Rates and Predictors of Disengagement and Strength of Engagement for People With a First Episode of Psychosis Using Early Intervention Services: A Systematic Review of Predictors and Meta-analysis of Disengagement Rates

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Disengagement is a problem in early intervention for psychosis services; identifying predictors is important to maximise mental-health care.

Aim: To establish the average disengagement rate, time to disengage, and predictors of disengagement or strength of engagement.

Methods: Papers were identified from 5 databases and citation searches; chosen if they reported disengagement in early intervention services, discarded if they didn’t give a clear definition of disengagement. The studies were rated for quality and a systematic review identified predictors of engagement; meta-analysis established the average disengagement rate. Meta-regression evaluated associations between disengagement and year of study or length of follow up.

Results: 26 papers were reviewed comprising over 6800 participants, meta-analysis of 15 eligible cohorts found that the average disengagement rate was 15.60% (95% confidence intervals 11.76%–20.45%), heterogeneity was considerable, important to note when reporting as a global average. Higher disengagement rates were associated with earlier studies and length of follow up; causal factors are unclear due to the lack of data and complex interaction between clinical and methodological issues. Robust predictors of disengagement were substance use, contact with the criminal justice system, medication non-adherence, and lower symptom severity.

Conclusions: Disengagement rates have declined although the cause is not clear partly due to methodological variation, we suggest a guide for defining disengagement. Underpinning reasons for disengagement could include people who struggle to engage (substance users), don’t want to engage (medication non-adherence) or feel they don’t need to engage (lower symptomology). Future research should focus on minority status, education/employment during treatment, and digital technologies.

Key words: drop-out/non-adherence/schizophrenia/first-episode/engagement

Introduction

The early intervention services for psychosis (EIS) model is generally accepted as the optimum treatment pathway for people experiencing a first episode of psychosis (FEP) across much of the world.1,2 Usually offered for the initial 2–3 years following a FEP, individually tailored care is combined with evidence-based interventions for medication, psychological therapies, and general support to promote recovery and improved functioning.3 A crucial element is the willingness and ability of service-users to engage in treatment, those who disengage or are only superficially engaged are at greater risk of relapse.4,5 This population is thought to be one of the hardest to engage and disengagement figures from EIS vary greatly from 1%6 to over 40%.7 A 2014 systematic review evaluated mental-health care for FEP samples and estimated an average disengagement rate of around 30%, they reported substance abuse and family support as robust predictors.8 The authors recognised some considerable methodological challenges to evaluating this body of research.

Since this review there has been a marked increase in the development and implementation of EIS models worldwide9 and the literature on FEP engagement has tripled: only 7 of the 26 papers in this review were previously evaluated by Doyle.8 Comparison of studies remains challenging: the defining and measuring of disengagement itself is a complex, dynamic and multi-dimensional phenomenon. Variations in service models
and lengths, inclusion/exclusion criteria, data collection methods, and types of measurement tools all make evaluation difficult.

The consequence of this is an evidence base that lacks clear agreement over disengagement rates and what factors can predict service disengagement. Early intervention is a key priority for the National Health Service (NHS) in the UK and globally, as such, it is important to identify a clearer picture if we are to increase the reach of EIS frameworks. Most recent reviews are either not systematic and/or not specific to EIS.5,12,13 This review updates what is known about predictors of and prevalence of dis/engagement. It is the first meta-analysis of disengagement in EIS samples and the first to offer guidance on a standardised research criterion in order to facilitate more meaningful comparisons.

**Method**

Our protocol was registered in advance with International Prospective Register of Systematic Reviews (PROSPERO), registration number CRD42020168451, available from https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=168451 and carried out according to PRISMA guidelines.14

**Eligibility Criteria**

Studies that report rates and/or predictors of service disengagement or strength of engagement from an FEP EIS population were included. Studies were excluded if they reported on disengagement on without explicitly defining how it was measured or if they focused only on medication adherence or a specific intervention within EIS. Follow up studies that collect data after EIS discharge and papers not in English were also excluded.

**Search Strategy**

Pubmed, PsychINFO, CINAHL, Embase, and Medline databases were searched using the following search terms:

- Psychosis OR psychoses OR psychotic OR schizophren* AND attendance OR engagement OR disengagement OR adherence OR non-adherence OR participation OR “drop out” OR discontinuation AND “first episode” OR “early intervention” OR EIS OR FEP

The last search date was 5th July 2021 and interrater reliability was checked by an independent researcher using the inclusion/exclusion criteria on a sample of 100 abstracts taken from the original search results. Hand searches identified one further paper.

**Procedure**

A flow diagram of the search and study selection process is shown in figure 1.

**Data Extraction**

We extracted reported rates of disengagement and time to disengage data in order to compare and contrast disengagement rates across studies with the aim of better understanding patterns in the research literature. We extracted all reported predictors of disengagement or strength of engagement to evaluate any consistent agreement across studies. Over 60 predictors were reviewed and included if a significant effect was found (with a P-value of ≤.05) in 3 or more studies, one author was approached and provided more clarity on P-values. A total of 14 main predictors were evaluated. Combined categories were made for predictors related to family support (living alone, living without family, or with no family members involved in treatment), Minority status (race, ethnicity, and immigration status) and substance use (past, persistent, or use at baseline). We also collected details about each EIS framework, sample size, demographics and study design.

**Study Quality**

The quality of the study methodology was rated according to the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies, see table 1. It is reliable, valid, and easy to use. It has been used successfully for other reviews of a similar nature and, has been adapted to include the four most relevant domains for non-randomised studies: selection bias, confounders, data collection methods, withdrawal, and drop-outs.

**Analytic Strategy**

Meta-analysis was performed using R version 4.0.0 “meta” and “metaphor” packages in R-Studio version 1.4.1. Disengagement rates were transformed using logit transformation and a random effects model calculated a summary effect with 95% confidence intervals (CI) using the Dersimonian Laird method that is customary for proportional meta-analysis. “Leave one out” analysis tested for influential studies, meta regression analysis tested for moderators. Sub-samples and overlapping cohort studies were removed and meta-analysis was conducted on 15 cohorts with a total of 6055 individual participants. Where multiple outcomes were measured, the most appropriate percentage score was used: Either the 2 year disengagement rate (the most common timescale measured), or the complete disengagement rate, (where disengagement was categorical rather than dichotomous). Where Albert et al’s study compared cohorts in a 2-year EIS plus 3 years of TAU against a 5 year EIS model, the 5 year experimental group was used on the basis that the 2 year plus TAU group is not reflective of the EIS care model. Iyer compared two cohorts from Canada and India and both these cohorts were included independently in the analysis.
Vulnerability to publication bias was tested using funnel plot visualisation and rank test for asymmetry.\textsuperscript{29,30}

**Results**

Interrater reliability agreement was 99\% with one additional article being identified by the second reviewer as relevant which was not previously selected. Exclusion of this paper was agreed by a consensus meeting with a senior research supervisor and no additional papers were added.

**Study Characteristics**

The search strategy yielded 2154 total results. After deduplication and screening by title/abstract, full text was obtained for 47 articles. Of these 26 met the inclusion criteria, seven of the selected studies were previously included in a systematic review of treatment disengagement in FEP samples (one strength of engagement and the rest disengagement rates).\textsuperscript{8} Three further studies from this review did not fit our inclusion criteria: one was focused on a specific psychological intervention and two were not based in an EIS setting. Generally, studies investigating strength of engagement were poorer quality due to selection bias (the need for informed consent) and the use of smaller samples. Study quality ratings are presented in table 1.

Papers ranged from 2006 to 2020 and all were cohort studies except one randomised trial.\textsuperscript{28} They looked at data from around 6800 individual participants (an exact figure is not possible due to overlapping cohorts from the PEPP program in Canada). Studies spanned across Australia (4), New Zealand (3), Canada (7), Europe (8), Asia (3), India (1), and the USA (1) over 20 cohorts and 16 research teams; 19 studies measured rates of disengagement and seven, strength of engagement. Frameworks in Western countries are predominantly based upon, or use the EPPIC framework, developed in Australia in the 1990’s by Patrick McGorry.\textsuperscript{45-47} In China and Singapore key components are consistent with Western models and include: MDT teams that provide antipsychotic medication, psychosocial interventions, including psychoeducation and encouragement of family involvement.

