period of neglecting myself, my identity, my race, my culture. (B08)</p> <p>I think that's something I'm pretty proud of actually, that just take people as they are. (B21)</p> <p>So yeah, I'm proud of where I've come, do you know what I mean, how far I've come, and that's what help, holds me from stopping and falling apart completely when I think about my daughter, and I get real mad sometimes...That knowing what I've got, and how I've achieved, and I don't want to lose it, cos when she comes to find me I want her to see that I've got these things, and that I'm not a complete arsehole living in a hostel, know what I mean? (C10)</p> |
| 2.2 Integration of experiences | Illness experiences become an accepted part of one's sense of self | <p>That stuff has happened in my life and that is just how it has turned out. Um yeah, that is unfortunate but it is not going to define everything about me. (A07)</p> <p>If there was a big red button on the table and somebody said would you like to switch off your diagnosis I would say no because I have accepted it now. Although it was horrid, it</p> |

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| | | <p>was horrible, I can't take anything away from that, but I have accepted that it has become part of my personality and I am happy with that and that's me. (A21)</p> <p>I think for a long time I was just existing with the mental health, getting to know, getting to understand it...Because there's very much negativity around it and I felt ashamed. (B06)</p> <p>You don't choose the issues that you've got but you can, you can make a choice to change. (C04)</p> <p>I am who I am because of what happened. (D04)</p> <p>The more I was able to make sense through telling my story of what had happened to me, it then started to have a meaning. (D11)</p> |
| 2.3 Valuing of experiences | Finding positives in the experience of illness | <p>I've had all these amazing experiences and you are just saying it's illness, I just didn't believe it...I feel that it's important and the messages I've got from being in an alternative reality have been extremely important. (A10)</p> <p>What they were calling symptoms that must be eradicated, were actually part of me and so I looked behind that and said that is where, that is where my creativity comes from. This is where, this is how I am able to take a photograph this is how I am able, when I am sitting at a piano to think of a tune. (A19)</p> <p>Whereas before I felt ashamed to have these mental health issues, I now feel really proud in a way because I know that I can use it for good and I can make a difference in my community. (B01)</p> <p>There is a liberation that comes through all of this, a personal kind of yeah, not sure it's full blown self-actualisation, but it's somewhere up close to the top of the pyramid. (D04)</p> <p>I am still me but I am a different me and I am stronger. (E05)</p> <p>I kind of thought that that was the best I could ever hope for and that was fine because I</p> |

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| | | <p>lived the life I have, I have had these experiences. (D04)</p> <p>And it's okay, because I wouldn't be where I was, had I not had the experiences that I've had. I don't know what sort of person I'd be, but I certainly wouldn't be where I, doing what I'm doing now. (D12)</p> |
| <p>3.4 Survivor mission</p> | <p>New growth of political consciousness or use of illness experiences to benefit others</p> | <p><Organisation> is about re-framing mental illness as a possible catalyst for possible transformation, so and the aim is to give hope to as many people as possible through the power of story-sharing, so I'm really grateful and passionate about this. (A11)</p> <p>I just see myself as hopefully being a beacon to others who are, you know, struggling, and others who are finding things difficult. And they can, you know, refer to me [inaudible] support person and they can look at me and think 'He can make it through all the things that happened to him, then I can make it too'. (B02)</p> <p>I think it's really important to give back to society. And I think that's what I'm doing through my work. This new chapter I'm going to start, with women now. (B06)</p> <p>And so, you know, I felt like I was becoming something. I'm, I could identify with more, kind of, politicised...the personal was political and I was beginning to become aware of that on a deeper level. So, I thought right, that's it and, I'm going to set up my own thing. (B09)</p> <p>And then as I came back out it was just like no, I wanted to help, I wanted to do something, I wanted to use this story, I wanted to actually, like you know... I wanted, that's when I started studying psychology and then I applied to go study in <place>...what's helped me recover was I find life, you know, I've got stuff I want to do, I want to help people, I want to, I want to do psychology. (B25)</p> <p>I've been looking forward to sharing my experience because um, by people sharing theirs has really helped me and you know, and that makes it feel like talking about it is a really worthwhile thing to do, because its gonna allow somebody else to grow, or just take a little bit from it that you know, it might benefit them or it might not, maybe they</p> |

