

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 UK¹⁰ and globally,¹¹ 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 disengagement. 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 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 schizophr* 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 $\leq .05$) in 3 or more studies, one author was approached and provided more clarity on *P*-values.¹⁵ 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,¹⁶ see table 1. It is reliable, valid,^{17,18} and easy to use. It has been used successfully for other reviews of a similar nature¹⁸ 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.¹⁹ “Leave one out” analysis tested for influential studies, meta regression analysis tested for moderators.¹⁹

Sub-samples and overlapping cohort studies were removed²⁰⁻²³ 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),^{15,24,25} or the complete disengagement rate, (where disengagement was categorical rather than dichotomous).^{26,27} Where Albert et al’s.²⁸ 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. Iyer⁶ compared two cohorts from Canada and India and both these cohorts were included independently in the analysis.

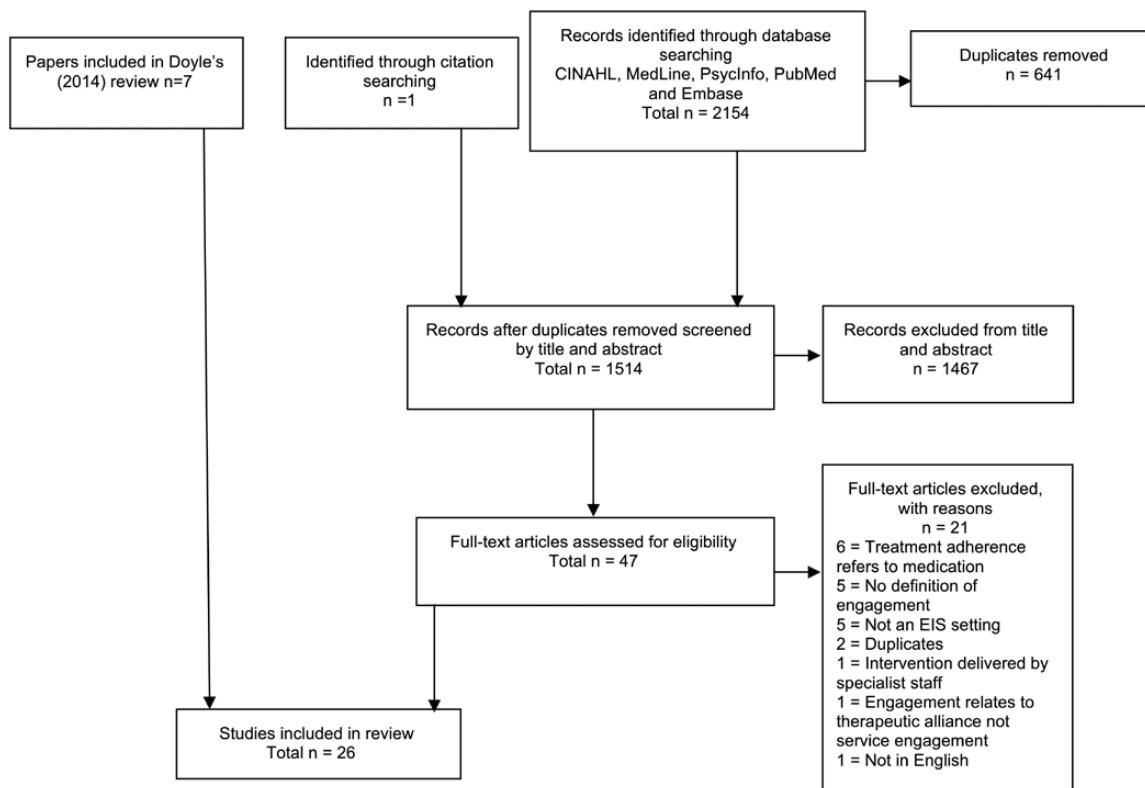


Fig. 1. A flow diagram showing the study selection process.

