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 in Early Psychosis

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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Abstract

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 dis/engagement 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 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.

Keywords: 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 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 worldwide [9] 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 dis/engagement 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 [10] 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 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 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.

Figure 1. A flow diagram showing the study selection process
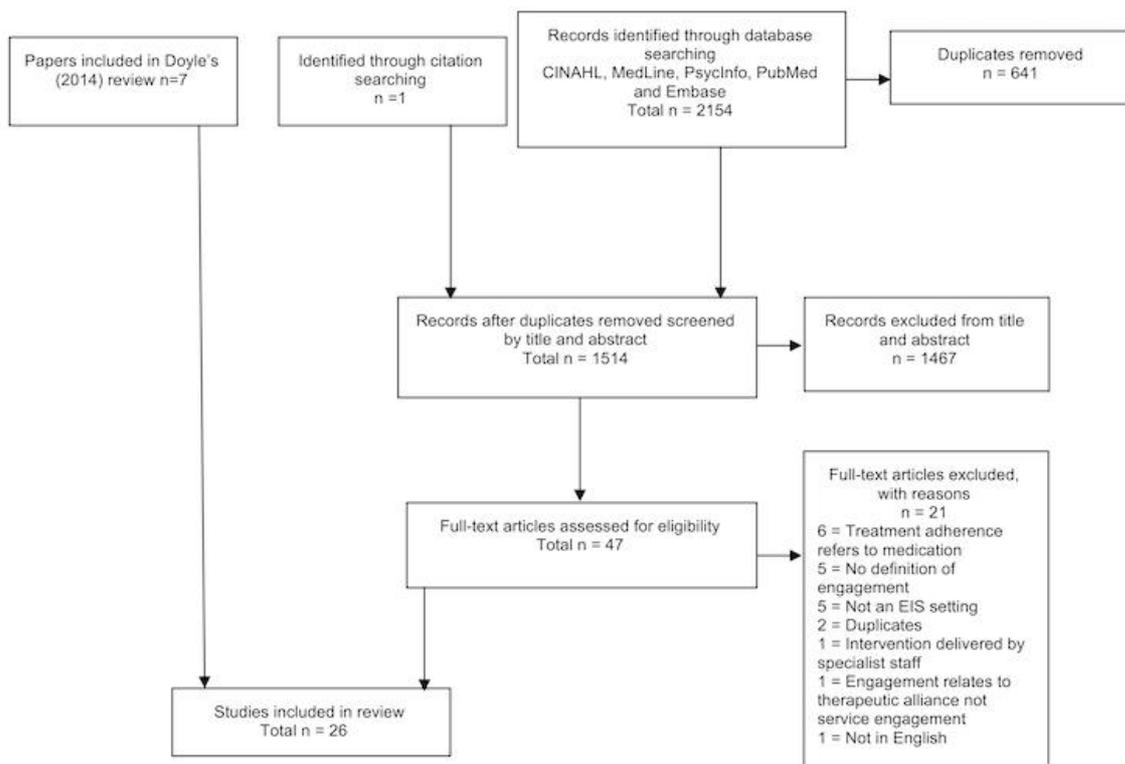
Data extraction

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 for more clarity on p-values[15]. A total of 14 main predictors were evaluated. A 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 EIS model framework, sample size and demographics, 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 nature [19] 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% CI using the Dersimonian Laird

method that is customary for proportional meta-analysis [20]. 'Leave one out' analysis tested for influential studies, meta regression analysis tested for moderators [20].

Sub-samples and overlapping cohort studies were removed [21–24] 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) [15,25,26], or the complete disengagement rate, (where disengagement was categorical rather than dichotomous) [27,28]. Where Albert et al's., [29] 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 [6] 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 [30,31].