Study characteristics are represented in table 2.

**Defining Disengagement**

Seventeen of the nineteen studies conceptualised disengagement as dichotomous. Some studies considered those not in treatment at the end of the study as disengaged and were not explicit about those who were appropriately discharged, others considered participants disengaged if they terminated treatment despite therapeutic need or were untraceable sometimes with a time limit of 3 months.

Two studies took a categorical approach: Zheng et al.\textsuperscript{26} categorised those who were disengaged, engaged, or in
telephone contact. Lau et al\textsuperscript{35} categorised those who dropped out then reengaged.

There was variation among how participants were treated who moved out of area and many lacked details or weren’t explicit. Solmi et al\textsuperscript{34} and Golay et al\textsuperscript{37} gave a detailed breakdown of the participant outcomes and how they were treated in the analysis. Some of the other studies excluded anyone who moved whereas others classed them as disengaged unless appropriately transferred; others treated transferees as engaged despite not knowing their final outcome. Similar inconsistency occurred if participants died or were imprisoned. These variations impacted disengagement rates, particularly when cohorts were relatively small. For example Turner et al\textsuperscript{22} counted those who moved without follow up as disengaged which accounted for 6\% of the reported

| Author                        | Selection Bias | Confounders | Data Collection Methods | Withdrawal/Drop-outs | Mean Global Rating | Study Quality |
|-------------------------------|----------------|-------------|-------------------------|----------------------|--------------------|---------------|
| Schimmelmann et al\textsuperscript{21} | 2              | 1           | 1                       | 1                    | 5/4 = 1.25         | Good          |
| Turner et al\textsuperscript{22} | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Turner et al\textsuperscript{23} | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Conus et al\textsuperscript{2010} | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Anderson et al\textsuperscript{2015} | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Stowkowy et al\textsuperscript{33} | 1              | 1           | 1                       | 2                    | 5/4 = 1.25         | Good          |
| Zheng et al\textsuperscript{2013}  | 1              | 2           | 1                       | 1                    | 5/4 = 1.25         | Good          |
| Chan et al\textsuperscript{34}   | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Ouellet-Plamondon et al\textsuperscript{24} | 3              | 3           | 1                       | 1                    | 8/4 = 2            | Fair          |
| Albert et al\textsuperscript{28}  | 2              | -           | -                       | 3                    | 5/2 = 2.5          | Fair/Poor     |
| Maraj et al\textsuperscript{35}   | 2              | 2           | 1                       | 1                    | 6/4 = 1.5          | Good/Fair     |
| Solmi et al\textsuperscript{34}   | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Kim et al\textsuperscript{27}     | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Lau et al\textsuperscript{35}     | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Hamilton et al\textsuperscript{7}  | 3              | 2           | 1                       | 3                    | 9/4 = 2.25         | Fair          |
| Maraj et al\textsuperscript{26}    | 2              | 1           | 1                       | 1                    | 5/4 = 1.25         | Good          |
| Reynolds et al\textsuperscript{20} | 1              | 2           | 1                       | 1                    | 5/4 = 1.25         | Good          |
| Iyer et al\textsuperscript{6}      | 2              | 1           | 1                       | 3                    | 7/4 = 1.75         | Good/Fair     |
| Golay et al\textsuperscript{37}    | 1              | 1           | 1                       | 1                    | 4/4 = 1            | Good          |
| Theuma et al\textsuperscript{38}   | 2              | 3           | 2                       | -                    | 7/3 = 2.33         | Fair          |
| Lecomte et al\textsuperscript{39}  | 2              | 3           | 1                       | -                    | 6/3 = 2            | Fair          |
| MacBeth et al\textsuperscript{40}  | 2              | 3           | 1                       | -                    | 6/4 = 1.5          | Good/Fair     |
| MacBeth et al\textsuperscript{41}  | 2              | 3           | 1                       | -                    | 6/4 = 2            | Good/Fair     |
| MacBeth et al\textsuperscript{42}  | 2              | 3           | 1                       | -                    | 6/4 = 2            | Good/Fair     |
| MacBeth et al\textsuperscript{43}  | 2              | 3           | 1                       | -                    | 6/4 = 2            | Good/Fair     |
| Casey et al\textsuperscript{44}    | 2              | 2           | 2                       | -                    | 6/4 = 2            | Good/Fair     |

Note:
Rating Scale across domains:
1 = Good, 2 = Fair, 3 = Poor, – = Not relevant to this study.
Selection Bias:
Good = Data collected for the entire cohort.
Fair = If the study focuses on a sub-group (i.e. adolescents) or is a research sample.
Poor = If the study focuses on a sub-group AND is a research sample.
Confounders:
Good = If it controlled for other predictors including substance use (a well-established predictor of service disengagement).
Fair = If it failed to control for substance use (unless substance users were excluded from the study).
Poor = If the study failed to adjust for no, or very few other predictors.
Data Collection Methods:
Good = If the study used validated measures and gave a detailed description of data collection.
Fair = If engagement strength was measured using self-report (see strength of engagement section) or unvalidated measures were used.
Poor = If strength of engagement was measured using self-report AND unvalidated scales were used.
Withdrawal/Drop-out:
Good = A detailed definition of engagement is given (eg gives full details on how data is treated for those who move out of catchment).
Fair = If a time scale was specified or reengagement was explicit (ie “no contact for 3 months before the end of treatment” or “those were discharged and reengaged within 6 months were counted as engaged”).
= = If no additional details were given beyond a definition of engagement (ie no clinical contact despite therapeutic need).
= = Studies investigating strength of engagement.
= = Studies investigating disengagement.
| Author Name          | Year                | Location          | Focus/ Aim                                                  | Setting                                                                 | Intervention Framework                                                                 | Sample Demographics                                                                 | Study details                                                                 | Operational definition or measure of engagement                                                                 | Disengagement Predictors                                                                                   | Disengagement Rate | Average time in treatment | Risk of disengagement |
|---------------------|---------------------|-------------------|-------------------------------------------------------------|-------------------------------------------------------------------------|---------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------|---------------------|-----------------------------|------------------------|
| Schimmelmann et al  | 2001                | Australia         | Predictors of disengagement in adolescents with FEP in EIS  | A stand-alone EIS in Melbourne                                           | EPPIC (Early Psychosis Prevention and Intervention Centre) a well-established 1.5-   | Sample size: 134                                                              | Design: Retrospective cohort study                                                                                      | Disengagement definition: “Actively refused any contact with the treatment facility or were not traceable” | Predictors of disengagement were:                                                                            | The overall disengagement rate at 2 years was 23.4% (n = 33). 21 refused contact 12 did not respond to phone calls, letters or home visits 18-month time to event analysis found the median time to disengagement was 15.6 months (CI 14.7-16.5) with a risk of 0.28 and a roughly linear distribution |
|                     |                     |                   |                                                             |                                                                          | 2-year program. Coordinated MDT care provides support for accommodation, vocational | Population: FEP                                                                   | Data collection: From clinical files                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | activities, recreation, welfare and primary health services. The program also       | Age: 15–18 years                                                                | Timescale: January 1998 – December 2000                                                                                       |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | provides psychoeducation, medical management, and access to psychological          | Mean age: 16.9(SD1.1)                                                            |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | interventions, family/carer therapy, physical health                              | Females: 29%                                                                   |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | interventions, psychosocial recovery groups and online support                    | Ethnicity: Not reported                                                          |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          |                                                                                   | Design: Longitudinal naturalistic cohort study                                    | Termination of treatment despite therapeutic need within 12 months of entry. Included those who moved without a referral but not those who were discharged to another mental-health service or appropriately out of services | Predictors of disengagement were:                                                                            |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          |                                                                                   | Data collection: From psychiatrist interview and case manager interview at admission |                                                                                                                                      | - Longer duration of untreated psychosis (DUP)                                                                     |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          |                                                                                   | for all referrals to the service Timescale: 2000–2005 N = 232                     |                                                                                                                                      | - Lower insight                                                                                              |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          |                                                                                   |                                                                                                                                      |                                                                                                             | - Lower symptom severity at baseline                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          |                                                                                   |                                                                                                                                      | - Substance use at baseline                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          |                                                                                   |                                                                                                                                      | - Diagnoses that were not mood disorders                                                                            |                                                                                                             |                     |                             |                        |
| Turner et al         | 2004                | New Zealand       | Predictors of 12-month service disengagement from EIS for people with FEP | A stand-alone EIS in Christchurch                                            | Totara House: Established in 1997. And offers MDT care for 2 years Mental health  | Sample size: 232                                                              | Design: Retrospective cohort study                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | nurses, social workers and occupational therapists have a case-load of 15.        | Population: FEP                                                                   | Data collection: From psychiatrist interview and case manager interview at admission for all referrals to the service Timescale: 2000–2005 N = 232 | Termination of treatment despite therapeutic need within 12 months of entry. Included those who moved without a referral but not those who were discharged to another mental-health service or appropriately out of services |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | With external supervision and ongoing training. Other staff include a clinical     | Age: 18–30 years                                                               |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | psychologist, Maori mental health worker and psychiatrist. Treatment provides     | Mean age: 22.4(SD3.9)                                                           |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | access to social and therapeutic groups, psychoeducation, family therapy,       | Females: 29.3%                                                                |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | individual CBT and substance abuse treatment program                            | Ethnicity: 16.5% Maori                                                          |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | Diagnosis: Schizophrenia spectrum disorders, Bi-polar disorder, major depressive   | Exclusions: IQ<70                                                               |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          | disorder with psychotic features & other psychoses                               | Those in the criminal justice system                                             |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |
|                     |                     |                   |                                                             |                                                                          |                                                                                   | FEP with greater than 12 weeks previous antipsychotic treatment                |                                                                                                                                      |                                                                                                             |                                                                                                             |                     |                             |                        |

