



The association between community and service level factors and rates of disengagement in individuals with first episode psychosis

Siobhan Reynolds^{a,b}, Ellie Brown^{a,b,d}, Da Jung Kim^{a,b}, Hellen Geros^{a,b}, Holly Sizer^{a,b}, Scott Eaton^{a,b,c}, Rachel Tindall^{a,b}, Patrick McGorry^{a,b}, Brian O'Donoghue^{a,b,c,*}

^a Orygen, The National Centre of Excellence in Youth Mental Health, 35 Poplar Road Parkville, Victoria 3052, Australia

^b Centre for Youth Mental Health, The University of Melbourne, 35 Poplar Road, Parkville, Victoria 3052, Australia

^c Orygen Youth Health, 35 Poplar Road, Parkville, Victoria 3052, Australia

^d Deakin University, IMPACT Strategic Research Centre, School of Medicine, Geelong 3220, Australia

ARTICLE INFO

Article history:

Received 23 January 2019

Received in revised form 21 May 2019

Accepted 26 May 2019

Available online 5 June 2019

Keywords:

Disengagement
First-episode psychosis
Psychotic disorders
Psychosis
Schizophrenia

ABSTRACT

Introduction: Individuals who experience a first episode of psychosis require early intervention and regular follow-up in order to improve their prognosis and avoid long-term negative outcomes. However, approximately 30% of individuals accessing support will end up disengaging from early intervention (EI) services. Although we know that individual factors can impact rates of disengagement, less is known about potential service and community level factors.

Methods: Data were gathered from a cohort of individuals attending a specialist youth mental health service in Melbourne, Australia between 1st January 2011 and 7th September 2014. Data were collected from clinical files and electronic medical records using a standardised audit instrument. Cox regression analysis was used to identify whether community level factors were predictors of disengagement.

Results: Data were available for 707 young people experiencing a first episode of psychosis. Individuals residing in neighbourhoods of higher social deprivation were at a higher relative risk of disengaging, with 4.7% increase in engagement for each increase in decile of deprivation. The introduction of a new clinic was not significantly associated with a difference in the proportion of individuals disengaging from the service and distance to service was not significantly associated with disengagement rates.

Discussion: Developing strategies focused on engaging young people with first episode psychosis who reside in more deprived areas may address the higher rates of disengagement these individuals experience. These findings suggest that location may not be a barrier to engagement, however services should be resourced in-line with the population demographic in their specific location.

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1. Introduction

It is well recognised that a first episode of psychosis (FEP) requires early intervention and appropriate sustained treatment to avoid poor clinical and functional outcomes (The Schizophrenia Commission, 2012). Disengaging from Early Intervention (EI) services has been associated with more severe psychopathology, an increased risk of relapse and hospital admissions, socio-functional decline, and poorer prognosis (Macbeth et al., 2013). Despite the established benefits of remaining under the care of an EI service, rates of disengagement from treatment are typically around 30% (Doyle et al., 2014a) with a range from 13% to 40% (Chan et al., 2014; Doyle et al., 2014b; Garety and Rigg, 2001). Understanding the factors that may contribute to disengagement

could help to identify areas of intervention to improve the engagement of this population.

Previous literature on disengagement in FEP has focussed on individual and disorder specific factors that lead to disengagement with services, such as age, co-morbid substance abuse, duration of untreated psychosis (DUP), symptom severity at baseline, and level of family support (Doyle et al., 2014a). For example, we recently reported findings from a cohort of 707 young people experiencing FEP (Kim et al., 2019), concluding that individuals who; were not in employment, education or training (NEET); did not have a family history of psychosis in second degree relatives; and had co-morbid cannabis use were more likely to disengage. It was hoped that identifying individuals more likely to disengage would inform the development of targeted preventive strategies and treatment adaptations (Stowkowy et al., 2012). However there has been limited consensus between studies (Doyle et al., 2014a; Nose et al., 2003) making the development of such strategies to tackle disengagement a challenge. In addition, there is growing global

* Corresponding author at: Orygen Youth Health, 35 Poplar Rd, Parkville, VIC 3052, Australia.