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

Table 1. Study Quality Ratings

Author	Selection Bias	Confounders	Data Collection Methods	Withdrawal/ Drop-outs	Mean Global Rating	Study Quality
Schimmelmann et al., 2006[22]	2	1	1	1	5/4=1.25	Good
Turner et al., 2007[23]	1	1	1	1	4/4=1	Good
Turner et al., 2009[26]	1	1	1	1	4/4=1	Good
Conus et al., 2010[32]	1	1	1	1	4/4=1	Good
Anderson et al., 2012[15]	1	1	1	1	4/4=1	Good
Stowkowy et al., 2012[33]	1	1	1	2	5/4=1.25	Good
Zheng et al., 2013[27]	1	2	1	1	5/4=1.25	Good
Chan et al., 2014[34]	1	1	1	1	4/4=1	Good
Ouellet-Plamondon et al., 2015[25]	3	3	1	1	8/4=2	Fair
Albert et al., 2017[29]	2	-	-	3	5/2=2.5	Fair/Poor
Maraj et al., 2018[24]	2	2	1	1	6/4=1.5	Good/Fair
Solmi et al., 2018[35]	1	1	1	1	4/4=1	Good
Kim et al., 2019[28]	1	1	1	1	4/4=1	Good
Lau et al., 2019[36]	1	1	1	1	4/4=1	Good
Hamilton et al., 2019[7]	3	2	1	3	9/4=2.25	Fair
Maraj et al., 2019[37]	2	1	1	1	5/4=1.25	Good
Reynolds et al., 2019[21]	1	2	1	1	5/4=1.25	Good
Iyer et al., 2020[6]	2	1	1	3	7/4=1.75	Good/Fair
Golay et al., 2020[38]	1	1	1	1	4/4=1	Good
Theuma et al., 2007[39]	2	3	2	-	7/3=2.33	Fair
Lecomte et al., 2008[40]	2	3	1	-	6/3=2	Fair
MacBeth et al., 2011[41]	2	3	1	-	6/4=1.5	Good/Fair
MacBeth et al., 2013[42]	2	3	1	-	6/4=2	Good/Fair
MacBeth et al., 2015[43]	2	3	1	-	6/4=2	Good/Fair
MacBeth et al., 2016[44]	2	3	1	-	6/4=2	Good/Fair
Casey et al., 2016[45]	2	2	2	-	6/4=2	Good/Fair

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 (for example 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 (i.e. 'no contact for 3 months before the end of treatment' or 'those were discharged and reengaged within 6 months were counted as engaged' Poor = If no additional details were given beyond a definition of engagement (i.e. no clinical contact despite therapeutic need)

☐ = Studies investigating strength of engagement

☐ = Studies investigating disengagement

Papers ranged from 2006 – 2020 and all were cohort studies except one randomised trial [29].
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, New Zealand, Canada, Europe, Asia, India and the USA 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 [46][47][48]. In
China and Singapore Key components common to EIS models are MDT teams that provide
antipsychotic medication, psychosocial interventions, including psychoeducation and
encourage family involvement.

Study characteristics are represented in Table 2.

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 Risk of disengagement
Schimmelmann et al. 2006[22] Australia Focus: Predictors of disengagement in adolescents with FEP in EIS Setting: A stand-alone EIS service in Melbourne	EPPIC (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	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 Organic disorders	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

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. 2007[23] New Zealand Focus: Predictors of 12-month service disengagement from EIS for people with FEP Setting: A stand-alone EIS in Christchurch	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. With external supervision and ongoing training. Other staff include a clinical psychologist, Maori mental health worker and psychiatrist. Treatment provides access to social and therapeutic groups, psychoeducation, family therapy, individual CBT and substance abuse treatment program	Sample size: 232 Population: FEP Age: 18-30 years Mean age: 22.4(SD3.9) Females: 29.3% Ethnicity: 16.5% 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 FEP with greater than 12 weeks previous antipsychotic treatment	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
Turner et al. 2009[26] New Zealand Focus: 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 Exclusions: IQ<70 Those in the criminal justice system	As above	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

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
Conus et al. 2010[32] Australia Focus: Rates and predictors of service disengagement Setting: A stand-alone EIS in Melbourne	EPPIC	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
Anderson et al. 2012[15] 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)