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| | | <p>need to hear a different story but, you know, somebody might, you know, might hear it and think well I'm really pleased that I've heard that because that's, that's gonna help me. (C03)</p> <p>I guess in my recovery I tried to be that person for other people, the thing that I didn't have. (C04)</p> <p>And my journey through prostitution, uh so I can talk to people about it now. And that's what I want to do, I want to go on and help people if I can that have been through the same thing. (C18)</p> |
| <p>4. Wellbeing</p> | <p>More active engagement in, and management of, one's own wellbeing and lifestyle</p> | |
| <p>4.1 Motivation</p> | <p>Increased determined to stay well, self-manage and not return to a bad situation</p> | <p>The violence started again and I had two broken jaws, a broken nose, scars on my head and scars on my body, but the biggest scar was in my heart and in my mind. I ended up... being put into a secure unit this time and I was meant to be there for three months. It ended up being two weeks, becoming a voluntary patient for a year. Touch wood and whistle, I swore from that day on, no man, money, love or beast would ever put me back into that situation again and I have stuck to it. (A15)</p> <p>I started to take my medication, I got rid of this awful man in my life who was my daughter's father. Which was very liberating and, suddenly had an epiphany through all the craziness and thought, I don't want this in my life anymore. If I get rid of certain things it will decrease some of the stress. (B06)</p> <p>I have been that low. And that ill, I have been there and I have seen the light and...I have come back from it. I have actually come out of it, I've been there, right there to the lowest of the low. And pulled myself back from it. And that's difficult to do. (C12)</p> |

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| | | <p>When I came out of hospital I was like “I can’t go back there again so I’ve got to sort myself out and I’ve got to build a better relationship with me and the girls”, you know, they’d been through so much. (D05)</p> <p>Rather than just aimlessly sort of treading water and doing things that I felt I was sort of having to do or other people were you know were saying I should do you know sort of planning about things that actually I enjoyed. (D13)</p> |
| 4.2 Being active | More engagement in the arts, music, sport, nature and learning | <p>I think the art has given me great kind of, great kind of structure. (A01)</p> <p>I didn't go into that dangerous space again but I did meet a lot of like-minded people and I played my violin a lot and I decided I wanted to do something with my violin...I would get like a kind of vision of what my purpose was, what my true purpose was in my life and, it was like you know, playing the violin, teaching the violin, it was, which I hadn't been doing because I was working in admin but it just felt really strongly, that is what, it wasn't to do with competition it just felt like, that's the right direction for me to go in and I need to go more and more in that direction, it felt like, like it was connecting me to my soul purpose somehow. (A10)</p> <p>I am someone that struggles with relaxing. So, um, gym, I find that I am someone who has to go to the gym, I have to exercise, um and as ridiculous as it sounds, eating as well. You know like I am someone that needs to treat myself good. In order to be good in myself. (A14)</p> <p>So that was quite liberating and I didn't think that it would help my mental health without even realising, but I think it did, I did become a bit obsessed with jogging because it was something, I guess, a bit of a break from my children and the monotony of life and the difficult relationship I was in, and the difficulties I had. (B06)</p> <p>And erm, and I believe that I need to give more time, a bit more time to, to interests. You know, like, er, I love nature. Absolutely adore nature, it's one of the places I've always felt safe, I could go and sleep in forests, more than I could go and sleep in someone's house. (B09)</p> |

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| | | <p>I've been reading quite a lot and educating myself on schizophrenia-affective disorder, plus all the things I've learned about meditation and that kind of thing I practice daily, and I've just found learning to be so rewarding and things, learning through recovery college as well, even though they do suggest reading up on your condition and that kind of thing. So I've just found learning to be so therapeutic and rewarding that I feel like I am at a point now where I can actually study and put my mind towards...doing something worthwhile. (B10)</p> <p>I play a lot of music, music is like my, it's my salvation. (E25)</p> <p>I could see my body changing and I felt stronger and I felt better and I stopped drinking for a month and I just felt amazing! (D05)</p> <p>It was also about sort of about finding activities that I enjoyed much more, rather than just aimlessly sort of treading water and doing things that I felt I was sort of having to do or other people were you know were saying I should do, you know, sort of planning about things that actually I enjoyed... One of the things I did was I joined the choir and you know it's one of [inaudible] gospel choir in South London for about, ever since I got there really and it's a very, very supportive environment, so that's been really critical and I've been able to sort of go there when I've been in every kind of mood state possible. (D13)</p> |
| <p>5. Relationships</p> | <p>More actively choosing and valuing relationships with others</p> | |
| <p>5.1 Choosing relationships</p> | <p>Actively choosing relationships to continue, to re-start or to end</p> | <p>He (counsellor) used a waiter analogy where the waiter is trying to please the clients but then more and more people come in and he is still trying to please them all but the quality of the food comes down and then people start complaining and then it is mad, so basically just concentrate on what you can do and don't try to please everybody...I also now try to mix with people who are just happy and positive and try to stay away from</p> |