Disengagement in Early Psychosis
| Author Name | Year | Location | Focus/Aim | Setting | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|-------------|------|----------|-----------|---------|---------------------|--------------|------------------------------------------------|--------------------------|----------------------|-------------------------|----------------------|
| Turner et al | 2023 | New Zealand | Outcomes for a 2-year EIS for FEP | A stand-alone EIS in Christchurch | Sample size: 236 | As above | Predictors of disengagement were baseline measures of: | - Unemployment at baseline | The overall disengagement rate at 2 years was 34% (n = 71) | 20 months | |
|              |      |          |           |         | Population: FEP | | - Higher global functioning scores at baseline | - Higher HoNOS score (greater impairment) | Including: 7% (n = 5) who were imprisoned | 20 months | |
|              |      |          |           |         | Age: 16–30 years | | | | 4% (n = 3) who committed suicides | |
|              |      |          |           |         | Mean age: 22.4(SD3.9) | | | | Time to event analysis at 105.7 weeks found the average time to disengagement was 45.2 weeks and was non-linear compared with 105.7 for those who completed treatment | |
|              |      |          |           |         | Females: 37.5% | | | | There was a roughly linear distribution | |
|              |      |          |           |         | Ethnicity: 16.9% Maori | | | | | |
|              |      |          |           |         | Diagnoses: Schizophrenia spectrum disorders, Bi-polar disorder, major depressive disorder with psychotic features & other psychoses | | | | | |
|              |      |          |           |         | Exclusions: | | | | | |
|              |      |          |           |         | IQ<70 | | | | | |
|              |      |          |           |         | Those in the criminal justice system | | | | | |
| Conus et al | 2022 | Australia | Rates and predictors of service disengagement | A stand-alone EIS in Melbourne | Sample size: 660 | Design: Retrospective cohort study | Disengagement definition: “Actively refused any contact with the treatment facility or were not traceable” Routine efforts were made by clinical staff by phone, letter and home visits to participants and/or their families. Disengagement was counted from date of last face-to-face meeting with | Predictors of disengagement were: | The overall disengagement rate at 18 months was 23.3% (n = 154) | 18-month time to event analysis found the mean time to disengagement was 15.8 months (CI 15.4–16.2) with a risk of 0.11 0–6 months 0.16 0–12 months 0.26 0–18 months There was a roughly linear distribution | |
|              |      |          |           |         | Population: FEP | Data collection: From clinical files | | - Forensic history | |
|              |      |          |           |         | Age: 15–29 | Timescale: January 1998–December 2000 | | - Lower baseline symptom severity | |
|              |      |          |           |         | Mean age: 22(SD3.4) | | | - Persistent substance use | |
|              |      |          |           |         | Females: 34.2% | | | - Living without family at discharge | |
|              |      |          |           |         | Ethnicity: Not reported | | | | | |
|              |      |          |           |         | Diagnoses: Schizophrenia spectrum disorders, bi-polar, NOS | | | | | |
|              |      |          |           |         | Exclusions: | | | | | |
|              |      |          |           |         | IQ<70 | | | | | |
|              |      |          |           |         | Organic conditions | | | | | |
| Author Name | Year | Location | Focus/ Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|-------------|------|----------|------------|---------|------------------------|---------------------|--------------|-----------------------------------------------|--------------------------|------------------|--------------------------|----------------------|
| Anderson et al15 | 2003 | Canada | Focus: Negative pathways to care and service disengagement | Setting: A stand-alone EIS in Montréal | PEPP – (Prevention and Early Intervention Program for Psychosis): A 2-year program individually tailored providing intensive case management, psychosocial (family and psychoeducation) and medical management | Sample size: 324 Population: FEP Age: 14–30 years Median age: 22.6 (IQR 19.8–25.9) Females: 30.2% Ethnicity: 60.5% White 13% Black 12.3% Asian Diagnoses: Affective or non-affective psychosis Exclusions: Organic disorders Epilepsy Developmental disorder Not in or soon likely to be in the criminal justice system IQ<70 30+ days of antipsychotic medication | Design: Longitudinal cohort study Data collection: From clinical files Timescale: January 2003 – October 2010 | No clinical contact for at least 3 consecutive months (not attending appointments and no response from phone calls). Not including those who moved or were transferred. Time to disengage was measured in months and recorded from program entry to the first month of no-contact | Predictors of disengagement were: - Older age - Ethnicity (black service-users were more likely to disengage compared to white) | The overall disengagement rate at 2 years was 28% (n = 89) The median time to drop out was 5 months (IQR 1–11) |
| Stowkowy et al32 | 1997 | Canada | Focus: Predictors of disengagement | Setting: A stand-alone EIS in Calgary | EPTS (Early psychosis treatment service) a well-established 3-year program that delivers psychiatric care, case management with a range of group programs, individual therapy and family interventions | Sample size: 266 Population: FEP (24% inpatients) Age: Not reported Mean age: 24.5(SD8.2) Females: 33% Ethnicity: 76.4% Caucasian Diagnoses: Schizophrenia spectrum disorders, NOS, brief psychotic disorder, delusional disorder Exclusions: Affective psychosis Neurological disorders Head injury Epilepsy Poor English language | Design: Longitudinal cohort study Data collection: By informed consent Prospective assessment Timescale: January 1997 – December 2000 | Dropping out of treatment before 30 months. Defined by no contact for 3 months. Reengagement anytime within the three years was not counted as disengaged | Predictors of disengagement were: - Lack of family involvement in treatment - Shorter DUP - Lower negative symptoms severity at baseline - Disengagement before 6 months was predicted by cannabis and other substance use | The overall disengagement rate at 30 months was 31% (n = 82) Time to event analysis at 30 months was roughly linear. Average time to disengage was not reported |
Table 2. Continued

