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Intellectual disability and patient activation after release from prison: a prospective cohort study

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ABSTRACT

Background: Intellectual disability (ID) and patient activation may be important drivers of inequities in health service access and health outcomes for people with ID transitioning from prison to the community. We assessed the association between ID and patient activation after prison release and examined whether this association varied depending on whether ID was identified prior to prison release.

Methods: Overall, 936 prisoners were screened for ID using the Hayes Ability Screening Index (HASI) and completed the Patient Activation Measure (PAM) within six weeks of prison release and again at 1, 3, and 6 months post-release. We estimated the association between ID status and PAM scores using a multilevel linear model, adjusting for sociodemographic, behavioural, health and criminogenic factors. We used propensity score-matching to estimate the impact of being identified with ID prior to release from prison on the change in mean PAM score after prison release.

Results: Compared to those who screened negative for ID, ex-prisoners who screened positive, both with and without prior identification of ID, had significantly decreased mean PAM scores [($B=-4.3$; 95%CI: -6.3, -2.4) and ($B=-4.5$; 95%CI: -6.8, -2.3), respectively] over six months of follow-up. Among those who reported being identified with ID prior to release from prison, a significant increase in PAM score at the six month follow-up interview ($B=5.89$; 95%CI: 2.35, 9.42; $p=0.001$) was attributable to being identified with ID prior to release.

Conclusions: Ex-prisoners screening positive for possible ID have decreased patient activation for at least six months after release from prison. However, individuals whose possible ID is unidentified appear to be particularly vulnerable. Incarceration is a pivotal opportunity for the identification of ID and for initiating transitional linkages to health and ID-specific community services for this marginalised population.

Key Words: intellectual disability; patient activation; prisoners; prospective studies

Intellectual disability and patient activation after release from prison: a prospective cohort study

INTRODUCTION

People with intellectual disability (ID) are over-represented in prisons internationally (Fazel *et al.* 2008, Søndena *et al.* 2008, Hassiotis *et al.* 2011a, Dias *et al.* 2013b). Among adult prisoners with identified ID, predominantly mild to borderline ID is observed (Herrington 2009) often in combination with mental health issues (Soldatic *et al.* 2014, National Mental Health Commission 2013, Vanny *et al.* 2009). Mental health comorbidity often makes mild to borderline ID complex to assess, identify and manage; evidence of ID prior to 18 years is required for a formalised diagnosis, further complicating diagnosis in prison (Soldatic *et al.* 2014, Holland *et al.* 2002). Therefore, ID remains largely 'hidden' in the criminal justice system and without prior identification of ID these individuals often do not qualify for ID-specific services either in prison or after release from custody (Baldry *et al.* 2013, Soldatic *et al.* 2014).

Upon release, ex-prisoners with ID often have complex physical health, mental health and substance use treatment needs (Heslop *et al.* 2014, Dias *et al.* 2013b, Tonge and Einfeld 2003, Dias *et al.* 2013a, Männynsalo *et al.* 2009, Bhandari *et al.* 2015) requiring active engagement with multiple health and support services. A lack of evidence-informed substance use interventions for ex-prisoners with ID makes the development of effective and responsive services for this population challenging (van Dooren *et al.* 2015). However, ex-prisoners who are motivated and supported to engage with the health care system and self-manage their own health-related needs, have improved physical and mental health compared with individuals who are unmotivated or poorly supported (Ludman *et al.* 2013) and may be better equipped to address the challenges of community re-entry.

The Patient Activation Measure (PAM) was developed to provide a measure of the extent to which an individual is 'activated' or motivated to actively participate in managing their own

healthcare (Hibbard *et al.* 2004). Patient activation has been negatively associated with smoking, obesity, hypertension, substance use disorder and depression severity (Greene *et al.* 2015, Salyers *et al.* 2009). Individuals with higher PAM scores are generally more knowledgeable about their health requirements and more likely to adopt healthy lifestyles, follow medical advice and take preventive steps to address their health issues (Fowles *et al.* 2009, Mosen *et al.* 2007, Hibbard and Tusler 2007).