Vulnerability to publication bias was tested using funnel plot visualisation and rank test for asymmetry.^{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).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.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.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 al²⁶ categorised those who were disengaged, engaged, or in

Table 1. Study Quality Ratings

Author	Selection Bias	Confounders	Data Collection Methods	Withdrawal/ Drop-outs	Mean Global Rating	Study Quality
Schimmelmann et al ²¹	2	1	1	1	5/4 = 1.25	Good
Turner et al ²²	1	1	1	1	4/4 = 1	Good
Turner et al ²⁵	1	1	1	1	4/4 = 1	Good
Conus et al 2010 ³¹	1	1	1	1	4/4 = 1	Good
Anderson et al 2012 ¹⁵	1	1	1	1	4/4 = 1	Good
Stokwowy et al ³²	1	1	1	2	5/4 = 1.25	Good
Zheng et al 2013 ²⁶	1	2	1	1	5/4 = 1.25	Good
Chan et al ³³	1	1	1	1	4/4 = 1	Good
Ouellet-Plamondon et al ²⁴	3	3	1	1	8/4 = 2	Fair
Albert et al ²⁸	2	-	-	3	5/2 = 2.5	Fair/Poor
Maraj et al ²³	2	2	1	1	6/4 = 1.5	Good/Fair
Solmi et al ³⁴	1	1	1	1	4/4 = 1	Good
Kim et al ²⁷	1	1	1	1	4/4 = 1	Good
Lau et al ³⁵	1	1	1	1	4/4 = 1	Good
Hamilton et al ⁷	3	2	1	3	9/4 = 2.25	Fair
Maraj et al ³⁶	2	1	1	1	5/4 = 1.25	Good
Reynolds et al ²⁰	1	2	1	1	5/4 = 1.25	Good
Iyer et al ¹⁶	2	1	1	3	7/4 = 1.75	Good/Fair
Golay et al ³⁷	1	1	1	1	4/4 = 1	Good
Theuma et al ³⁸	2	3	2	-	7/3 = 2.33	Fair
Lecomte et al ³⁹	2	3	1	-	6/3 = 2	Fair
MacBeth et al ⁴⁰	2	3	1	-	6/4 = 1.5	Good/Fair
MacBeth et al ⁴¹	2	3	1	-	6/4 = 2	Good/Fair
MacBeth et al ⁴²	2	3	1	-	6/4 = 2	Good/Fair
MacBeth et al ⁴³	2	3	1	-	6/4 = 2	Good/Fair
Casey et al 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.

telephone contact. Lau et al³⁵ 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 al³⁴ and Golay et al³⁷ 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 al²² counted those who moved without follow up as disengaged which accounted for 6% of the reported

Table 2. Study Characteristics and Main Findings

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
Schimmelmann et al ²¹	EPIC (Early Psychosis Prevention and Intervention Centre) a well-established 1.5-2 year program. Coordinated MDT care provides support for accommodation, vocational activities, recreation, welfare and primary health services. The program also provides psychoeducation, medical management, and access to psychological interventions, family/ carer therapy, physical health interventions, psychosocial recovery groups and online support	EPIC (Early Psychosis Prevention and Intervention Centre)	Predictors of disengagement in adolescents with FEP in EIS	A stand-alone EIS service in Melbourne	Sample size: 134 Population: FEP Age: 15–18 years Mean age: 16.9(SD1.1) Females: 29% Ethnicity: Not reported Diagnoses: Schizophrenia spectrum disorders Bi-polar 1 & other psychoses (NOS, major depressive disorder with psychotic symptoms, delusional disorder, brief psychotic episode, substance-induced psychosis) Exclusions: IQ<70	Design: Retrospective cohort study Data collection: From clinical files Timescale: January 1998 – December 2000	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 the date of last face-to-face meeting with	Predictors of disengagement were: - Lower symptom severity at baseline - Living without family during treatment - Persistent substance use during treatment	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 15.6months (CI 14.7-16.5) with a risk of 0.28 and a roughly linear distribution	
Turner et al ²²	Totara House: Established in 1997. And offers MDT care for 2 years Mental health nurses, social workers and occupational therapists have a case-load of 15.	Totara House	Predictors of 12-month service disengagement from EIS for people with FEP	A stand-alone EIS in Christchurch	Sample size: 232 Population: FEP Age: 18–30 years Mean age: 22.4(SD3.9) Females: 29.3% Ethnicity: 16.5% Maori With external supervision and ongoing training. Other staff include a clinical psychologist, Maori mental health worker and psychiatrist.	Design: Longitudinal naturalistic cohort study 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	Predictors of disengagement were: - Longer duration of untreated psychosis (DUP) - Lower insight - Lower symptom severity at baseline - Substance use at baseline - Diagnoses that were not mood disorders	The overall disengagement within 12 months was 24.6% (n = 57) 68.4% (n = 39) self-discharged 24.6% (n = 14) moved out of catchment without follow up 3.5% (n = 2) committed suicide 3.5% (n = 2) were imprisoned	