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
Stowkowy et al. 2012[33] 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
Zheng et al. 2013[27] Singapore Focus: Rates and predictors of disengagement Setting: Stand-alone EIS in Singapore	EPIP (Early Psychosis Intervention Program) Established 2001 MDT case management, medical treatment and psychosocial interventions	Sample size: 775 Population: FEP or minimal prior treatment Age: 15-40 years Mean age: Not reported 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	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	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)

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
Chan et al. 2014[34] Hong Kong Focus: Prevalence and predictors of disengagement Setting: A stand alone EIS in Hong Kong	EASY (Early Assessment Service for Young people with psychosis) Established 2001 3 main components: Public education Easy referral process 2yr 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	Continuous default of appointments till the end of 2ears 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 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
Ouellet-Plamondon et al. 2015[25] Canada Focus: A comparison of the effect of immigration status on service engagement in EIS Setting: 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)

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
Albert et al. 2017[29] Denmark Focus: Comparison of 5 years of OPUS model vs 2 years of OPUS plus 3 years TAU Setting: 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	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
Maraj et al. 2018[24] Canada Focus: Disengagement and immigrant groups Setting: A stand-alone EIS in Montréal	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 Diagnoses: Affective or non-affective psychosis with <1-month medication Exclusions: Organic conditions, Pervasive developmental disorder IQ<70 Epilepsy Substance induced psychosis	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: - Age (first generation immigrants) - Material deprivation (second generation immigrants) - Medication non-adherence (all groups) Disengagement was not affected by immigrant status or ethnicity	The overall disengagement rate at 2 years was 24.2% (n = 72)

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
Solmi et al. 2018[35] England Focus: Predictors of disengagement Setting: 6 stand-alone EIS in a mixed rural and urban setting in East Anglia	NHS EIS's in East Anglia* MDT care up to 5 years Pharmacological and psychological interventions, family and social support, supported employment, and physical health care checks	Sample size: 786 Population: 'suspected' FEP Age: 16-35 years Mean age: Not reported Females: 33.2% Ethnicity: 74.8 % White 25.2 % Black Diagnoses: Not reported Exclusions: Intellectual disability Organic conditions	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 - A duration of illness between 5-8 weeks (compared to 0-4 weeks)	The overall disengagement rate at 3 years was 11.7% (n = 92) A total of 59.4% (n = 467) participants were discharged early, 5.1% (n = 40) to another service Median time in treatment for those who disengaged was 15.0 months (IQR = 8.2-21.2).
Kim et al. 2019[28] Australia Focus: Rates and determinants of disengagement and re-engagement Setting: A stand-alone EIS in Melbourne	EPPIC	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, 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-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 (2nd degree relative but not 1st degree) - Cannabis use There were no predictors of re-engagement	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 166.5days (SD ±178.9, IQR = 64.25 – 321.75) The mean duration of first episode of disengagement was 82days (SD±83.7)

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. 2019[36] Hong Kong Focus: Rates and predictors of disengagement comparing 15-25 vs 26 to 64-year olds in EIS Setting: 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 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 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 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. 2019[36] USA Focus: Treatment retention in an integrated Co-ordinated Speciality Care (CSC) service Setting: An integrated service in a community mental health setting for FEP in Texas	Co-ordinated Speciality Care for FEPI 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. 2019[37] Canada Focus: Vocational inactivity and disengagement Setting: A stand-alone EIS in Montréal	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 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. 2019[21] Australia Focus: Community and service level factors associations with disengagement Setting: A stand-alone EIS in Melbourne	EPPIC	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 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/ 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
Iyer et al. 2020[6] 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. Both comprise low dose antipsychotics, case management in Canada 1:22-25 and in India 1:30-35, psychoeducational and psychosocial interventions	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 1% (n=2) in the Indian cohort
Golay et al. 2020[38] Switzerland Focus: Rates and predictors of disengagement Setting: Treatment and early intervention in Psychosis 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 -Patents who committed offenses during the treatment period -A diagnosis of schizophreniform/ brief psychotic disorder	The overall disengagement rate at 36 months was: 6.3% (n=21)