Patient activation after release from prison is likely an important driver of inequities in health service access and health outcomes for ex-prisoners with ID transitioning to the community. However, to our knowledge the association between ID and patient activation after release has not been explored. Therefore we aimed to 1) identify prisoners screening positive for possible ID, including those who have had their ID previously identified and those with possible ID who have not been identified by a clinician or ID-specific services; 2) assess the association between ID status and PAM score over six-months post-release; and 3) examine whether prior identification of ID predicts temporal changes in PAM score after release.

METHODS

Participants

This study used data from the Passports study, a randomised controlled trial of a service brokerage intervention described elsewhere (Kinner *et al.* 2013, Kinner *et al.* 2014, Kinner *et al.* 2016). Briefly, a total of 1325 adult (≥ 18 years) prisoners from seven prisons in Queensland, Australia completed a baseline interview within six weeks of expected release from custody between 1 August 2008 and 31 July 2010. Follow-up interviews were administered 1, 3, and 6 months post-release in the community or in custody for participants re-incarcerated at the scheduled follow-up. All participants provided informed, written consent.

Measurements

Baseline self-report measures included age, sex, Indigenous status, relationship status (married/stable relationship versus unstable relationship/single), years of school completed (<10/≥10 years), social visits in the previous month in custody (none/any), transitional program participation (yes/no), juvenile incarceration history (yes/no), and history of traumatic brain injury (TBI) and/or lead poisoning (yes/no).

Longitudinal self-report measures assessed at each follow-up included location of the follow-up interview (community/prison), living arrangements (living with others/alone), type of accommodation (stable/unstable), and employment status (employed/unemployed). If the follow-up interview was conducted in custody, the reported measure referred to the follow-up period in the community prior to being re-incarcerated.

Administrative Data Sources

Previous history of adult incarceration, parole conditions, and admission and release dates for re-incarceration during the follow-up period were evaluated by deterministic record-linkage using a unique prisoner identification number from Queensland Corrective Services (QCS). For those reincarcerated during follow-up, total days in prison after baseline release was calculated for each participant, censored at the last interview date. Total days in the community was calculated by subtracting total days in prison from total days under observation (i.e., from date of release after baseline interview to the date of last follow-up interview completed). Prior adult prison sentences were collapsed dichotomously to indicate whether the baseline prison sentence was an initial or repeat incarceration. Parole status on the day of release was assessed as a binary variable (parole/no parole).

Pre-incarceration mental health disorders were identified by probabilistic data-linkage with emergency department (ED) and hospital records. International Classification of Diseases, 10th edition, Australian Modification (ICD-10-AM) codes were used to ascertain mental health disorders from ED presentations and hospital separations where mental illness (F01-F09; F20-F99) and/or a substance use disorder (SUD) (F10-F19) was indicated as a primary or

secondary diagnosis (National Centre for Classification in Health 2004). Individuals who had diagnoses of both mental illness and SUD during the same hospital separation or had ED presentations for both mental illness and SUD prior to baseline were considered positive for dual disorder. As a proxy for chronic physical comorbidity, hospital separation ICD-10-AM codes were used to generate a Charlson Index score (Charlson *et al.* 1987, Sundararajan *et al.* 2004). Medically-verified hepatitis C virus (HCV) infection was identified by probabilistic data-linkage with a statewide notifiable conditions register (Department of Health 2016b). The probabilistic data-linkage methodology used in this study has been previously validated (Brameld *et al.* 1999) and described in detail elsewhere (Department of Health 2016a).

In-prison health encounters

Data from in-prison participant health encounters were extracted from prison medical records by two trained researchers. International Classification of Primary Care, 2nd Edition (ICPC-2) codes were used to identify healthcare encounters in prison with an associated diagnosis of mental illness (P70-P76; P79-P82; P86; P98; P99) and/or SUD (P15; P18; P19) (ICPC-2 1998). Individuals with both mental illness and SUD during their prison sentence were considered positive for dual disorder.