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
Turner et al. ²⁵ New Zealand	Outcomes for a 2-year EIS for FEP Setting: A stand-alone EIS in Christchurch	Totara House	Sample size: 236 Population: FEP Age: 16–30 years Mean age: 22.4(SD3.9) Females: 37.5% Ethnicity: 16.9% Maori Diagnoses: Schizophrenia spectrum disorders, Bi-polar disorder, major depressive disorder with psychotic features & other psychoses	As above Exclusions: IQ<70 Those in the criminal justice system	As above (at 24 months) Additionally, patients who discontinued treatment but returned within 6 months were considered engaged	Predictors of disengagement were baseline measures of: - Unemployment at baseline - Higher global functioning scores at baseline - Higher HoNOS score (greater impairment)	The overall disengagement rate at 2 years was 34% ($n = 71$) Including: 7% ($n = 5$) who were imprisoned 4% ($n = 3$) who committed suicides 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
Conus et al. ³¹ Australia	Focus: Rates and predictors of service disengagement Setting: A stand-alone EIS in Melbourne	EPIC	Sample size: 660 Population: FEP Age: 15–29 Mean age: 22(SD3.4) Females: 34.2% Ethnicity: Not reported Diagnoses: Schizophrenia spectrum disorders, bi-polar, NOS Exclusions: IQ<70 Organic conditions	Design: Retrospective cohort study Data collection: From clinical files Timescale: January 1998–December 2000	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: - Forensic history - Lower baseline symptom severity - Persistent substance use - Living without family at discharge	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 15.8months (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

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
Anderson et al. ¹⁵	2010	Canada	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	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	Design: Longitudinal cohort study Data collection: From clinical files Timescale: January 2003 – October 2010 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	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.	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 (QR 1–11)	
Stowkowy et al. ³²	2009	Canada	Predictors of disengagement	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, NOS, spectrum disorders, brief psychotic disorder, delusional disorder	Design: Longitudinal cohort study Data collection: By informed consent Prospective assessment Timescale: January 1997 – December 2000 Exclusions: Affective psychosis Neurological disorders Head injury Epilepsy Poor English language	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	Intervention Framework	Sample Demographics	Study details	Operational definition or measure of engagement	Disengagement Predictors	Disengagement Rate Average time in treatment Risk of disengagement
Zheng et al. ³⁶ Singapore		EPIP (Early Psychosis Intervention Program) Focus: Rates and predictors of disengagement Setting: Stand-alone EIS in Singapore	MDT case management, medical treatment and psychosocial interventions	Sample size: 775 Population: FEP or minimal prior treatment Age: 15–40 years Mean age: Females: 49% Ethnicity: 77% Chinese, 14% Malay, 7% Indian Diagnoses: Schizophrenia spectrum disorders, Bi-polar disorder, major depressive disorder with psychotic features and other psychoses Exclusions: Substance use Forensic involvement Major medical illness Major neurological illnesses	Design: Naturalistic longitudinal cohort study Data collection: From clinical records Timescale: April 2001 – 2009 Diagnoses: Schizophrenia spectrum disorders, Bi-polar disorder, major depressive disorder with psychotic features and other psychoses Exclusions: Substance use Forensic involvement Major medical illness Major neurological illnesses	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	Predictors of disengagement were: - Malay ethnicity - Lower levels of education - Longer DUP Type (iii) 7% (n = 55) and Type (iv) 7% (n = 54) 1.5% (n = 118) only maintained telephone contact type (ii)	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) 1.5% (n = 118) only maintained telephone contact type (ii)
Chan et al. ³³ Hong Kong		Prevalence and predictors of disengagement Setting: A stand alone EIS in Hong Kong	EASY (Early Assessment Service for Young people with psychosis) Focus: 3 main components: Public education Easy referral process 2 yr phase specific interventions that include: Psychosocial education covering stress and coping strategies; psychotherapy for comorbidities and cognitive therapy	Sample size: 700 Population: FEP Age: 15–25 years Mean age: 20.5(SD3.4) Females: 48.5% Ethnicity: Not reported Diagnoses: Psychotic disorders Exclusions: Drug induced psychosis Organic conditions IQ < 50	Design: Longitudinal cohort study Data collection: From clinical records Timescale: January 2001 – December 2003 Diagnoses: Psychotic disorders Exclusions: Drug induced psychosis Organic conditions IQ < 50	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: - Poor medication compliance - Lower negative symptoms - Diagnosis other than Schizophrenia spectrum disorders 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	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