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. 2007[39] New Zealand Focus: 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 The team treats up to 40 patients at one time and comprises a psychiatric nurse, family worker, occupational therapist, psychiatrist and psychologist.	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 Diagnoses: Schizophrenia Exclusions: Unclear	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 (igreater impairment) - Lower medication adherence	Not measured
Lecomte et al. 2008[40] Canada Focus: 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 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 Diagnoses: Schizophrenia, Schizoaffective disorder, bi-polar, NOS or 'early psychosis' Exclusions: IQ<70 Organic disorders Drug induced psychosis	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. 2011[41] Scotland Focus: Attachment, mentalization and their correlates Setting: 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 Diagnoses: Schizophrenia spectrum disorders, Bi-polar, delusional disorder, mania Exclusions: A primary diagnosis of substance use Head injury Organic disorder	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 al. 2013[42] Scotland Focus: Clinical and premorbid correlates of engagement Setting: 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 Diagnoses: Schizophrenia spectrum disorders, Bi-polar, delusional disorder, mania, major depressive disorder with psychotic features Exclusions: A primary diagnosis of substance use Head injury Organic disorder	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 al. 2015[43] Scotland Focus: Quality of Life associations with symptomology and premorbid adjustments Setting: 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: 23.5(SD7.0) Females: 33% Ethnicity: 90.6% White British Diagnoses: Schizophrenia, Schizoaffective disorder, delusional disorder and bipolar Exclusions: A primary diagnosis of substance use Head injury Organic disorder	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 al. 2016[44] Scotland Focus: Associations between metacognition in FEP and engagement Setting: A stand-alone NHS EIS in Glasgow and Clyde	NHS EIS 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, bi-polar, delusional disorder, mania Exclusions: A primary diagnosis of substance use Head injury Organic disorders	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

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
Casey et al. 2016 England Focus: Predictors of engagement in FEP Setting: An NHS stand-alone EIS in Birmingham	NHS EIS Birmingham*	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	Weaker engagement was predicted by: - The belief that social stress causes mental illness	N/A

Abbreviations
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
* The 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
☐ = Disengagement studies

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. [27] categorised those who were disengaged, engaged, or in telephone contact. Lau et al., [36] 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. Some excluded anyone who moved whereas others classed them as disengaged unless appropriately transferred; others treated transferees as engaged despite not knowing their final outcome. Solmi et al., [35] and Golay et al., [38] gave a detailed breakdown at the end of treatment period of the participant outcomes and how they were treated in the analysis. 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., [23] counted those who moved without follow up as disengaged which accounted for 6% disengagement; changing the criteria to exclude them reduces their disengagement rate from 24.6% to 19.7%. Zheng et al., [27] 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 CI's).

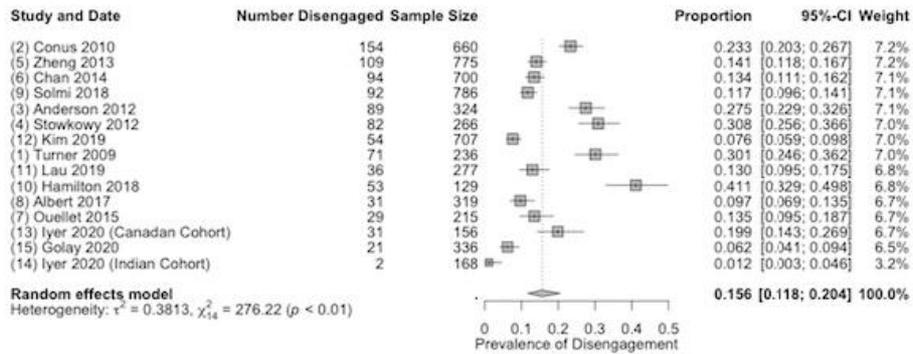Figures 2 A-D. Meta-analysis and meta regression plots