A composite variable was created with exclusive categories for no disorder, mental illness only, SUD only, and dual disorder by aggregating pre-incarceration ICD-10-AM diagnoses and ICPC-2 diagnoses in-prison.

Ascertainment of exposure – ID status

All participants were screened for ID using the Hayes Ability Screening Index (HASI) with scores <85 (range: 48.7-96.4) indicating possible ID according to standard practice (Hayes 2000). Although potentially over-inclusive of borderline ID, the HASI has been established as valid for the identification of ID in prisoners (Hayes 2000) with excellent inter-rater reliability when scored separately by multiple researchers (Young *et al.* 2015). Baseline ID status was categorised into two 'exposure' groups, herein referred to as 'ID prior-identified' and 'ID not-

identified', and a comparison group who screened negative for ID. The ID prior-identified group screened positive on the HASI and self-reported a history of (a) attendance at a special school, and/or (b) a diagnosis of ID from a clinician, to increase the specificity of ID ascertainment (Dias et al. 2013b). The ID not-identified group included all participants who screened positive on the HASI but reported no additional ID-specific service or special school contact; thus likely ascertaining previously unidentified or service-naïve possible ID cases.

Study outcomes

The primary study outcome was score on the 13-item PAM (Hibbard *et al.* 2005), a non-condition specific, valid measure for quantifying engagement with, and the capacity to self-manage, healthcare (Hibbard et al. 2004). Specifically, the PAM assesses the skills, knowledge and confidence required for effective, sustained self-care. The PAM has been established as a reliable predictor of healthcare engagement and health outcomes for disadvantaged and marginalised populations (Lubetkin *et al.* 2010, Gerber *et al.* 2011, Salyers et al. 2009, Greene et al. 2015). The PAM was administered at baseline and at 1, 3, and 6 month follow-up interviews. A total scaled PAM score (range: 0-100) was calculated at each time-point for each participant (Hibbard et al. 2005). Participants lost to follow-up, those who only had in-prison follow-up interviews with no prior days in community and those with incomplete data on the PAM were excluded from analysis.

Statistical Analyses

Descriptive statistics were calculated for all variables. T-tests and unadjusted logistic regression were initially used to compare differences between those included and excluded in analyses. Crude differences between ID prior-identified, ID not-identified, and No ID groups were compared using unadjusted linear regression and chi-squared analyses for continuous and categorical outcomes, respectively.

We modelled total PAM scores as a function of ID status, time, and sociodemographic, behavioural, health and criminogenic factors. To account for correlation between repeated measures, we used a multilevel linear model with a random intercept and slope at every time point for each individual. The parameters in the covariance matrix were estimated using an unstructured covariance matrix.

All models were adjusted for sex, age, Indigenous status, relationship status, years of school completed, participation in transitional programs, parole status upon release, juvenile incarceration history, prior adult prison sentences, history of TBI or lead poisoning, pre-release mental health diagnoses, HCV exposure, Charlson Index of comorbidity, and the Passports intervention (Kinner et al. 2013) at baseline. Interview location (i.e., prison versus community), living arrangements, accommodation, and employment status at each interview were fitted as time-varying covariates. Days spent in the community under follow-up was fit as a covariate accounting for differences in follow-up time due to re-incarceration, interview occurrence, loss to follow-up or death.

Sensitivity Analysis

Propensity score-matching was conducted to estimate the impact of being identified with ID prior to release from prison on the change in mean PAM score after prison release.