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	
Ouellet-Plamondon et al. ²⁴	2011	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 EPIC 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% (<i>n</i> = 7) 1 st generation immigrants 15% (<i>n</i> = 8) 2 nd generation immigrants 22% (<i>n</i> = 8)	Attrition at 12 months: Total = 10.7% Non-immigrants 6% (<i>n</i> = 7) 1 st generation immigrants 15% (<i>n</i> = 8) 2 nd generation immigrants 22% (<i>n</i> = 8)	Attrition at 24 months: Total: 13.5% Non-immigrants 8% (<i>n</i> = 9) 1 st generation 25% (<i>n</i> = 13) 2 nd generation 19% (<i>n</i> = 7)	Attrition at 24 months: Total: 13.5% Non-immigrants 8% (<i>n</i> = 9) 1 st generation 25% (<i>n</i> = 13) 2 nd generation 19% (<i>n</i> = 7)
Albert et al. ²⁸	2012	Denmark	Comparison of 5 years of OPUS model vs 2 years of OPUS plus 3 years TAU	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.	Non-attendance/no contact for the last 3 months before the end of the study time	Data collection: By informed consent at 19 to 24 months into treatment Follow up after 5 years Timescale: 2009–2012	Data collection: By informed consent at 19 to 24 months into treatment Follow up after 5 years Timescale: 2009–2012	Data collection: By informed consent at 19 to 24 months into treatment Follow up after 5 years Timescale: 2009–2012	Data collection: By informed consent at 19 to 24 months into treatment Follow up after 5 years Timescale: 2009–2012	

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
Maraj et al. ³³	2012	PEPP	Sample size: 297 Population: FEP Age: 14–35 years Mean age: Not reported Females: 31.6% Ethnicity: 66.2% White 14.1% Black 7% Asian	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.	Predictors of disengagement were: - Age (first generation immigrants) - Material deprivation (second generation immigrants) - Medication non-adherence (all groups)	The overall disengagement rate at 2 years was 24.2% (<i>n</i> = 72)					
Solmi et al. ³⁴	2013	Epilepsy	Sample size: 786 Population: “suspected” FEP Age: 16–35 years Mean age: Not reported Females: 33.2% Ethnicity: 74.8% White 25.2% Black	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: - Not meeting an FEP diagnostic criteria - Being in employment or education - Substance use, particularly poly-substance abuse - Lower negative symptoms - Less first rank delusions	The overall disengagement rate at 3 years was 11.7% (<i>n</i> = 92)					

Table 2. Continued

Author Name	Year	Location	Focus/ Aim	Intervention Framework	Sample Demographics	Study details	Operational definition or measure of engagement	Disengagement Predictors	Disengagement Rate
Kim et al ²⁷	EPIC	Australia	Rates and determinants of disengagement and re-engagement	Sample size: 707 Population: FEP Age: 15–24 years Mean age: 19.3(SD2.9) Females: 39.9% Ethnicity: Not reported	Design: Naturalistic cohort study recorded prospectively with retrospective interview Data collection: From clinical files Timescale: January 2011–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 were: - Not being in employment or education at baseline - Family history of psychosis (2 nd degree relative but not 1 st degree) - Cannabis use There were no predictors of re-engagement	At 2 years 56.3% (<i>n</i> = 394) disengaged at least once Of those: 42.9% (<i>n</i> = 169) disengaged once 27.2% (<i>n</i> = 107) disengaged twice 18.8% (<i>n</i> = 74) disengaged three times 11.2% (<i>n</i> = 44) disengaged more than three times 7.6% never re-engaged (<i>n</i> = 54)	The median time to disengagement was 166.5days (SD±178.9, IQR = 64.25 – 321.75) The mean duration of first episode of disengagement was 82days (SD±83.7)