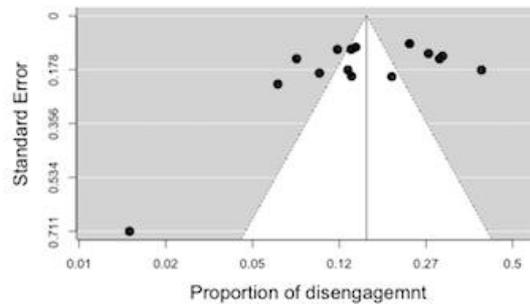Figure 2B - Funnel plot showing publication symmetry

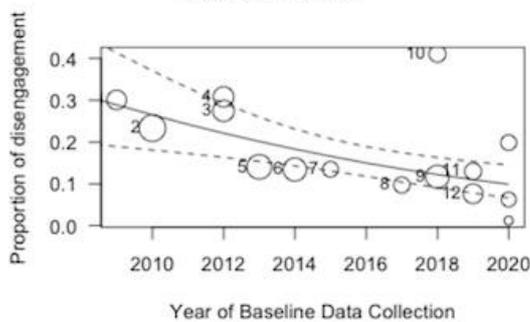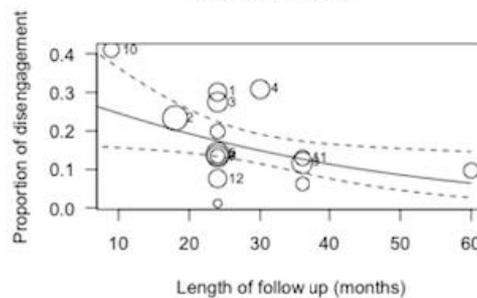Figure 2C – Meta regression plot for disengagement rates by year of start

Figure 2D – Meta regression plot for disengagement rates length of follow up

Publication Bias

Non-comparative studies such as these that report proportion of patients who are 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 [31] (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 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), increasing to a slightly stronger and highly significant effect (QM(1)=18.21, p<.0001) when an influential case (Z=2.13) [7] is removed (R2=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 (R2=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 factors like improvements to research design over the last few decades, such as a better understanding of reengagement patterns or the development of more effective care models.

For example, Kim et al., [28] 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 by

researchers. Despite having the longest follow up time of 5 years, Albert et al., [29] reported one of the lowest disengagement rate of 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 rates of 6.3% [38] 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. [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., [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 [6,34,36] or explicitly excluded people with substance use disorder [27] (see predictors of disengagement below). The Indian cohort reported disengagement rates of just 1% and was the only one in the sample funded by a non-government organisation.

Time to disengage

9 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 [49] the others reported a mean or median time to disengage. The average time to disengage varied from 5 months [15] to 22.4 months [34] 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 [26] 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 [40–44] used the clinician rated service engagement scale (SES) [50], Casey et al. [45] used the subjective patient measure, SOLES (Singh O'Brian level of engagement scale) [51]. The seventh study used a clinician rated strength of engagement Likert-scale [39].

All of these studies were limited by their small sample size (n=34-118), although Casey et al., [45] used bootstrapping and Windsorizing 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 [52] and more willingness to complete outcome measures [6].

Predictors of Engagement

Table 3 shows the 14 most frequently reported predictors across the studies

Where disengagement is categorised [28,36], the results for complete disengagement have been used