| Author Name   | Year   | Location | Focus/ Aim                        | Setting | Sample Demographics | Study details | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|---------------|--------|----------|-----------------------------------|---------|---------------------|---------------|--------------------------|-------------------|--------------------------|-----------------------|
| Zheng et al²⁶ | Singapore | Focus: Rates and predictors of disengagement | Setting: Stand-alone EIS in Singapore |          | Sample size: 775    | Design: Naturalistic longitudinal cohort study | Semi-structured scale measured at 2 years: (i) Did not disengage (ii) Telephone contact with service user, family or both (iii) Telephone contact with family only (iv) No contact (iii) & (iv) were deemed disengaged Those who returned within 2 years of dropping out were considered engaged Those who moved or were discharged to private care were excluded Continuous default of appointments till the end of 2 years despite therapeutic need and active tracing from staff for follow up. Predictors of disengagement were: - Malay ethnicity - Lower levels of education - Longer DUP At 2 years 29% of participants (n = 127) disengaged at some level: 14% (n = 109) were deemed to have completely disengaged: Type (iii) 7% (n = 55) and Type (iv) 7% (n = 54) 15% (n = 118) only maintained telephone contact type (ii) |          |          | |
| Chan et al³³  | Hong Kong | Focus: Prevalence and predictors of disengagement | Setting: A stand alone EIS in Hong Kong |          | Sample size: 700    | Design: Longitudinal cohort study | From clinical records Timescale: January 2001 – December 2003 | Predictors of disengagement were: - Poor medication compliance - Lower negative symptoms - Diagnosis other than Schizophrenia spectrum disorders The overall disengagement rate at 2 years was 13% (n = 94) 24-month time to event analysis found the mean time to disengagement was 671.8days (CI 659.51–684.02) with a risk of: 0.05 0–6 months 0.09 0–12 months 0.13 0–24 months There was a roughly linear distribution |          |          | |
| Author Name | Year | Location | Focus/ Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|-------------|------|----------|------------|---------|------------------------|---------------------|---------------|-----------------------------------------------|----------------------------|-------------------|-----------------------------|---------------------|
| Ouellet-Plamondon et al 24 | 2005–2012 | Canada | A comparison of the effect of immigration status on service engagement in EIS | 2 stand-alone EIS in Montréal | 5-year specialised EIS based on EPPIC guidelines | Sample size: 215 Population: FEP Age: 18–30 years Mean age: Not reported Females: Not reported Ethnicity: Not reported Diagnoses: Psychotic disorder (primary diagnosis) Exclusions: Developmental disability Inadequate proficiency in English or French | Design: Longitudinal cohort study Data collection: Informed consent Timescale: 2005–2012 | Attrition rates at 12 months and 24 months Excluded if they were referred to another service | A predictor of disengagement was: - Immigration status | Attrition at 12 months: Total = 10.7% Non-immigrants 6% \((n = 7)\) 1st generation immigrants 15% \((n = 8)\) 2nd generation immigrants 22% \((n = 8)\) | Attrition at 24 months: Total: 13.5% Non-immigrants 8% \((n = 9)\) 1st generation 25% \((n = 13)\) 2nd generation 19% \((n = 7)\) | There was a highly significant difference between the two experimental groups. The disengagement rate for the 5-year group was 9.6% compared to 44.4% for the 2 year plus treatment as usual group |
| Albert et al 28 | 2009–2012 | Denmark | Comparison of 5 years of OPUS model vs 2 years of OPUS plus 3 years TAU | A 5-year stand-alone EIS in Copenhagen | OPUS II MDT with 12-person caseloads 3 core elements: Modified assertive treatment Family involvement Social skills training Plus, individually tailored groups or individual interventions | Sample size: 319 Population: FEP Age: 18–35 years Mean age: 25.6 (SD4.3) Females: 51% Ethnicity: Not reported Diagnoses: Schizophrenia spectrum disorders Exclusions: IQ<70 | Design: Randomised superiority group comparison. Stratified sampling with blinded outcome assessment and statistical analysis. Data collection: By informed consent at 19 to 24 months into treatment Follow up after 5 years Timescale: 2009–2012 | Non-attendance/ no contact for the last 3 months before the end of the study time | Not evaluated | | | |
| Author Name   | Year | Location | Focus/ Aim Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment of disengagement |
|--------------|------|----------|--------------------|------------------------|---------------------|--------------|------------------------------------------------|--------------------------|-------------------|------------------------------------------|
| Maraj et al23 | 2012 | Canada   | Disengagement and immigrant groups | PEPP                   | Sample size: 297   | Design: Longitudinal cohort study Data collection: By informed consent Timescale: Between January 2003–July 2012 | No clinical contact for at least 3 consecutive months (not attending appointments and no response from phone calls). Not including those who moved or were transferred. Time to disengage was measured in months and recorded from program entry to the first month of no-contact. | Predictors of disengagement were: | The overall disengagement rate at 2 years was 24.2% ($n = 72$) |
| Solmi et al34 | 2013 | England  | Predictors of disengagement Setting: 6 stand-alone EIS in a mixed rural and urban setting in East Anglia | NHS EIS’s in East Angliaa | Sample size: 786 | Design: Naturalistic longitudinal cohort study Data collection: From clinical files Timescale: July 2009 to March 2013 | Considered to be disengaged after all possible ways to engage had been explored by the clinical team. Usually 6–8 attempts over 2–3 months | Predictors of disengagement were: | The overall disengagement rate at 3 years was 11.7% ($n = 92$) |

- Age (first generation immigrants)
- Material deprivation (second generation immigrants)
- Medication non-adherence (all groups)

Disengagement was not affected by immigrant status or ethnicity.
| Author Name | Year | Location | Focus/ Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate |
|-------------|------|----------|------------|---------|------------------------|---------------------|--------------|-----------------------------------------------|---------------------------|-------------------|
| Kim et al27 | Australia | Focus: Rates and determinants of disengagement and re-engagement | Setting: A stand-alone EIS in Melbourne | | EPPIC | Sample size: 707 | Design: Naturalistic cohort study recorded prospectively with retrospective data collection | Disengagement definition: “Actively refused any contact with the treatment facility or were not traceable” | Predictors of disengagement were: - Not being in employment or education at baseline - Family history of psychosis (2nd degree relative but not 1st degree) - Cannabis use | At 2 years 56.3% (n = 394) disengaged at least once Of those: 42.9% (n = 169) disengaged once 27.2% (n = 107) disengaged twice 18.8% (n = 74) disengaged three times 11.2% (n = 44) disengaged more than three times 7.6% never re-engaged (n = 54) The median time to disengagement was 166.5 days (SD±178.9, IQR = 64.25 – 321.75) The mean duration of first episode of disengagement was 82 days (SD±83.7) |

- Average time in treatment: 
- Risk of disengagement: 
- Disengagement rate: 
- Sample size and demographics: 
- Study details: 
- Disengagement predictors: 
- Disengagement definition: 
- Routine efforts were made by clinical staff by phone, letter and home visits to participants and/or their families. Disengagement was counted from date of last face-to-face meeting with participants and/or their families.