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 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 Diagnoses: Schizophrenia spectrum disorders and other psychosis Exclusions: Drug induced psychosis Organic condition IQ < 50	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	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 9.7% were >25 years old Type 2: n = 12 (4.3%) 4.9% were <25 3.9% were >25 years old Type 3: n = 37 (13.4%) 18% were <25 9.7 were >25 years old	
Hamilton et al ³⁵ USA		Co-ordinated Speciality Care for FEP est. 2015 Focus: Treatment retention in an integrated Co-ordinated Speciality Care (CSC) service	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%	

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
Maraj et al ³⁶	2018	PEPP	Sample size: 394 Population: FEP Age: 14–35 years Mean age: 22.7(SD3.55) Females:28.1% Ethnicity: 59.8% white Diagnoses: Affective or non-affective psychosis with <1-month medication	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.	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	2018	EPIC	Sample size: 707 Population: FEP Age: 15–24 years Mean age: 19.3(SD2.9) Females: 39.9% Ethnicity: Not reported Diagnoses: Schizophrenia spectrum disorders, Bi-polar disorder, major depressive disorder with psychotic features, and other psychoses	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	(As Kim et al) - Higher social deprivation						

Table 2. Continued

Author Name Year	Location	Focus/ Aim Setting	Intervention Framework	Sample Demographics	Study details	Operational definition or measure of engagement	Disengagement Predictors
Iyer et al. ³⁶ Canada and India Focus: Family and patient engagement in low- and middle-income countries vs high-income countries Setting: 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 India: 168 Population: FEP Age: 16-35 Mean Age: Canada: 24.20(SD5.3) India: 26.60(SD5.24) Females: Canada: 33% India: 51% Ethnicity: Canada: 58% White India: Not reported Diagnoses: Schizophrenia spectrum disorders Affective psychosis Exclusions: Antipsychotic treatment <30 days IQ<70	Design: A prospective cohort study Data collection: Clinician assessment and by informed consent Timescale: 2012 to 2018	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	Predictors of disengagement were: -Lack of family contact -Higher income country (Canada)	The overall disengagement rate at 24 months was: 19% ($n = 31$) in the Canadian cohort 10% ($n = 2$) in the Indian cohort	
Golay et al. ³⁷ Switzerland Focus: Rates and predictors of disengagement Setting: Treatment and early intervention in Psychiatry Program Lausanne, Switzerland	A three-year EIS that offers MDT care and assertive community outreach	Sample size: 336 Population: FEP Age: 18-35 Mean Age: 24.53(SD4.69) Females: 35% Ethnicity: Not reported Diagnoses: Schizophrenia spectrum disorders Affective psychosis Major depressive disorder with psychotic features Bi-polar disorder other Exclusions: Antipsychotic treatment >6 months IQ<70 Organic disorders Drug induced psychosis	Design: Longitudinal cohort study Data collection: Clinician rated through structured questionnaire and semi-structured interview with access to clinical data granted for research purposes Timescale: 2004-2017	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.	Predictors of disengagement: -Low socioeconomic status -Patients who committed offenses during the treatment period -A diagnosis of schizophrenia/brief psychotic disorder	The overall disengagement rate at 36 months was: 6.3% ($n = 21$)	

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
Theuma et al ³⁸ New Zealand	1997		A 2-year EIS in New-Zealand est. 1997 based on the EPPIC framework		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 ³⁹ Canada			Care frameworks from 2 stand-alone EIS around Vancouver, one specialized psychosis outpatients service and one general psychiatric outpatient clinic		Care frameworks from 2 stand-alone EIS around Vancouver, one specialized psychosis outpatients service and one general psychiatric outpatient clinic	Sample size: 118 Population: FEP Age: 18+ years Mean age: 25(SD5.9) Females: 39% Ethnicity: 60% Caucasian 16% Asian 5% First nations	Design: Cross-sectional cohort study (SES): A clinician rated 14 item scale to assess overall engagement with four subscales: availability, collaboration, help seeking and treatment adherence.	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		