E-mail address: brian.odonoghue@orygen.org.au (B. O'Donoghue).

evidence that mental disorders are socially determined (Lund et al., 2018), with social and economic factors directly influencing illness prevalence and severity. It stands to reason therefore that these societal factors may also influence disengagement from mental health service. Support for this comes from a study in the USA and Canada, which found that lower socio-economic status was associated with disengagement from general outpatient mental health services (Edlund et al., 2002). A more recent study from Canada found material deprivation predicted disengagement in second-generation immigrants with FEP (Maraj et al., 2017). In addition, a study from the UK found that individuals living in more deprived areas had higher rates of relapses of psychotic disorders (Puntis et al., 2018). It is plausible that if there are higher rates of disengagement in these areas, this could in part contribute to the risk of relapse and also potentially lengthen the time taken for the relapses to be identified and treated.

The importance of service and community level factors of disengagement from EI services have been proposed as potential new targets to inform service protocols aimed at reducing rates of disengagement (Lal and Malla, 2015; Smith et al., 2013). For example, the availability, type, and accessibility of EI services are variables that may be augmented to improve disengagement rates (Bechard-Evans et al., 2007). There is potential that by tailoring services to the communities they represent – by ensuring their accessibility, and considering how resources are allocated to populations most in need – could improve engagement (Kirkbride and Jones, 2013). To date however, no such empirical evidence exists. For example, location of services, and thus their accessibility, is often thought to be a global barrier to accessing and remaining engaged with healthcare providers (Ballon et al., 2004; Brown et al., 2016; Elliott and Larson, 2004; Myers et al., 2010) however this view typically comes from subjective data from questionnaires or interviews.

The present study aimed to look at the impact of a number of community and service level factors on rates of disengagement in a population of young people experiencing first episode psychosis. The factors we were able to examine were the impact of the neighbourhood, i.e. levels of social deprivation and social fragmentation, the distance to the EI service from the individual's place of residence, and whether establishing a clinic in a new location was associated with a change in disengagement rates.

2. Methods

2.1. Setting

This sample comprised a population-based cohort of individuals with FEP, consecutively admitted to the Early Psychosis Prevention and Intervention Centre (EPPIC) service in Melbourne, Australia between 1st January 2011 and 7th September 2014. The EPPIC service is a specialist youth mental health service that provides multi-disciplinary care for young people with FEP between the ages of 15 and 24 managed by Orygen Youth Health. Individuals are referred by multiple avenues such as local mental health services, general practitioners, law enforcement agencies, community support services, family members and friends, and by self-referral.

The service caters for a large catchment area (approx. 1500 km²), covering the north-west suburbs of Melbourne, and includes 59 different postcodes and a population of approximately 1.2 million. Initially, all individuals accessing EPPIC were seen at an outpatient clinic in the suburb of Parkville, until the introduction of a second clinic in the suburb of Sunshine in July 2013.

During their 24 months of treatment at EPPIC, individuals benefit from various components of the service. Treatment and support is provided at regular case management sessions with psychologists, social workers, outreach services, family support and addiction services, with regular medical reviews by consultant psychiatrists. Individuals are treated according to the Australian Clinical Guidelines for Early Psychosis (Early Psychosis Guidelines Writing Group, 2016). Services

operate Monday-Friday, 9 am to 5 pm, with out-of-hours cover from an acute crisis team (Youth Access Team) services between 5 pm and 10 pm. Orygen Youth Health also operates a 16 bedded inpatient unit in Footscray, a suburb approximately half way between Parkville and Sunshine.

2.2. Participants

Individuals included in this study were those identified as having FEP. This was defined as having a DSM-IV or DSM-V diagnosis of schizophrenia, schizophreniform disorder, schizoaffective disorder, substance-induced psychotic disorder, delusional disorder, bipolar disorder with psychotic features, major depressive disorder with psychotic features, brief psychotic disorder, and psychotic disorder not otherwise specified (NOS). Clients were given a provisional diagnosis at 3 months, then reassessed at discharge from service by the treating consultant psychiatrist.

Individuals were able to access EPPIC if they (i) had a diagnosis of FEP as outlined above (ii) were aged of between 15 and 24 years at the time of presentation; (iii) resided within the North-Western catchment area at the time of presentation; and (iv) had no previous history of a psychotic disorder. Individuals with comorbid substance misuse or dependence, comorbid personality disorders, and intellectual disability were included.

2.3. Design and procedure

This is a naturalistic cohort study in which the data were recorded prospectively but collected retrospectively from clinical files. Demographic and clinical data were extracted from clients' paper files and electronic medical records using a specifically designed audit tool. The data form part of a dataset in which treating clinicians were responsible for collecting original data with researchers transferring these data to the study database.