**Table 2. Continued**
| Author Name | Year | Location | Focus/ Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|-------------|------|----------|------------|---------|------------------------|---------------------|--------------|-----------------------------------------------|--------------------------|----------------|----------------------------|---------------------|
| Lau et al[^35] | 2011 | Hong Kong | Rates and predictors of disengagement comparing 15–25 vs 26 to 64-year olds in EIS | A stand-alone EIS in Hong Kong | EASY (See Chan 2014 above) In 2011 it extended its service to a 3-years with the age range widened from 16–25 to 15–64 | Sample size: 277 Population: FEP Age: 15–64 years Mean age: Not reported Females: 53% Ethnicity: Not reported | Design: Longitudinal cohort study Data collection: From service-user records Timescale: Patients newly registered from January to December 2012 | Defines 3 different types of disengagement: Type 1: Complete disengagement despite therapeutic need (continuous default until the end of the three years) Type 2: Disengaged and re-engaged through hospitalisation Type 3: Disengaged at least twice and re-engaged through outpatients Those who died or were transferred were excluded | Predictors of disengagement were: - Previous suicide attempts (type 3) - Persistent substance use (type 3) - Medication non-adherence (type 3) at an early stage (types 1&2) - Overall, the younger age group predicted disengagement | The overall disengagement rate at 3 years was: 30.7% Type 1: n = 36 (13%) 17.2% were <25 years old Type 2: n = 12 (4.3%) 4.9% were <25 years old Type 3: n = 37 (13.4%) 18% were <25 years old |
| Hamilton et al[^35] | 2015 | USA | Treatment retention in an integrated Co-ordinated Speciality Care (CSC) service for FEP in Texas | An integrated service in a community mental health setting | Co-ordinated Speciality Care for FEP est. 2015 Recovery orientated integrated care model within a community mental health clinic Individualised care using core concepts from PREP (Prevention and Recovery in Early Psychosis) Evidence-based, person-centred, phase specific, integrated, continuous and comprehensive care Pharmacotherapy with an FEP trained psychiatrist Home-based service including CBT, employment support and education, case management and peer support | Sample size: 129 Population: FEP Age: 15–30 Mean age: 23.14 Females: 41% Ethnicity: 53.9% African-American Diagnoses: Schizophrenia, Bi-polar disorder & major depressive disorder with psychotic features Exclusions: People with pre-existing medical insurance | Design: A mixed methods retrospective service evaluation (mixed methods) Data collection: By informed consent Timescale: A 2015 pilot study | Those remaining in treatment for less than 9 months | Predictors of disengagement were: - Female gender - Not undertaking a home-based CBT (cognitive behavioural therapy) course - Non-African American ethnicity | The overall disengagement rate at 9 months was: 41.1% |
| Author Name | Year | Location | Focus/ Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|-------------|------|----------|------------|---------|------------------------|--------------------|--------------|-------------------------------------------------|------------------------|-----------------|-------------------------|----------------------|
| Maraj et al 36 | Canada | Vocational inactivity and disengagement | A stand-alone EIS in Montréal | PEPP | Sample size: 394 Population: FEP Age: 14–35 years Mean age: 22.7(SD 3.55) Females: 28.1% Ethnicity: 59.8% white Diagnoses: Affective or non-affective psychosis with <1-month medication Exclusions: Organic conditions IQ<70 Substance induced psychosis | Design: Cross-sectional cohort study Data collection: By informed consent Timescale: January 2003-February 2018 | No clinical contact for at least 3 consecutive months (not attending appointments and no response from phone calls). Not including those who moved or were transferred. Time to disengage was measured in months and recorded from program entry to the first month of no-contact. | Predictors of disengagement were: - Those not in employment or education during the first year of treatment There was no difference between rates of disengagement for those who were vocationally active or inactive at baseline | N/A | |
| Reynolds et al 20 | Australia | Community and service level factors associations with disengagement | A stand-alone EIS in Melbourne | EPPIC | Sample size: 707 Population: FEP Age: 15–24 years Mean age: 19.3(SD 2.9) Females: 39.9% Ethnicity: Not reported Diagnoses: Schizophrenia spectrum disorders, Bi-polar disorder, major depressive disorder with psychotic features, and other psychoses Exclusions: None reported Includes those with intellectual disabilities and comorbid personality disorders | Design: Naturalistic cohort study recorded prospectively with retrospective Data collection: From clinical files Timescale: January 2011 to September 2014 | Disengagement definition: “Actively refused any contact with the treatment facility or were not traceable” Routine efforts were made by clinical staff by phone, letter and home visits to participants and/or their families. Disengagement was counted from date of last face-to-face meeting with | Predictors of disengagement: - Higher social deprivation | (As Kim et al) | |
| Author Name | Year | Location | Focus | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Rate | Risk of disengagement |
|-------------|------|----------|-------|---------|------------------------|---------------------|--------------|-----------------------------------------------|-------------------|------------------------|
| Iyer et al | 2006 | Canada and India | Family and patient engagement in low- and middle-income countries vs high-income countries | Two stand-alone EIS models in Montreal Canada and Chennai, India | Both are 2-year programs based on international guidelines (i.e. the EPPIC framework) In Montreal publicly funded and in Chennai funded by the NGO Schizophrenia Research Foundation (SCARF) in collaboration with the Montreal service. | Sample size: 333 Canada: 165 | A prospective cohort study | Disengagement definition: Patients were considered disengaged if they had not been in contact with the clinical team for three consecutive months. Patients who reengaged after disengaging for 3 months were considered disengaged | The overall disengagement rate at 24 months was: 19% (n = 31) in the Canadian cohort | 1% (n = 2) in the Indian cohort |

| Golay et al | 2017 | Switzerland | Rates and predictors of disengagement | Treatment and early intervention in Psychosis Program Lausanne, Switzerland | A three-year EIS that offers MDT care and assertive community outreach | Sample size: 336 | A longitudinal cohort study | Disengagement definition: Actively refused and contact with the treatment team despite active and repeated attempts or when contact was impossible despite attempts throughout the entire treatment period. Participants who moved, were referred out of services or died were excluded. | The overall disengagement rate at 36 months was: 6.3% (n = 21) | -Low socioeconomic status -Patients who committed offenses during the treatment period -A diagnosis of schizophreniform/brief psychotic disorder |
| Author Name | Year | Location | Focus/ Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|-------------|------|----------|------------|---------|------------------------|--------------------|--------------|-------------------------------------------------|--------------------------|---------------------|------------------------|---------------------|
| Theuma et al | 2018 | New Zealand | Service evaluation of an EIS for FEP | setting: A stand-alone EIS in New-Zealand | A 2-year EIS in New-Zealand est. 1997 based on the EPPIC framework | Sample size: 100 Population: FEP Age: 15-40 years Mean age: Not reported Females: 44% Ethnicity: 52% European 15% Maori 14% Pacific islanders 7% Asian | Design: Longitudinal cohort study (mixed methods) Data collection: Clinician rated Informed consent not clear Timescale: Date unclear (post 1997) | Engagement is a secondary outcome measure where clinicians rated strength of engagement at four timepoints on a 5-point Likert scale from 1 = Nil to 5 = Excellent. | Weaker engagement was predicted by: - Male gender - Higher score for negative symptoms over time - Higher HoNOS score (greater impairment) - Lower medication adherence | Not measured |
| Lecomte et al | 2019 | Canada | Predictors and profiles of treatment non-adherence and service engagement in EIS for FEP | setting: 4 EIS in Vancouver 2 stand-alone EIS and 1 specialised care psychosis clinic and one general psychiatric outpatient clinics | Care frameworks from 2 stand-alone EIS around Vancouver, one specialized psychosis outpatient service and one general psychiatric outpatient clinic | Sample size: 118 Population: FEP Age: 18+ years Mean age: 25(SD 5.9) Females: 39% Ethnicity: 60% Caucasian 16% Asian 5% First nations | Design: Cross-sectional cohort study Data collection: By Informed consent Timescale: Not clear | The Service Engagement Scale (SES): A clinician rated 14 item scale to assess overall engagement with four subscales: availability, collaboration, help seeking and treatment adherence. | Weaker engagement was predicted by: - High agreeableness - Low neuroticism - Poor therapeutic alliance - Male gender - Forensic history - Childhood physical abuse | N/A |
| Author Name         | Year | Location | Focus/ Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|---------------------|------|----------|------------|---------|------------------------|---------------------|--------------|-----------------------------------------------|--------------------------|------------------|------------------------|------------------------|
| MacBeth et al.40     |      | Scotland | Attachment, mentalization and their correlates | A stand-alone NHS EIS in Glasgow and Clyde | NHS EIS Glasgow and Clyde | Sample size: 34 Population: FEP Age: 15–45 Mean age: Not reported Females: 42% Ethnicity: 94.1% white | Design: A cross-sectional cohort study Data collection: By informed consent in the first 12 months of treatment Time scale: November 2004–November 2007 | Service Engagement Scale (SES): A clinician rated 14 item scale to assess overall engagement with four subscales: availability, collaboration, help seeking and treatment adherence. | Weaker engagement was predicted by: - Insecure attachment style (either preoccupied or dismissing) - Preoccupied attachment style for the sub-scale treatment adherence | N/A |  |  |
| MacBeth et al41      |      | Scotland | Clinical and premorbid correlates of engagement | A stand-alone NHS EIS in Glasgow and Clyde | NHS EIS Glasgow and Clyde | Sample size: 64 Population: FEP Age: 15–45 years Mean age: Not reported Females: 33% Ethnicity: 90.6% white | Design: A cross-sectional cohort study Data collection: By informed consent in the first 12 months of treatment Time scale: November 2004–November 2007 | Service Engagement Scale (SES) (as above) | Weaker engagement was predicted by: - Higher negative symptoms | N/A |  |  |
| Author Name         | Year | Location | Focus/ Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Disengagement Rate | Average time in treatment | Risk of disengagement |
|---------------------|------|----------|------------|---------|------------------------|--------------------|--------------|-----------------------------------------------|--------------------------|----------------------|--------------------------|------------------------|
| MacBeth et al⁴²     |      | Scotland | Quality of Life associations with symptomology and premorbid adjustments | A stand-alone NHS EIS in Glasgow and Clyde | NHS EIS Glasgow and Clyde⁴ | Sample size: 64  
Population: FEP  
Age: 15–45 years  
Mean age: 23.5(SD7.0)  
Females: 33%  
Ethnicity: 90.6% White British | Design: Cross-sectional cohort study  
Data collection: By informed consent in first 12 months of treatment  
Timescale: October 2005–March 2008 | Service Engagement Scale (SES) (as above) | Weaker engagement was predicted by Quality of Life factors:  
- Poorer perceived quality of interpersonal relationships  
- Poorer perceived quality of environment | N/A |
| MacBeth et al⁴³     |      | Scotland | Associations between metacognition in FEP and engagement | A stand-alone NHS EIS in Glasgow and Clyde | NHS EIS Glasgow and Clyde⁴ | Sample size: 34  
Population: FEP  
Age: 15–45 years  
Mean age: 23.3(SD7.6)  
Females: 43%  
Ethnicity: 94% White | Design: Cross-sectional cohort study  
Data collection: By informed consent  
Timescale: 2014 Cohort | Service Engagement Scale (SES) (as above) | Weaker engagement was predicted by:  
- Higher negative symptoms  
- Higher cognitive disorganisation symptomology  
- Poorer cognitive identification scores (an item from the “Understanding of One’s Own Mind” sub-scale from the revised metacognition assessment scale) (but non-significant when adjusted for negative symptoms) | N/A |
Table 2. Continued