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
MacBeth et al. ⁴⁰ Scotland	Focus: Attachment, mentalization and their correlates Setting: A stand-alone NHS EIS in Glasgow and Clyde ^a	NHS EIS Glasgow and Clyde ^a	Sample size: 34 Population: FEP Age: 15-45 Mean age: Not reported Females: 42% Ethnicity: 94.1% white Diagnoses: Schizophrenia spectrum disorders, Bi-polar, delusional dis- order, mania Exclusions: A primary diagnosis of substance use Head injury Organic disorder	Design: A cross-sec- tional cohort study Data collection: By informed consent in the first 12 months of treatment Time scale: November 2004-No- vember 2007	Service Engage- ment Scale (SES): A clinician rated 14 item scale to assess overall en- gagement with four subscales: availability, col- laboration, help seeking and treat- ment adherence.	Weaker engagement was predicted by: - Insecure attachment style (ei- ther preoccupied or dismissing) - Preoccupied attachment style for the sub-scale treatment ad- herence	N/A
MacBeth et al. ⁴¹ Scotland	Focus: Clinical and pre- morbid correlates of engagement Setting: A stand-alone NHS EIS in Glasgow and Clyde ^a	NHS EIS Glasgow and Clyde ^a	Sample size: 64 Population: FEP Age: 15-45 years Mean age: Not reported Females: 33% Ethnicity: 90.6% white Diagnoses: Schizophrenia spectrum disorders, Bi-polar, delusional dis- order, mania, major de- pressive disorder with psychotic features Exclusions: A primary diagnosis of substance use Head injury Organic disorder	Design: A cross-sec- tional cohort study Data collection: By informed consent in the first 12 months of treatment Time scale: November 2004-No- vember 2007	Service Engage- ment Scale (SES) (as above)	Weaker engagement was predicted by: - Higher 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	Disengagement Rate	Average time in treatment	Risk of disengagement
MacBeth et al ⁴²	2011	NHS EIS Glasgow and Clyde ^a	Quality of Life associations with symptomatology and premorbid adjustments	A stand-alone NHS EIS in Glasgow and Clyde	Sample size: 64 Population: FEP Age: 15–45 years Mean age: 23.5(SD7.0) Females: 33% Ethnicity: 90.6% White British Diagnoses: Schizophrenia, Schizoaffective disorder, delusional disorder and bipolar	Design: Cross-sectional cohort study Data collection: By informed consent in first 12 months of treatment Timescale: October 2005–March 2008 Exclusions: A primary diagnosis of substance use Head injury Organic disorder	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 al ⁴³	2014	NHS EIS Glasgow and Clyde ^a	Associations between metacognition in FEP and engagement	A stand-alone NHS EIS in Glasgow and Clyde	Sample size: 34 Population: FEP Age: 15–45 years Mean age: 23.3(SD7.6) Females: 41% Ethnicity: 94% White Diagnoses: Schizophrenia spectrum disorders, bipolar, delusional disorder, mania	Design: Cross-sectional cohort study Data collection: By informed consent Timescale: 2014 Cohort Exclusions: A primary diagnosis of substance use Head injury Organic disorders	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	Intervention Framework	Sample Demographics	Study details	Disengagement Predictors	Disengagement Rate	Average time in treatment	Risk of disengagement
Casey et al ⁴⁴ England	NHS EIS Birmingham ^a				Sample size: 103 Population: FEP Age: Not reported Mean age: 23 (SD not reported) Females 29% Ethnicity: 33% White 24% Black, 35% Asian Diagnoses: Not reported Exclusions: Not reported	Design: Cross sectional cohort study Data collection: By informed consent Timescale: recruited over a 2-year period	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	N/A		

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.
^aThe NHS EIS care model is a community MDT providing 3 years treatment including: CBT for psychosis, family interventions, antipsychotic medication, education and employment support, physical health assessments, psychosocial wellbeing.

 = Strength of engagement studies.