Specifically, we conducted a sensitivity analysis restricting analysis to participants with possible ID (i.e., the ID prior-identified/ID not-identified groups only). To adjust for pre-existing, systematic differences between the 'exposure' groups we estimated the propensity of being identified with ID prior to prison release. A propensity score (Rosenbaum and Rubin 1983) was generated with the outcome being ID prior-identified/ID not-identified (coded as a dichotomous variable) and all covariates from the final model plus quadratic and interaction terms. Individuals from the ID prior-identified group were then matched on estimated propensity score to their nearest neighbour (2:1) with replacement from the ID not-identified group as recommended previously (d'Agostino 1998, Abadie and Imbens 2011). We report the impact of being identified with ID prior to release for those who reported prior

identification of ID (i.e., the average treatment effect on the treated) on mean PAM score after prison release (Imbens 2004). To test the appropriateness of the matching procedure, standardised differences on baseline characteristics were calculated. All analyses were conducted using STATA v14.1 (StataCorp 2015).

Ethical Considerations

The Passports study was approved by the University of Queensland Behavioural and Social Sciences Ethical Review Committee (Project #2007000607), QCS Research Committee, Queensland Health Human Research Ethics Committee (HREC/11/QHC/40) and Australian Institute of Health and Welfare Ethics Committee (EC2012/4/58). The parent trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12608000232336).

RESULTS

Participant Inclusion

Overall, 256 (19.3%) individuals had no post-release follow-up interviews; 89 (6.7%) had only in-prison follow-up interviews with no prior days in community; and a further 44 (3.3%) were excluded due to missing data. The remaining 936 (70.6%) participants were included in analysis.

Cohort characteristics according to inclusion status are displayed in Table 1. Compared to the No ID group, the ID not-identified group were more likely to be lost to follow-up ($p=0.001$), however no differential loss to follow-up was observed when the ID prior-identified group was compared to the No ID ($p=0.612$) or the ID not-identified ($p=0.103$) groups. Compared with individuals excluded from analysis ($n=389$; 29.4%), the study group was older; and less likely to be Indigenous, have a juvenile incarceration history or prior adult prison sentences. Conversely, participants in the study group were more likely than those excluded to report being in a stable relationship, to have completed 10 or more years

of school, to have had social visits in the past 4 weeks in custody at baseline and to have parole conditions upon release (Table 1).

<Table 1>

Follow-up Interview Timing

PAM assessment occurred at a median (inter-quartile range) of 33 (31-36), 97 (93-117), and 197 (186-235) days after release from prison for the 1, 3, and 6 month follow-up interviews, respectively. The mean total days of community follow-up did not differ between ID status groups ($p=0.234$).

ID status

Study group characteristics overall and by ID status are presented in Table 2. A total of 208 (22.2%) participants screened positive on the HASI for possible ID; this included 83 (8.9%) participants who reported prior identification of ID (ID prior-identified group) and 125 (13.4%) who reported no prior identification of ID or ID-specific service involvement (ID not-identified group). No significant difference in total HASI score (mean \pm standard deviation(SD)) between the ID not-identified (75.8 \pm 7.5) and the ID prior-identified (73.6 \pm 7.7) groups was observed ($p=0.063$). The mean(\pm SD) age of participants was 33.3(\pm 11.3) years, the majority of the study group was male ($n=731$; 78.1%) and 20.2% ($n=189$) were Indigenous. Compared to the No ID group, participants in the ID-screened positive groups were more likely to be male, Indigenous, to have completed less than 10 years of school, and to have a history of juvenile incarceration (Table 2).

<Table 2>

The proportion of participants living alone, unemployed, experiencing unstable accommodation and in custody by interview sequence is displayed in Figure 1. Although variation over time was observed, a greater proportion of the ID-screened positive sub-

groups reported living alone, being unemployed, having unstable accommodation, and being in prison at the six month follow-up (Figure 1).

<Figure 1>

ID status and PAM scores

The unadjusted mean PAM score is presented by ID subgroup and interview sequence in Figure 2. The mean(\pm SD) baseline PAM scores for the No ID, ID not-identified and ID prior-identified groups were 69.0(\pm 17.4), 66.6(\pm 18.1) and 61.9(\pm 15.5) and the mean(\pm SD) PAM score averaged across each follow-up period was 64.6(\pm 15.0), 59.8(\pm 12.7), and 60.4(\pm 13.5), respectively. Compared to the respective baseline PAM score, significantly decreased mean follow-up PAM scores were observed for the No ID group (Mean difference (M_{diff})=4.41; 95%CI: 2.98, 5.85; $p<0.001$) and the ID not-identified group (M_{diff} =6.84; 95%CI: 3.32, 10.4; $p<0.001$). The mean PAM score for the ID prior-identified group did not differ between baseline and follow-up ($p=0.441$).