| Author Name       | Year | Location | Focus/Aim | Setting | Intervention Framework | Sample Demographics | Study details | Operational definition or measure of engagement | Disengagement Predictors | Risk of disenagement | Average time in treatment | Disengagement Rate |
|-------------------|------|----------|-----------|---------|------------------------|--------------------|--------------|-----------------------------------------------|---------------------------|---------------------|------------------------|---------------------|
| Casey et al44     | 2015 | England  | Predictors of engagement in FEP | An NHS stand-alone EIS in Birmingham | NHS EIS Birmingham | Sample size: 103 | Design: Cross sectional cohort study | Singh O’Brien Level of Engagement Scale (SOLES): A 16 item self-report scale validated for FEP that predicts longitudinal disengagement, cross sectional disengagement and appointment attendance | Weaker engagement was predicted by: | N/A | 2-year period | 445 |
|                   |      |          |           |         |                        | Population: FEP   | Data collection: By informed consent | | - The belief that social stress causes mental illness | | | |
|                   |      |          |           |         |                        | Age: Not reported | Timescale: recruited over a 2-year period | | | | | |
|                   |      |          |           |         |                        | Mean age: 23 (SD not reported) | | | | | | |
|                   |      |          |           |         |                        | Females 29% Ethnicity: 33% White | | | | | | |
|                   |      |          |           |         |                        | 24% Black, 35% Asian Diagnoses: Not reported | | | | | | |
|                   |      |          |           |         |                        | Exclusions: Not reported | | | | | | |

Note: CI, 95% Confidence intervals; DUP, Duration of untreated psychosis (time period from first psychotic symptom to treatment compliance); EIS, Early intervention for psychosis service; FEP, First episode psychosis; HoNOS, Health of the Nation Outcomes Scales a 12-item scale measuring behaviour, impairment, symptoms and social functioning. Higher scores indicate more problematic features; IQR, Interquartile range; MDT, Multi-disciplinary team; NHS, National Health Service (UK); NOS, Non-specific psychotic disorder; NGO, Non-government organisation; SD, Standard deviation.

= Strength of engagement studies.

= Disengagement studies.
### Table 3. Main Predictors of Disengagement or Strength of Engagement

| Predictor of disengagement | Predictors of strength of engagement |
|----------------------------|--------------------------------------|
| Author and date            |                                       |
| Schimmelmann et al., 2006 | (EPPIC, Melbourne)                    |
| Turner et al., 2006        | (Totara Hse, Christchurch)            |
| Turner et al., 2006        | (Totara Hse, Christchurch)            |
| Comar et al., 2010         | (EPPIC, Melbourne)                    |
| Comar et al., 2012         | (EPPIC, Montreal)                     |
| Anderson et al., 2012      | (PEPP, Montreal)                      |
| Stokowski et al., 2012     | (EIS, Calgary)                        |
| Zheng et al., 2013         | (EIS Singapore)                       |
| Chan et al., 2014          | (EASY, Hong Kong)                     |
| Ouellet-Plamondon et al.,  | (EIS Montreal)                        |
| Maroti et al., 2015        | (EIS, East Anglia)                    |
| Sei et al., 2018           | (HNS EIS)                             |
| Maroti et al., 2019        | (EPPIC, Montreal)                     |
| Laut et al., 2019          | (EASY, Hong Kong)                     |
| Hamilton et al., 2019      | (SCC, Ottawa)                         |
| MacBeth et al., 2013       | (Glasgow NHS EIS)                     |
| Casey et al., 2016         | (NHS EIS East Anglia)                 |
| Iyer et al., 2020          | (EIS, Canadian Sample)                |
| Golay et al., 2020         | (TIPP, Switzerland)                   |
| Theuma et al., 2007        | (New Zealand EIS)                     |
| Lecomte et al., 2008       | (4 EIS Vancouver)                     |
| MacBeth et al., 2013       | (Glasgow NHS EIS)                     |
| Casey et al., 2016         | (NHS EIS East Anglia)                 |
| MacBeth et al., 2013       | (Glasgow NHS EIS)                     |
| Casey et al., 2016         | (NHS EIS East Anglia)                 |
| Iyer et al., 2020          | (EIS, Canadian Sample)                |
| Golay et al., 2020         | (TIPP, Switzerland)                   |
| Theuma et al., 2007        | (New Zealand EIS)                     |
| Lecomte et al., 2008       | (4 EIS Vancouver)                     |
| MacBeth et al., 2013       | (Glasgow NHS EIS)                     |
| Casey et al., 2016         | (NHS EIS East Anglia)                 |

↑ = Disengagement is predicted by higher prevalence of predictor; ↓ = Disengagement is predicted by lower prevalence; × = Probability of any effect is not significant >.05.
24.6% disengagement. Changing this criteria to exclude those who moved without follow up reduces the disengagement rate to 19.7%. Zheng et al.\textsuperscript{26} reported some of the lowest disengagement rates and excluded participants who moved out of area, had they used Turner’s criteria, their disengagement rate would have increased from 14% to 20%. This overall lack of agreement contributes to differing rates of disengagement and makes it difficult to compare across studies.