2.4. Variables

Data were collected on individuals' socio-demographics, location and living status, primary treating team and treatment location. A number of other socio-demographic and clinical factors were collected, including; age, gender, marital status, employment/education/training status (those who are 'not in education, employment or training' are identified as 'NEET'), duration of untreated psychosis, family history of psychosis (first and second degree relative), type of psychotic disorder (non-affective vs. affective), comorbid substance abuse, alcohol, amphetamine, and cannabis use. The primary outcome of interest, whether individuals had disengaged, comprised of two aspects: whether it had occurred; and how many episodes there were.

2.4.1. Disengagement

Disengagement was defined using the definition adopted by Conus and colleagues, and was rated as present "if case notes suggested patients actively refused any contact with the treatment facility or were not traceable" (Conus et al., 2010). This definition of disengagement does not include a set length of time that an individual needs to be non-contactable for to be considered disengaged. Rather that it is declared so by the treating team. Case notes often clearly stated that disengagement had occurred. Furthermore, the case notes also showed that case managers and the mobile intensive treating team made extensive efforts to re-engage individuals by repeated phone-calls, letters to individuals and their families, and home visits throughout the treatment period. This is in accordance with the services 'principles of practice', a series of guiding principles within a defined service delivery model for clinicians. The date of last face-to-face contact between the case manager and a disengaged individual was considered as the date of disengagement. Individuals were not considered to have disengaged if they

moved out of area and if they informed the clinical team of their move. In these cases, the clinical team would refer the young person to an appropriate service in their new area of residence.

2.4.2. Neighbourhood characteristics

Social deprivation is a term used to describe relative socio-economic disadvantage within the community. The following data were used as the construct of social deprivation for this study. Neighbourhood demographic data were collected from publicly available components of the Australian National 2011 Census for all 665 postcodes in the Australian State of Victoria. This data included the total population within a postcode as well as the total population aged 15 to 24 years. The Australian Bureau of Statistics have used this census data to develop the 'Socio-Economic Indexes for Areas (SEIFA)' which ranks areas in Australia according to relative socio-economic advantage and disadvantage. The SEIFA consists of four indexes, each being a summary of a different subset of Census variables and focuses on a different aspect of socio-economic advantage and disadvantage. The index used in this current study was the Index of Relative Socio-Economic Disadvantage (IRSD) which is a general socio-economic index that summarises a range of information about the economic and social conditions of people and households within an area. For example, an area would have a low score if there are: many households with low income, many people with no qualifications, or many people in low skill occupations. Within the IRSD, all areas are ordered from lowest to highest score, the lowest 10% of areas are given a decile number of 1, the next lowest 10% of areas are given a decile number of 2 and so on, up to the highest 10% of areas which are given a decile number of 10. This means that areas are divided up into ten equal sized groups, depending on their score. As a result, each suburb is given a disadvantage decile; 1 representing the most disadvantaged and 10, the least disadvantaged.

To determine social fragmentation, we used the measure developed by Congdon and colleagues, which has been utilised in a number of other studies examining the association between social fragmentation and psychotic disorder incidence (Congdon, 1996; O'Donoghue et al., 2016b; Omer et al., 2014). This measure of social fragmentation is composed of four variables collected in National Censuses: the percentage of single-person households, dwellings rented, persons having lived at a different address one-year prior, and (socially defined) unmarried persons. Data for these variables were collated for all 58 included postcodes in the catchment area (3026 was not included as it had a population-at-risk of just 6). Sample mean and standard deviation were calculated for each of the four census variables. For each postcode, the deviation from the mean (z-score) was calculated for each of these census variables. For the census variable of the percentage of persons having lived at a different address one-year prior, all negative z-scores were multiplied by negative one to give a positive value, as a negative value still represents a positive level of population mobility (i.e. mobility out of the postcode). The social fragmentation score for a postcode is the sum of the postcode's z-scores for each of these four census variables.