<Figure 2>

Estimates from the mixed linear regression models are presented in Table 3. After controlling for covariate effects, the ID not-identified and ID prior-identified groups had significantly decreased mean PAM scores [($B=-4.3$; 95%CI: -6.3, -2.4; $p<0.001$) and ($B=-4.5$; 95%CI: -6.8, -2.3; $p<0.001$), respectively] over six months of follow-up compared to the No ID group (Table 3). The multivariate model indicated that being female, being in the community at follow-up, having unstable accommodation, being unemployed, not being in a stable relationship at baseline, having a history of juvenile incarceration, having a pre-release SUD and having pre-release dual disorders were significant independent predictors of decreased PAM scores after release from prison (Table 3).

<Table 3>

The predicted effect of being identified with ID prior to release in the ID prior-identified group on mean PAM score over the post-release follow-up period is displayed in Figure 3. A propensity score-matched model indicated a significant increase in PAM score at the six month follow-up interview ($B=5.89$; 95%CI: 2.35, 9.42; $p=0.001$) attributable to being identified with ID prior to release (Figure 3). Standardised differences indicated adequate balance (<0.1) for all significant covariates in the initial logistic model (Austin 2009), except for the dual diagnosis indicator variable.

<Figure 3>

DISCUSSION

To our knowledge this is the first study to assess patient activation in ex-prisoners screening positive for possible ID. In this large cohort, we observed that compared to ex-prisoners without ID, ex-prisoners who screened positive for possible ID at baseline experienced significantly lower patient activation for at least six months after prison release. This association remained after adjustment for multiple sociodemographic, behavioural, health and criminogenic factors. Importantly, propensity score-matched analyses revealed that in participants who reported being identified with ID prior to prison release, a significant increase of post-release patient activation over six months of community follow-up was attributable to the identification of ID prior to release from prison.

Our findings suggest that pre-release identification of ID, likely a proxy for post-release ID-specific support (Baldry et al. 2013), improved patient activation during the first six months after release from prison for individuals who had been identified with ID prior to prison release. Prior research has shown that individuals with ID who do not receive support from ID-specific services have greater health risks and access healthcare services less frequently (Emerson 2011). Individuals with ID may experience increased negative impact from life stressors (Hatton and Emerson 2004) and have fewer resources available to ameliorate their impact (Lunsky and Neely 2002) compared to those without ID. During stressful life events

such as prison re-entry, increased support in the community has been observed as protective against mental and behavioural problems for people with ID (Scott and Havercamp 2014).

For participants who screened positive for possible ID in custody, we observed mean post-release PAM scores which indicate that this population may initiate actions for self-care but have insufficient skills and confidence required for effective self-care and likely need considerable support to maintain robust self-care (Hibbard et al. 2004). Compared to pre-release PAM scores, we observed significant post-release decreases in patient activation for individuals without ID and for those in the ID not-identified group, whereas no difference was observed in the ID prior-identified group. Greater pre-release patient activation may reflect frequent access to low intensity healthcare servicing and support in prison (Feron *et al.* 2005). Being identified with ID by a clinician and/or an ID-specific service before release from prison may increase the likelihood of care and support continuing during the early post-release period, possibly mediating patient activation levels. Conversely, a post-release decrease in patient activation could reflect pre-release optimism in individuals without previously identified complex health needs, leading to them viewing their post-release health needs as less pronounced and more manageable. A lack of formalised needs assessment, health management planning and support after release from prison for the No ID and ID not-identified group may contribute to decreased patient activation; managing healthcare during the re-entry period remains challenging for many ex-prisoners, especially those with unmet health needs and entrenched socioeconomic disadvantage. However, individuals with unidentified, decreased intellectual functioning appear to be particularly vulnerable. Sub-optimal continuity of care and/or support during the critical transition period may place ex-prisoners at risk of health service inequities, unmet health needs and deleterious health outcomes (Jarrett *et al.* 2012).