Table 3. Main Predictors of Disengagement or Strength of Engagement

Predictor of disengagement	Predictors of strength of engagement
Author and date	
Casey et al., 2016 (NHS EIS Birmingham) ⁴⁴	
MacBeth et al., 2013 (Glasgow NHS EIS) ⁴¹	↑ ↑ ↑
Lecomte et al., 2008 (4 EIS Vancouver) ³⁹	↑
Theuma et al., 2007 (New Zealand EIS) ³⁸	→
Golay et al., 2020 (TIPP, Switzerland) ³⁷	×
Iyer et al. 2020 (EIS, Canadian Sample) ⁴⁷	→ × × ×
Reynolds et al., 2019 (EPPIC, Melbourne) ²⁰	→ ↑
Maraj et al., 2019 (PEPP, Montréal) ³⁶	×
Hamilton et al., 2018 (CSC, Texas) ⁷	↑
Lau et al., 2019 (EASY, Hong Kong) ³⁵	→ ↓ × ×
Kim et al., 2019 (EPPIC, Melbourne) ²⁷ (EPPIC, Melbourne)	↑
Solmi et al., 2018 (NHS EIS East Anglia) ³⁴	← → →
Maraj et al., 2018 (PEPP, Montréal) ²³	→ ×
Ouellet-Plamondon et al., 2015 (2 EIS Montréal) ²⁴	
Chan et al., 2014 (EASY, Hong Kong) ³³	→ ↓ → →
Zheng et al., 2013 (EIS Singapore) ²⁶	×
Stowkowy et al., 2012 (Calgary EIS) ³²	↓ ×
Anderson et al., 2012 (PEPP, Montréal) ¹⁵	→ ×
Conus et al., 2010 (EPPIC, Melbourne) ³³	↑
Turner et al., 2009 (Totara Hse, Christchurch) ²⁵	↑ ↓
Turner et al., 2007 (Totara Hse, Christchurch) ²²	× × ×
Schimmelmann et al., 2006 (EPPIC, Melbourne) ²¹	→ ↑
	1. Medication compliance 2. Past, persistent or baseline substance use 3. Negative symptom severity 4. Positive symptom severity 5. Total symptom severity 6. Minority race/ethnicity or immigration status 7. Living alone/without family or no family member involved in treatment 8. Global functioning (baseline) 9. Contact with the criminal justice system 10. NEET (not in education or employment) 11. Age 12. Male gender 13. Education levels 14. Duration untreated psychosis

↑= 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 al²⁶ 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%⁶ to 41%.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 ($I^2 = 94.93\%$, $Q(14) = 276.22$, $P = <.0001$), 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 correlation³⁰ ($Tau = -0.1$, $P = 0.63$) 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 ($Z = 2.13$)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 ($QE(1) = 5.17$, $P = .023$) 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 al²⁷ 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 al²⁸ 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%)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 al¹⁷ 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.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^{6,33,35} or explicitly excluded people with substance use disorder²⁶ (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 analysis⁴⁸ the others reported a mean or median time to disengage. The average time to disengage varied from 5 months¹⁵ to 22.4 months³³ 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 distribution²⁵ 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