2.5. Data analysis

Statistical analysis was performed using SPSS version 25 software. We used descriptive statistics to describe the cohort and rate of disengagement from EI services, average time to disengagement and the number of periods of disengagement. Chi-Square and Mann-Whitney Tests were used to analyse service factors such as distance to clinic used. The relationship between neighbourhood characteristics and disengagement was analysed using univariate and multivariate Cox regression analysis. For disengagement, time-to-event was defined as the number of days from first contact recorded with services until disengagement from services. This analysis was used to determine hazard ratios (HRs) and adjusted HRs (aHRs) with 95% confidence intervals (CIs) for predictors of disengagement, as it is a time dependent variable. A HR of 1 indicates the same relative risk of disengagement compared to the

reference group (did not disengage); an HR < 1 indicates lower relative risk, and an HR > 1 indicates higher relative risk. First, univariate analysis was conducted in which social deprivation and social fragmentation variables were entered into Cox regression models, with a separate analysis conducted for each. Following this univariate Cox regression analysis, multivariate analysis (using the Enter method) was undertaken using variables that we knew were significant predictors of disengagement in our population (Not being in education, employment or training (NEET), having a second degree relative with history of psychosis and cannabis abuse, Kim et al. (2019)). Missing values (which was minimal), were excluded from the analysis. Finally, the correlation between parametric continuous variables was calculated using Pearson's correlation (r).

2.6. Ethics

This study was approved by the Royal Melbourne Human Research and Ethics Committee as a quality assurance project (ref: QA2018034). As the data was collected retrospectively and a full cohort was required to ensure representativeness and generalisability, a waiver of consent was approved by the governing ethics committee.

3. Results

3.1. Participant demographics

A total of 707 individuals presented with FEP between 1st January 2011 and 3rd September 2014. The mean age of the cohort was 19.3 years (SD ± 2.9), and 60.1% of the sample were male. Approximately 20% of the sample had a 1st degree family history of a psychotic disorder, with 20% also having a history in second degree relatives. A total of 37.4% (N = 262) had a diagnosis of schizophreniform disorder or schizophrenia at baseline assessment and 16.0% (N = 112) had a diagnosis of bipolar affective disorder. Co-morbid substance use in the total cohort was 60.0%. These demographics and baseline clinical characteristics of the population can be found in Table 1.

Table 1
Demographic and clinical characteristics of total cohort.

	Total sample (n = 707)
Age (M ± SD, n = 695)	19.3 ± 2.9
Male sex (N (%), n = 707)	425 (60.1%)
Not married (N (%), n = 701)	673 (95.2%)
Living with parents (N (%), n = 701)	457 (65.3%)
Not in employment, education or training (NEET) (N (%), n = 700)	292 (41.7%)
Family history of psychosis (N (%), n = 700)	
First-degree relative	140 (20.0%)
Second-degree relative	141 (20.1%)
Diagnosis at baseline (N(%), n = 700)	
Schizophrenia	188 (26.9%)
Schizophreniform disorder	74 (10.6%)
Schizoaffective disorder	52 (7.4%)
Delusional disorder	12 (1.7%)
Substance-induced psychotic disorder	55 (7.9%)
Bipolar affective disorder	112 (16.0%)
Depression with psychosis	49 (7.0%)
Psychotic disorder NOS	98 (14.0%)
Brief psychotic disorder	13 (1.9%)
Not differentiated	47 (6.7%)
Substance use disorder (N(%), n = 701)	
Any co-morbid substance use	421 (60.0%)
- Alcohol	121 (17.3%)
- Cannabis	371 (52.9%)
- Amphetamine	189 (27.0%)
- MDMA	41 (5.85%)
DUP, weeks (Median (I.Q.R.), n = 596)	8 (2–32)

3.2. Disengagement

The proportion of individuals who disengaged from the service in this cohort was 55.7% ($n = 394$), of which 42.9% had one period of disengagement, 27.2% had two periods of disengagement, 18.8% had three periods, and 11.2% had four or more. The mean time to first disengagement was 214.7 days (median of 166.5), approximately 7 months.

3.3. Community factors (neighbourhood characteristics)

3.3.1. Social deprivation

Data on level of social deprivation were available for 690 young people within the 707 sample. Within this cohort, 28% ($N = 195$) of young people lived in neighbourhoods with the highest level of disadvantage and 68.9% ($N = 480$) resided in neighbourhood below the median level of disadvantage. In the sub-group of young people who had an episode of disengagement, the median decile of level of disadvantage was 3 (I.Q.R. 1–6) indicating a high level of disadvantage. In those who did not disengage, the median decile of the level of disadvantage was 4 (I.Q.R. 2–7). Using Cox regression analysis, the level of social deprivation classified according to deciles was found to be associated with disengaging from services, with each increase in decile towards most disadvantaged area representing a 5% increased risk of disengaging ($HR = 1.047$, 95% CI. 1.01–1.09, $p = 0.014$).