Our findings indicate that ex-prisoners with possible ID who are female, unemployed, not in a stable relationship, experiencing unstable accommodation, and/or have a history of juvenile incarceration, SUD or dual disorders may have particular difficulty self-managing healthcare needs post-release. Prison providers, community support workers and clinicians should be aware that these characteristics likely place ex-prisoners with ID or borderline ID at risk of health inequities and poor health outcomes after release from prison. Young Indigenous ex-prisoners with ID may be a particularly vulnerable group (Frize *et al.* 2008) and increasing capacity to engage with primary care early during the re-entry period is likely critical as early primary care contact has been associated with increased access to specialist healthcare for Indigenous ex-prisoners (Kinner *et al.* 2015).

It is also worth noting that almost one in four (22.3%) participants scored below 85 on the HASI and almost one in ten (8.9%) screened positive for ID using a composite screening measure developed previously (Dias *et al.* 2013b). Our findings are consistent with prior research indicating that ID is overrepresented in prisoners (Hassiotis *et al.* 2011b, Dias *et al.* 2013a, Søndena *et al.* 2008, Hellenbach *et al.* 2016). More than one in ten participants (13.4%) screened positive on the HASI for possible ID but did not report having been identified by a clinician or ID-specific service prior to prison release. This striking finding is consistent with other findings suggesting that a substantial proportion of ex-prisoners with ID remain unidentified and unsupported after release from prison (Board *et al.* 2015).

People living with ID and complex needs often experience multiple and overlapping barriers to self-care due to issues such as physical limitations, lack of social and emotional support, poor health service access, and complications that occur when the treatment or symptoms of one condition aggravate another condition (Bayliss *et al.* 2003). Our findings suggest that when ID is not identified prior to release from prison, reduced patient activation may exacerbate the existing healthcare inequities experienced by ex-prisoners with ID, likely contributing to the greater health inequalities observed in this marginalised population (Dias

et al. 2013b). Accordingly, prior research has concluded that enhancing patient activation is crucial to improving health outcomes for disadvantaged groups in the community (Lubetkin et al. 2010) and self-care interventions are warranted to overcome service barriers, healthcare inequities and address health inequalities in marginalised populations (Lubetkin et al. 2010) such as ex-prisoners with complex health needs (Johnson *et al.* 2015). Recent research has demonstrated that self-care interventions, if tailored and delivered appropriately, are effective for improving access to healthcare, health literacy, patient-physician communication and health outcomes in people with ID (Wilson and Goodman 2011, Taggart *et al.* 2015). There is a pressing need to pilot and rigorously evaluate such programs for prisoners and ex-prisoners with ID.

Our findings are of particular relevance to the Australian setting as the National Disability Insurance Scheme (NDIS) is currently being introduced across the country. Ex-prisoners with ID are potentially eligible for a range of disability support services under the NDIS, however self-activation is crucial for those having their eligibility assessed (Soldatic et al. 2014). Individualised support plans for people with ID in the Netherlands have been asserted to require an increased role by the individual in the navigation of individually-tailored service and support networks (Herps *et al.* 2015). With no clear in-reach strategy and enrolment requirements defined for NDIS funding for prisoners transitioning to the community (National Disability Insurance Agency n.d.), patient activation for ex-prisoners may be a key determinant in accessing NDIS assistance during re-entry, when many experience complex healthcare and support needs (Männynsalo et al. 2009). Accessing the NDIS for ex-prisoners with ID will be further complicated if they do not have appropriate referrals and continuity of care immediately after release from prison.