Rates of Disengagement: Meta-analysis

Reported disengagement rates varied from 1%\textsuperscript{6} to 41%.\textsuperscript{7} The pooled percentage of participants who completely disengaged from services was 15.62% (95% CI = 11.76%–20.45%), heterogeneity among studies was very high ($F = 94.93\%$, $Q(14) = 276.22$, $P < .0001$), results are presented in forest plot figure 2A ordered by precision (effect sizes with the narrowest CIs).

Publication Bias

Non-comparative studies such as these that report the proportion of patients who disengaged do not have significant/non-significant outcomes and are, therefore, unlikely to be vulnerable to publication bias; low disengagement rates are as likely to be published as high disengagement rates. Funnel plot (see figure 2B) and rank correlation\textsuperscript{30} (Tau = −0.1, $P = 0.63$) confirms that the data is highly unlikely to be asymmetrical; although it should be noted that with the high between study heterogeneity and relatively small number of studies, bias detection is not especially accurate.

Moderators of Disengagement Rates

Meta-regression analysis (figure 2C) found earlier studies to be significant and negatively correlated with disengagement rates ($QM(1) = 6.80$, $P < .01$) accounting for almost a third of the heterogeneity ($R^2 = 31.65\%$, $QE(13) = 173.23$, $P < .0001$), this increases to a slightly stronger and highly significant effect ($QM(1) = 18.21$, $P < .0001$) when an influential case ($Z = 2.13$)\textsuperscript{7} is removed ($R^2 = 65.85\%$, $QE(12) = 87.15$, $P < .0001$) see figure 2C, case number 10.

Meta-regression also suggested length of follow up was a significant moderator ($QE(1) = 5.17$, $P = 0.023$) that might account for around a fifth of the overall variance ($R^2 = 20.17\%$, $QE(13) = 207.83$, $P < .0001$), see figure 2D.

Lack of data prevents more detailed investigation, making it impossible to know what portion can be accounted for by improvements to research design over the last few decades. For example, better understanding of reengagement patterns or the development of more effective care models.

For example, Kim et al.\textsuperscript{27} found that 56.3% of participants disengaged at least once but overall only 7.6% of the cohort never re-engaged over the 2 year treatment period. They found that the average length of first episode disengagement was 83.7 days. This highlights the relevance of a 3-month time limit sometimes used as a benchmark for disengagement. Despite having the longest follow up time of 5 years, Albert et al.\textsuperscript{28} reported one of the lowest rates of disengagement (9.6%). This supports the idea that service-users might drop-in and out of treatment over time whether by choice (reengaging with community teams) or necessity (hospitalisation). A recent good quality study from Switzerland also reported very low disengagement rate (6.3%)\textsuperscript{37} with a 3 year follow up time. A feature of this care model was access to an intensive case management team if needed.

Hamilton et al.\textsuperscript{7} had the highest rate of disengagement and the shortest follow-up time of 9 months raising the possibility that the disengagement rate captured some participants who had temporarily disengaged, the cohort also contained 53.9% African Americans (see minority status in predictors of disengagement).

All three Asian studies and Iyer et al.’s.\textsuperscript{6} Indian cohort found low rates of disengagement suggesting possible cultural differences. However, these studies either reported low rates of substance use disorder within their sample\textsuperscript{6,33,35} or explicitly excluded people with substance use disorder\textsuperscript{26} (see predictors of disengagement below). The Indian cohort reported the lowest disengagement rate of just 1%, notably it was the only one in the sample funded by a non-government organisation.

Time to Disengage

Nine studies evaluated the average time to disengage across 8 different cohorts over a range of 2–3 years. Five used a Kaplan–Meier time-to-event analysis\textsuperscript{48} the others reported a mean or median time to disengage. The average time to disengage varied from 5 months\textsuperscript{15,33} to 22.4 months\textsuperscript{33} with a median time to disengage of 15 months. It is worth noting that the longest average time to disengage was reported from an Asian study that reported low rates of substance use among its cohort.

Of the studies that used Kaplan–Meier analysis, one found a non-linear survival curve distribution\textsuperscript{25} suggesting increased disengagement in the first year of treatment; the rest found a linear distribution. Where reported, large standard deviations and interquartile ranges suggest wide within sample variation. This, along with large differences for the average disengagement time across studies make it difficult to pinpoint any particular increased risk period across treatment times, especially given the risk that shorter follow up times might capture temporary disengagement.

Strength of Engagement

Seven studies conceptualised engagement as a therapeutic construct rather than measuring disengagement rates or
time to disengage. Five\textsuperscript{39–43} used the clinician rated service engagement scale (SES).\textsuperscript{49} Casey et al\textsuperscript{44} used the subjective patient measure, SOLES (Singh O’Brien level of engagement scale).\textsuperscript{50} The seventh study used a clinician rated strength of engagement Likert-scale.\textsuperscript{38} All of these studies were limited by their small sample size ($n = 34–118$), although Casey et al\textsuperscript{44} used bootstrapping and Winsorizing to mitigate some of the bias created by this. They also all relied on participation by informed consent and so captured a research sub-sample likely to have better social functioning skills\textsuperscript{51} and more willingness to complete outcome measures.\textsuperscript{6}

### Predictors of Engagement

Table 3 shows the 14 most frequently reported predictors across the studies. Items 1–8 show those where findings were consistent.

Where disengagement is categorised,\textsuperscript{27,35} the results for complete disengagement have been used.

### Consistent Findings

The most robust predictors of disengagement were substance use and poor medication adherence. Consistent with previous findings\textsuperscript{5} and the wider literature\textsuperscript{5,13} all four studies that reported on it found medication...
non-adherence a strong predictor of disengagement or poor engagement. Eight out of twelve studies reported substance use as a significant predictor. One found those who dropped out in the first 6-months of treatment were significantly more likely to be substance users.22 Of the four that found no effect, three included alcohol within their definition of substance use6,15,25 and one was focused on an immigrant sub-sample.23

Half of the studies that reported on symptom severity found lower symptoms a risk factor for disengagement. All three studies that reported its effect on strength of engagement found higher symptom severity, particularly negative symptoms, is a risk factor for weaker engagement.38,41,43 In other words, people who have low symptoms but do not disengage are still less likely to engage well with services, suggesting that maybe their motivation is more external (for example, pressures to attend from family) rather internal factors such as belief the treatment will work.52

Results also suggest that minority status is a strong predictor of disengagement7,15,24,26 however, cultural differences in the studies’ origins makes comparisons difficult (see demographics in table 2) and may suggest different reasons for disengagement such as spirituality26 or community stigma.15 One study23 found no difference in disengagement rates across immigrant and non-immigrant groups, however the authors suggest that underpinning reasons may differ due to sociodemographic factors.

Some evidence was found for the impact of family support as cited in previous reviews8,12 five out of 12 studies found an effect, two from the same cohort.21,31 However, measures lack consistency and more research is needed to understand the role of family support, family contact with services, and living arrangements particularly over the course of treatment rather than just baseline measures.

Very small but consistent effects suggest that higher global functioning at baseline predicted disengagement (Hazard Ratio’s of 1.004–1.04) but this mostly disappeared in multivariate analysis.

Finally, three out of four studies found medium to strong effects suggesting that contact with the criminal justice system predicted disengagement31,37 or weaker engagement.39

**Mixed Findings**

Table 3 items 9–14 shows those predictors where reported findings were mixed. Of these, the impact of education/employment is possibly a relevant predictor requiring more investigation. Four out of nine studies agreed there was a greater risk of disengagement for those who were not in education or employment (NEET).25,27,31,36 One that specifically focused on the impact of NEET36 found no difference between those employed or not employed at baseline but those with sustained unemployment at 12 months were over eight and a half times more likely to disengage. Solmi et al34 found a small increased risk of disengagement for those people who were employed at baseline; possibly suggesting greater functioning and therefore less perceived need. Of the four remaining studies, 2 found a trend towards significance suggesting unemployment predicts disengagement22,26 and one was a sub-sample of adolescents25 and, therefore perhaps a different demographic.