In order to control for potential individual factors that may confound this relationship, multivariable Cox regression analysis was performed and included the three individual level factors known in this cohort to be associated with disengagement (Not being in education, employment or training (NEET), having a second degree relative with history of psychosis and cannabis abuse). When these factors were controlled for, social deprivation remained a significant predictor of disengagement ($HR = 1.044$, 95% CI. 1.01–1.08, $p = 0.022$).

3.3.2. Social fragmentation

Information pertaining to the level of social fragmentation in the area of residence was available for 675 young people within the 707 sample. Of those who disengaged, 53% ($N = 202$) lived in neighbourhoods with the lowest levels of social fragmentation, whilst 47% ($N = 180$) lived in areas with highest levels of social fragmentation. Univariate Cox regression analysis revealed that decile scores of social fragmentation were not a significant predictor of risk of disengaging from services ($HR = 1.003$, 95% CI. 0.97–1.04, $p = 0.86$).

3.4. Service factors (clinic location)

In regards to clinic location, there was one main site for the youth mental health service across the catchment area prior to July 2013, when a further Hub site was established. Therefore, between 1st January 2011 and 1st July 2013, all young people with FEP attended the outpatient clinic situated at the original site (Parkville) and the median distance to this site from all areas of the catchment was 13.7 km (I.Q.R. 6.1–23.8). After the establishment of the second site, the catchment area was separated into two distinct, geographically defined sectors (Region A and Region B) and young people residing in each area attended the corresponding Hub clinic. A total of 136 young people had completed their episode of care prior to the establishment of the new Hub and this group consisted of individuals from all regions of the catchment area. A total of 51.5% ($N = 69$) of this group had an episode of disengagement. During this period, all clients attended the original clinic that was based in Region A. The proportion of young people who resided in Region A and disengaged was 46.6% ($N = 34$) compared to 57.4% ($N = 35$) of young people who resided in Region B (but had to travel to Region A to attend the clinic).

Whilst these data represent a trend towards individuals who disengaged being more likely to have had to travel further, it was not significantly different ($\chi^2 = 1.55$, $df = 1$, $N = 134$, $p = 0.21$). Of those who

disengaged, the median distance to travel to the initial Hub was 13.9 km (I.Q.R. 8.9–22.9) and for those who did not disengage, 10.6 km (I.Q.R. 5.1–24.7), again this difference was not significantly different (Mann-Whitney $Y = 2022.5$, $N = 135$, $p = 0.27$).

We were able to explore whether opening a new clinic in Region B had an impact on disengagement rates, in other words, whether distance to the clinic was associated with the level of disengagement. In July 2013, an additional Hub was opened within Region B, thus reducing the distance to travel to receive services for individuals in the Region B area. The proportion of individuals residing in Region B who disengaged after the introduction of a closer clinic was 65.5% ($n = 112$), compared to 55.6% ($n = 35$) prior to the establishment of the clinic, a non-significant difference ($\chi^2 = 1.948$, $p = 0.163$) but a trend towards individuals disengaging more after the new clinic opened.

3.5. Referral rate and disengagement

In order to establish if rates of disengagement could be associated with the volume of referrals a service experiences, post-hoc analysis of referral rates were examined. It was found that Region A had a relatively constant rate of referrals at approximately 70 per year, whereas there was an increase in referrals in Region B from 82 per year to 137 per year over the 3-year study period.

The mean number of new cases per quarter was 44.5 (sd \pm 9.2) (data were normally distributed). The proportion of individuals disengaging was not correlated with the number of cases (i.e. new referrals of FEP) within each quarter ($r = 0.11$, $p = 0.70$). When this was examined according to region, in Region A, the mean number of new cases per month was 18.1 (sd \pm 3.3) and the proportion of individuals disengaging was not correlated with the number of cases within each quarter ($r = -0.04$, $p = 0.90$). In Region B, the number of new cases per month was 25.5 (sd \pm 7.5) and the proportion of individuals disengaging was not correlated with the number of cases within each quarter ($r = 0.02$, $p = 0.95$).