Finally, our findings highlight the importance of ID screening and identification within the criminal justice system. Identification of ID in this population is a prerequisite for access to ID-specific services in prison, and critical to enhancing continuity of care through integration

with ID-specific services during and after the transition from prison to community (Murphy *et al.* 2015). Furthermore, prisoners with unidentified mild to borderline ID are highly vulnerable and identifying, targeting and supporting their unmet needs post-release should be a public health priority (McBrien 2003). Expanding the scope of re-entry planning to include both targeting of support to ex-prisoners with mild to borderline ID, and efforts to increase patient activation in this vulnerable group, may result in more effective engagement with health services and better health outcomes.

Our findings should be interpreted in the context of some limitations. Some measures were obtained through self-report which may be subject to various forms of bias. Possible ID was ascertained using the HASI and this should not be interpreted as a clinical diagnosis of ID. Although possibly over-inclusive of borderline ID (Cashin *et al.* 2006), the HASI appears to have good predictive utility in identifying individuals with borderline intellectual functioning who are likely to encounter problems navigating, accessing and managing their own healthcare requirements. Furthermore, the HASI cut-off has been recently validated for use in populations with comorbid psychiatric and substance use disorders (To *et al.* 2015). Our comparison of the total HASI scores between the ID prior-identified/not-identified subgroups demonstrated that the prior identification of ID was not an indication of impairment severity. However, it should be acknowledged that this difference approached significance and we may be underpowered to detect this trend. While loss to follow-up was not extensive, it was differential across exposure groups and the included and excluded groups differed on some covariates which may have implications for the generalisability of our findings. Although a well-validated measure, the PAM assesses perception of the ability to self-manage healthcare. Objective self-care outcomes were not examined, thus it is unclear what the observed decrease in patient activation among ex-prisoners with possible ID equates to in terms of health behaviours, health service utilisation and related health outcomes. Further research examining the relationship between patient activation and ID in ex-prisoners is warranted.

Conclusion

Ex-prisoners screening positive for possible ID have decreased patient activation for at least six months after release from prison. For ex-prisoners who reported being identified with ID prior to prison release, a significant increase of patient activation over six months of follow-up was attributable to being identified with ID. Incarceration is a pivotal opportunity for the identification of ID and initiating transitional linkages to ID-specific services for this vulnerable population.

AUTHOR DISCLOSURES:

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Contributors

SK, RA, and NL developed the original research proposal, methodology, and data collection protocol. Author JY developed and conducted the statistical analysis. JY wrote the initial draft manuscript with contributions from CC and KvD. All authors contributed significantly to the interpretation and synthesis of results, and were involved with the development of the final manuscript submitted.

Conflict of Interest

Apart from the funding resources disclosed in the acknowledgements section, all authors declare no conflicts of interest.

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Tables and Figures

Table 1 – Characteristics of participants included and excluded from the current study.