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| | | <p>people who aren't. (A09)</p> <p>But you need the right quality of people around you, network, for you to be able to stay in your mental health, going forward. (B02)</p> <p>I got rid of this awful man in my life. (B06)</p> <p>I needed to go back to a couple of my old primary school friends' houses and ask for their forgiveness for something. (B07)</p> <p>I'd also come to realise before then that the relationship I was in was not quite what it was as he told me lots of things that were untrue that I discovered so I ended that as well and that was having a clean slate but it took me a long time to get literally over it. (B17)</p> |
| <p>5.2 Valuing relationships</p> | <p>Placing more value on relationships with others</p> | <p>My children they come at the weekend I give them 100% I give them 100% because I want to be giving them 100%. (A01)</p> <p>But then in another sense it's brought the incredible closeness with people with mental health with my, with my immediate family and friends so it has different angles. (A03)</p> <p>It's been a process of learning that I needed, I need desperately, I desperately needed family, you know, people I feel safe with, to be myself. And I needed people to help me normalise my feelings rather than be freaked out and hiding and terrified of expressing. (B09)</p> <p>Now I do feel a lot more stable than I did back then, and then when I go to these kinds of experiences you know, I've started to like, connections have become my thing because connections are what saved me from like, connections with people, a spiritual connection and this connection between people, there's interconnection between people is essentially what saves people... That power of coming together is so powerful, that is worth fighting for, worth dying for, it's worth me giving my time for. (B25)</p> <p>Having the friendship, the respect that built up over that in learning from each other, you</p> |

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| | | <p>Now I'm sort of growing older I know they're spirit animals, I still have them and so it's the wolves that are the most powerful so I do feel protected by those. Um and the other one is [inaudible] spiritual as well I always used to feel some [inaudible] egocentric, sort of like, wounds, [inaudible] kind of reaching out to people because I've always felt like I'm [inaudible] ever since I was really little which has why I have gone into mental health, to help people. (A18)</p> <p>But I think the longer deal is this, this, internal shift, they call it a psychic shift, an internal psychic shift, which is more about that spiritual experience and I don't know anything else that, that would work with me, do you know what I mean. And so, erm, since about 2009, that's what I've been kind of exploring in a, in a sort of ad hoc way. (B04)</p> <p>But when you kind of realise that there is something bigger than you, you start to realise don't hurt yourself, have more respect for yourself, and you also don't harm others in a sense, not but everything falls into place. The world has meaning, has greater meaning. (C19)</p> |
| <p>6.2 Spiritual engagement</p> | <p>New or renewed engagement with spiritual or religious practices, helping with meaning-making and providing comfort and security</p> | <p>Like wow so I ran over to them and they kind of just guided me so I was just being guided by all of the spirits and stuff and they guided me up the hill into the woods. (A02)</p> <p>...was actually, uh, around all of this I was sort of meditating and looking at the more spiritual aspects of my life and you know, just looking for help and I was, I was meditating. It, it, it brought a lot of pain but I was looking at that. (A08)</p> <p>I became very um sort of what's the word, like spiritual as well. I found the church very comforting and kind of a place I would be, to trust and yeah, it just gave a sense of security for some reason. (A14)</p> <p>So, you know, if it wasn't, if it wasn't for yoga, my Buddhist practice and community, who get, who don't, who, who see that there's something valuable from raw emotion, that</p> |

SRQR Checklist

| No. | Topic | Item | Location in text |
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| | Title and abstract | | |
| S1 | Title | Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | Title |
| S2 | Abstract | Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | Abstract |
| | Introduction | | |
| S3 | Problem formulation | Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | Introduction |
| S4 | Purpose or research question | Purpose of the study and specific objectives or questions | Introduction last paragraph |
| | Methods | | |
| S5 | Qualitative approach and research paradigm | Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended | Methods Procedures paragraph 2 |
| S6 | Researcher characteristics and reflexivity | Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | Methods Procedures and Methods Analysis |
| S7 | Context | Setting/site and salient | Methods Setting |

| | | contextual factors | |
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| S8 | Sampling strategy | How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale | Methods Setting |
| S9 | Ethical issues pertaining to human subjects | Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | Methods paragraph 1 |
| S10 | Data collection methods | Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings | Methods Procedures and Online Supplement 2 |
| S11 | Data collection instruments and technologies | Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | Online Supplement 2 |
| S12 | Units of study | Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | Table 1 |
| S13 | Data processing | Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts | Methods Procedures last paragraph |
| S14 | Data analysis | Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale | Methods Analysis and Online Supplement 1 and 3 |

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| S15 | Techniques to enhance trustworthiness | Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale | Methods Analysis |
| | Results/findings | | |
| S16 | Synthesis and interpretation | Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | Results Major themes |
| S17 | Links to empirical data | Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | Results Category descriptions and Online Supplement 4 |
| | Discussion | | |
| S18 | Integration with prior work, implications, transferability, and contribution(s) to the field | Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | Discussion |
| S19 | Limitations | Trustworthiness and limitations of findings | Discussion paragraph 2 |
| | Other | | |
| S20 | Conflicts of interest | Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | Competing Interests statement |
| S21 | Funding | Sources of funding and other support; role of funders in data collection, interpretation, and reporting | Funding statement |