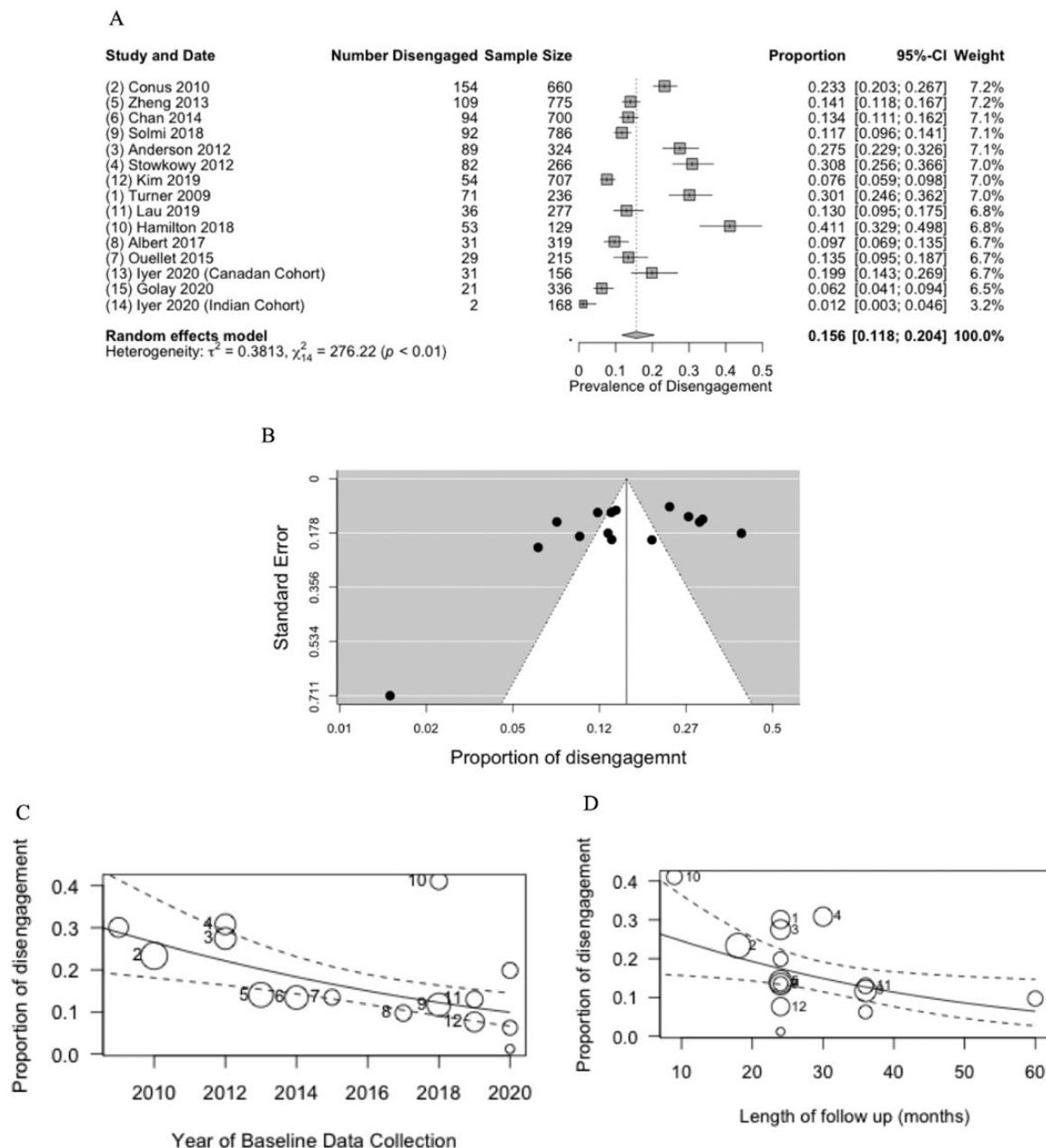


Fig. 2. A–D. Meta-analysis and meta regression plots.

time to disengage. Five^{39–43} used the clinician rated service engagement scale (SES),⁴⁹ Casey et al⁴⁴ used the subjective patient measure, SOLES (Singh O'Brian level of engagement scale).⁵⁰ The seventh study used a clinician rated strength of engagement Likert-scale.³⁸

All of these studies were limited by their small sample size ($n = 34–118$), although Casey et al⁴⁴ used bootstrapping and Windsorsizing 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 skills⁵¹ and more willingness to complete outcome measures.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,^{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 findings⁸ and the wider literature^{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.³² Of the four that found no effect, three included alcohol within their definition of substance use^{6,15,25} 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 than internal factors such as belief the treatment will work.⁵²

Results also suggest that minority status is a strong predictor of disengagement^{7,15,24,26} 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 reviews,^{8,12} 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 disengagement^{31,37} 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 disengagement^{22,26} and one was a sub-sample of adolescents²¹ 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 which³⁵ 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,³⁸ or co-occurrence of forensic history for males in the treatment program.³⁹

Discussion

This review sought to establish the rates and predictors of disengagement in EIS FEP populations. In contrast to Doyle's⁸ 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,⁷ no study since 2013 has reported a disengagement rate of more than 19%, in contrast, Doyle's 2014 systematic review⁸ 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^{27,35} 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^{33,35} reported low rates of substance abuse in their cohorts; Zheng et al²⁶ 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 history²⁶ or those with drug induced psychosis.^{33,35}

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 disengaged⁷ whereas, one of the lowest reported disengagement rate of 9.6% was from a 5 year EIS program.²⁸ 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 skills⁵¹ which is related, in the wider literature to stronger service engagement.^{53,54} These studies do, however, add evidence to our findings that poor medication non-adherence³⁸ and contact with the criminal justice system³⁹ is associated with disengagement and weak engagement.^{38,41,44} 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.^{8,55} 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.⁵⁶ 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 motivation⁵⁷ 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 delivery⁵⁸⁻⁶⁰ 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 al³⁶ 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 al²⁶ 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 al¹⁵ 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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