4. Discussion

In this large, epidemiological cohort of young people with FEP, the overall rate of disengagement was 55.7%, with many of these individuals having multiple episodes of disengagement whereby they subsequently re-engaged and later disengaged again. Individuals residing in neighbourhoods of higher social deprivation were more likely to have an episode of disengagement. The introduction of a new clinic location did not have a significant impact on the rates of disengagement, but it was associated with an increase in referrals.

This is, to the best of our knowledge, one of the only studies to have looked at the association between socio-economic deprivation and disengagement from FEP services. This is despite the well-established link between socio-economic background and a higher risk of psychosis and delayed initial presentation (O'Donoghue et al., 2016a). Both these factors may influence subsequent disengagement from services. In addition, a recent cohort study showed deprivation to be a risk factor for relapse in FEP individuals (Puntis et al., 2018). What Puntis et al. (2018), as well as our current study, were not able to conclude is what it is about living in an area of greater socio-economic deprivation that leads to a greater risk of both relapse and disengagement. Our finding lends supports to the argument that where you live matters (Pickett and Pearl, 2001; Riva et al., 2007). Specifically, services covering more deprived areas could be under-resourced to manage their complex case-load, and indeed be indicative of a further failing of services to cater to this vulnerable population. Further research is needed in this area to understand resource need and develop tailored care for these individuals.

Another community level factor looked at in this study was the introduction of a new outpatient clinic location. It was anticipated that seeing individuals in a more convenient location for them would reduce

disengagement. Our results suggest that the establishment of a new clinic and thus the distance to service did not have an impact on disengagement. This is one of the first studies to provide empirical evidence linking accessibility to EI services with disengagement rates. One explanation for the lack of impact of distance on disengagement could be that a high proportion (65%) of young people using the EPPIC service live at home with their parents who may support them in accessing services. In addition, it was found that the opening of the new clinic was associated with an increase in referrals and it is possible that these individuals would not otherwise have engaged (due to distance or other logistical barriers) and were now able to access the service. It is possible that the introduction of a new service did not improve disengagement rates because it was not adequately resourced to manage this sudden increase in client-load however, our post-hoc analysis of the correlation between referral rates and disengagement rates did not suggest that this was the case.

4.1. Limitations of study

There are several limitations in this study. As data were collected through clinical file audit, there is the potential that the data quality and validity were limited. However, given that researchers had access to a number of different sources, we are confident that the consistency and reliability of our data was of a high standard. Another limitation is that this study used a specific definition of disengagement not necessarily used in other datasets. However, this is not uncommon (Doyle et al., 2014a) and lends further support to the argument that a gold standard definition of disengagement should be developed and implemented. The measure of social deprivation used in this study was based on statistical data from the Australian Bureau of Statistics. As a result, this relates to the area in which an individual lives, rather than an individual's personal circumstances.

One challenge with comparing disengagement rates before and after the introduction of the Region B clinic was that over the three-and-a-half-year study period, the suburbs covered by each EPPIC team changed as the catchment areas grew, and so some suburbs were reclassified to different Region B sub-teams. It is possible that changing teams had an impact on the individual's therapeutic relationships, potentially confounding our results. Additionally, because we left individuals who may have had part of their treatment at the new clinic and part at main clinic out of our analysis (to reduce confounding), our sample size was substantially reduced. As a result, it is possible that the results related to clinic location were underpowered to detect a difference.

4.2. Future directions

In this study we assessed the impact that introducing a new outpatient clinic location had on rates of disengagement. However, since the study period, there has been introduction of additional EPPIC satellite clinics at two suburbs in North-West Melbourne; Melton and Wyndham Vale. Analysis of data collected since that date will allow us to determine whether the introduction of these clinics had any further impact on disengagement rates. This analysis would provide valuable data for service development and policy, both nationally in Australia, and internationally where EI services are continuing to be developed and implemented.

4.3. Conclusion

In this study we have explored novel community and service level factors that impact on the risk of disengaging from EI services in a large naturalistic cohort attending a specialist service in Melbourne, Australia. Our findings suggest the need to focus on supporting individuals living in areas of higher social-deprivation and gaining a greater understanding of why these individuals might be more likely to disengage from services. Specifically tailoring EI services to the populations they

represent could potentially improve patient engagement. It was interesting to find that when more service locations were introduced, individuals still disengaged at a substantial rate, suggesting that location of service was not a significant barrier to engagement.

Role of funding source

There are no funding sources associated with this project.

Declaration of Competing Interest

The authors do not have any conflicts of interest to report.

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