Table 3. Main Predictors of disengagement or strength of engagement

Author and date	Predictor of disengagement																		Predictors of strength of engagement				
	Schimmelmann et al., 2006 (EPPIC, Melbourne)	Turner et al., 2007 (Totara Hse, Christchurch)	Turner et al., 2009 (Totara House, Christchurch)	Conus et al., 2010 (EPPIC, Melbourne)	Anderson et al., 2012 (PEPP, Montréal)	Stowkowy et al., 2012 (Calgary EIS)	Zheng et al., 2013 (EIS Singapore)	Chan et al., 2014 (EASY, Hong Kong)	Ouellet-Plamondon et al., 2015 (2 EIS Montréal)	Maraj et al., 2018 (PEPP, Montréal)	Solmi et al., 2018 (NHS EIS East Anglia)	Kim et al., 2019 (EPPIC, Melbourne)	Lau et al., 2019 (EASY, Hong Kong)	Hamilton et al., 2018 (Co-ordinated care, Texas)	Maraj et al., 2019 (PEPP, Montréal)	Reynolds et al., 2019 (EPPIC, Melbourne)	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 and Clyde NHS EIS)	MacBeth et al., 2016 (Glasgow and ClydeNHS EIS)	Casey et al., 2016 (NHS EIS Birmingham)
Age	×	×		×		×	×	×		↑	×	↑	↓	×	×		↓	×					×
Male gender	×	×		×	×	×	×	×	×	×	×	×	↓	×	×	×	×	×	↑	↑	↓		×
Minority race/ ethnicity or immigration status		×			↑		↑		↑	×	×				↑	×							×
Living alone/ without family or no family member involved in treatment	↑	×		↑	×	↑	×		×	×			×		×		↑	×					×
NEET (not in education or employment)	×	×	↑	↑			×				↓	↑			↑			×					
Education levels						↓	×			↑			×					×					↑
Contact with the criminal justice system				↑									×				↑			↑			
Duration untreated psychosis	×	↑		×		↓	↑	×					×		×			×					×
Global functioning	↑		↑	↑			×		↑	×								×					
Negative symptom severity		×				↓	×	↓			↓		×		×		×		↑		↑	↑	
Positive symptom severity		×				×		↓			↓		×				×				↑	×	
Total symptom severity	↓	↓		↓	×													×			↑		
Past, persistent or baseline substance use	↑	↑		↑	×	↑		↑	×	↑	↑	↑				×	×						
Medication compliance										↓		↓			↓		↓		↓				

↑ = Disengagement is predicted by higher prevalence of predictor   ↓ = Disengagement is predicted by lower prevalence   × = Probability of any effect is not significant >.05

Consistent Findings

The most robust predictors of disengagement were substance use and poor medication adherence. Consistent with previous findings [8] 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 [33]. Of the four that found no effect, three included alcohol within their definition of substance use [6,15,26] and one was focused on an immigrant sub-sample [24].

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 [39,42,44]. 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 [53].

Results also suggest that minority status is a strong predictor of disengagement [7,15,25,27] however, cultural differences in the studies' origins makes comparisons difficult (see demographics in Table 2) and may suggest different reasons for disengagement such as spirituality [27] or community stigma [15]. One study [24] 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 [22,32]. However, measures lack consistency, and more research is needed to understand the role of family support, family contact with services and living arrangement on disengagement; particularly over the course of treatment rather than just baseline measures.

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 [32,38] or weaker engagement[40].

Mixed Findings

Of the mixed results, 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) [26,28,32,37]. One that specifically focused on the impact of NEET [37] 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 al., [35] 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 [23,27] and one was a sub-sample of adolescents [22] 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 an effect for an older age group (26-65 year olds) [36] 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[24]. Significant findings for male gender are attributed to

either service level factors: the presence of a male therapist [7], interpersonal style of staff [39] or co-occurrence of forensic history for males in the treatment program [40].

Discussion

This review sought to establish the rates and predictors of disengagement in EIS FEP populations. In contrast to Doyle's [8] 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 in 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 that 19%, in contrast, Doyle's 2014 systematic review [8] 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 [28,36] and the recent inclusion in the literature of three Asian studies and one Indian cohort

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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 [34,36] reported low rates of substance abuse in their cohorts; Zheng et al., [27] 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 [27] or those with drug induced psychosis [34,36].

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 [7] whereas, one of the lowest reported disengagement rate of 9.6% was from a 5 year EIS program [29]. 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 [52] which is related, in the wider literature to stronger service engagement [54,55]. These studies do, however, add evidence to our findings that poor medication non-adherence[39] and contact with the criminal justice system[40] is associated with disengagement and weak engagement[39,42,44]. 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 [8,56]. 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 [57]. 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 [58] 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 [59–61] 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., [37] 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., [27] 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., [15] 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 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.

Conflict of interest

The authors declare no conflict of interest

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