The remaining four variables had weak evidence to associate them as predictors, either heavily outweighed by null effects (age and gender), or with no clear pattern or direction (education and duration of untreated psychosis (DUP)). One study that found younger age predicted disengagement compared 26–65 year olds with a younger group which15 was not comparable against the other studies with a much lower mean sample age of, typically, early to mid 20’s. Three others found small effects two only in univariate analyses and one found age to be associated with first generation immigrants only.23 Significant findings for gender are attributed to either service level factors; the presence of a male therapist impacting on female disengagement,7 interpersonal style of staff impacting on male disengagement,28 or co-occurrence of forensic history for males in the treatment program.29

**Discussion**

This review sought to establish the rates and predictors of disengagement in EIS FEP populations. In contrast to Doyle’s systematic review which found an average disengagement rate of around 30%, meta-analysis of 15 relevant cohorts found the average rate of disengagement to be around half that figure at 15.6%. The median time to disengage across 9 relevant studies was 15 months with a wide range across studies (5–24 months) and the most robust predictors of disengagement were medication non-adherence, substance use, and contact with the criminal justice system. Lower symptom severity predicted disengagement, but higher symptom severity is a risk factor for weaker engagement.

The great variation in disengagement rates across studies means that as a global average, 15.6% should be reported with caution and within the context discussed in this review. Meta-regression provides strong evidence that a proportion of this variability can be explained by changes over time, at least, this is the case for disengagement rates in published research studies which have reported reduced rates in more recent years. With one exception,6 no study since 2013 has reported a disengagement rate of more than 19%, in contrast, Doyle’s 2014 systematic review6 found the range of disengagement rates was 20.5–50%. A lack of data means any deeper understanding as to the impact of clinical vs methodological improvement is purely narrative. With this in mind we consider some factors that might be influential to both reduction in disengagement over time and methodologies that contribute to heterogeneity.
Two likely methodological factors that contribute to reduced disengagement figures over time are the more careful consideration in some recent studies of re-engagement patterns and the recent inclusion in the literature of three Asian studies and one Indian cohort which report some of the lowest rates of disengagement in the world. Reasons for this could be cultural: for example, papers from the EASY study reported low rates of substance abuse in their cohorts; Zheng et al evaluated a cohort where 95% of participants were living at home. Other reasons could be sampling bias: excluding substance users or those with a forensic history or those with drug induced psychosis.

Clinically, it is possible that, over time, the fidelity to treatment frameworks have shifted as they have become embedded into practice and as time pressures on clinicians have increased. For example, less intensive efforts in community outreach for those considered to be highly likely to disengage; and/or, less willingness to take on those with diagnostic uncertainty.

One likely contributor to high sample heterogeneity is variation in study length where shorter studies may capture an artificially inflated disengagement rate including those who have temporarily dropped out. The highest disengagement rate came from a study that measured disengagement at 9 months and found 41% had disengaged whereas, one of the lowest reported disengagement rate of 9.6% was from a 5 year EIS program. A possible confound here though, is that Hamilton’s sample was made up of over 50% African Americans pointing to the possibility of inflated disengagement rates through sampling bias (where minority status could predict disengagement). A second influencing factor might be how engagement is defined, for example a study counting those who moved without an appropriate referral as disengaged will report higher disengagement rates than a study who excluded those participants, especially with smaller cohorts.

There was great variation in the length of time to disengagement across the sample but also at study level, aside from the fact that variation in study length makes differences hard to quantify; some of the heterogeneity could be explained by clinical differences such as how much effort was invested on keeping individuals engaged, or methodological differences such as the efficiency of record keeping or when a person is actually counted as being disengaged.

Several papers reported on strength of engagement rather than disengagement. However, these studies are limited because they rely on informed consent, creating a sub-sample likely to have better functioning skills which is related, in the wider literature to stronger service engagement. These studies do, however, add evidence to our findings that poor medication non-adherence and contact with the criminal justice system is associated with disengagement and weak engagement. Importantly, they add to our understanding of the disparate role symptom severity plays in disengagement and engagement strength.

In line with existing literature, medication non-adherence and substance use (although not necessarily alcohol use) are robust predictors of service disengagement. Research finds the risk of lifetime substance use drops from 74% to 36% for people with FEP who have completed an 18 month EIS treatment plan. This highlights the crucial importance of understanding engagement patterns in early intervention treatment programs for people with comorbid FEP and substance use disorder.

Findings suggest that lower symptom severity, play a role in service disengagement. Lower symptom severity is associated with better functioning and higher motivation which could indicate a perception of reduced need for treatment or, possibly, that attendance takes a lower priority than work, education, or leisure activities. With recent advances in digital technologies, for these individuals, incorporating models of remote or blended delivery could promote engagement on a more casual and convenient basis preventing complete disengagement and discharge. Other findings are that NEET is a risk factor for disengagement. In a focused study, Maraj et al found large effects on disengagement if NEET continued throughout the first twelve months of treatment. To better understand these patterns, a more detailed evaluation of NEET throughout treatment is needed. One of the key targets of an EIS is to support employment or education, therefore it is possible that those who gain employment through a treatment intervention will be more likely to stay engaged to continue accessing that support.

There is some evidence that minority groups are at increased risk of disengaging, although more research should be carried out and placed in the context of the country of origin to ascertain any differing underpinning reasons across black and minority ethnic groups. For example: Zheng et al suggest that, due to a more spiritual belief system, that Malay families have a higher level of family support compared to Chinese or Indian families and are less likely to accept a medical model of mental illness therefore putting less belief in treatments. Anderson et al speculate that ethnic groups may experience increased stigma from their communities and therefore a propensity to deny a need for treatment to fit in with their subjective or cultural norms. Similarly, more detailed research is required to establish why many studies find no association with family support while others do. Where “living with family” is often a measure used that implies family support this may not necessarily represent a supportive environment while at the same time a family supportively involved with treatment might not represent a service-users internally driven motivation to engage.

Predictors of disengagement suggest the presence of sub-groups with different underpinning reasons for disengagement: perceived lack of need (low
symptomology), inability to engage (substance use disorder), or no desire to engage (medication non-adherence). Going forward a more detailed investigation of antecedent variables should be employed to ascertain a more fine-grained understanding of mediators and moderators involved in the motivations for disengagement and to identify appropriate strategies to reengage or maintain low intensity contact (for example through remote technologies).

In the meantime, it is imperative to implement more cohesive methodologies across studies so that clinical comparisons can be made more accurately. Based on the evidence, we propose that disengagement be effectively defined as complete lack of contact or untraceable for three months despite a need for treatment, counted from the date of the last clinical contact. Participants who move out of catchment or are appropriately discharged should be excluded from analyses. Those who die or are imprisoned should also be excluded from analysis on the basis that any conclusions about engagement cannot be drawn from these events. Researchers should be explicit about treatment fidelity in order to accurately evaluate specific treatment models. Finally, studies should be at least eighteen months in duration to avoid inflated disengagement rates created by capturing participants who might have only temporarily disengaged. It is advised that comparisons across cultures is done with caution particularly in individualist and collectivist cultures where inherent societal factors are likely to impact on disengagement.

Conclusion

A sizable barrier to understanding disengagement is methodological differences across studies and this should be delineated according to the standardised guidance set out above.

Overall findings are that about 15% of people drop out of EIS during the first one to two years of treatment and time to disengagement varies considerably across studies. Future research should focus on the impact of family involvement, minority status, and education/employment status. One particularly robust predictor of disengagement is substance use and interventions to address this comorbidity are important for EIS care models. There is also evidence that those with lower symptoms are more vulnerable to disengagement. A solution might be for these service-users to remain on EIS caseloads allowing the option for low-intensity support and monitoring, perhaps via remote technology.

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