| Characteristic | Study Group N (%) 936 (70.6%) | Exclusion Group N (%) 389 (29.4%) | Total Passports Cohort N (%) N = 1325 | Crude OR(95%CI) | p-value ^b |
|--|-------------------------------------|---|--|---------------------------------|----------------------|
| ID Status | | | | | |
| - No ID | 728 (77.8%) | 251 (70.5%) | 979 (75.8%) | 1.00 | |
| - ID Not-identified | 125 (13.4%) | 73 (20.5%) | 198 (15.3%) | 0.59(0.43, 0.81) | 0.001 |
| - ID Prior-identified | 83 (8.9%) | 32 (9.0%) | 115 (8.9%) | 0.89(0.58, 1.38) | 0.612 |
| | | | 1292 (97.5%)* | | |
| Gender | | | | | |
| - Male | 731 (78.1%) | 314 (80.7%) | 1045 (78.9%) | 1.00 | |
| - Female | 205 (21.9%) | 75 (19.3%) | 280 (21.1%) | 1.17(0.87, 1.58) | 0.287 |
| | | | 1325 (100.0%) | | |
| Age at Baseline (Years ± SD) | 33.3±11.3 | 31.6±10.4 | 32.8±11.1 | -1.7(-3.0, -0.4) ^c | 0.013 ^a |
| Indigenous Status | | | | | |
| - Non-Indigenous | 747 (79.8%) | 240 (61.7%) | 987 (74.5%) | | |
| - Indigenous | 189 (20.2%) | 149 (38.3%) | 338 (25.5%) | 0.41(0.31, 0.53) | <0.001 |
| | | | 1325 (100.0%) | | |
| Stable Relationship at Baseline | | | | | |
| - No | 517 (55.2%) | 251 (66.4%) | 768 (58.4%) | | |
| - Yes | 419 (44.8%) | 127 (33.6%) | 546 (41.6%) | 1.60(1.25, 2.06) | <0.001 |
| | | | 1314 (99.2%)* | | |
| Years of School | | | | | |
| - ≥ 10 Years | 560 (59.8%) | 187 (48.6%) | 747 (56.6%) | | |
| - < 10 Years | 376 (40.2%) | 198 (51.4%) | 574 (43.4%) | 1.58(1.24, 2.00) | <0.001 |
| | | | 1321 (99.7%)* | | |
| Social Visits in Prison | | | | | |
| - No | 461 (49.2%) | 251 (64.5%) | 712 (53.7%) | | |
| - Yes | 475 (50.8%) | 138 (35.5%) | 613 (46.3%) | 1.87(1.47, 2.39) | <0.001 |
| | | | 1325 (100.0%) | | |
| Participation in transitional programs | | | | | |
| - No | 757 (80.9%) | 304 (78.3%) | 1061 (80.1%) | | |
| - Yes | 179 (19.1%) | 84 (21.7%) | 263 (19.9%) | 0.86(0.64, 1.15) | 0.295 |
| | | | 1324 (99.9%)* | | |
| Released on Parole | | | | | |
| - No | 571 (61.0%) | 261 (67.6%) | 832 (62.9%) | | |
| - Yes | 365 (39.0%) | 125 (32.4%) | 490 (37.1%) | 1.33(1.04, 1.71) | <0.024 |
| | | | 1322 (99.8%)* | | |
| Juvenile Incarceration History | | | | | |
| - No | 726 (77.6%) | 220 (58.5%) | 946 (72.1%) | | |
| - Yes | 210 (22.4%) | 156 (41.5%) | 366 (27.9%) | 0.41(0.32, 0.53) | <0.001 |
| | | | 1312 (90.0%)* | | |
| Adult Prison Sentence | | | | | |
| - First | 334 (35.7%) | 90 (23.5%) | 424 (32.1%) | | |
| - Repeat | 602 (64.3%) | 293 (76.5%) | 895 (67.9%) | 0.55(0.42, 0.73) | 0.001 |
| | | | 1319 (99.5%)* | | |
| TBI / Lead Poisoning History | | | | | |
| - No | 866 (92.5%) | 357 (91.8%) | 1223 (92.3%) | | |
| - Yes | 70 (7.5%) | 32 (8.2%) | 102 (7.7%) | 0.90(0.58, 1.40) | 0.642 |
| | | | 1325 (100.0%) | | |
| Pre-release Mental Health Diagnoses | | | | | |
| - None | 438 (46.8%) | 186 (47.9%) | 624 (47.1%) | 1 | - |
| - Mental Illness | 79 (8.4%) | 23 (5.9%) | 102 (7.7%) | 1.46(0.89, 2.39) | 0.135 |
| - Substance Use Disorder | 217 (23.2%) | 99 (25.5%) | 316 (23.9%) | 0.93(0.69, 1.25) | 0.632 |
| - Dual Disorder | 202 (21.6%) | 80 (20.6%) | 282 (21.3%) | 1.07(0.79, 1.46) | 0.660 |
| | | | 1324 (99.9%)* | | |
| Hepatitis C exposure | | | | | |
| - No | 799 (85.4%) | 319 (82.2%) | 1052 (84.4%) | | |
| - Yes | 137 (14.6%) | 69 (17.8%) | 206 (15.6%) | 0.79(0.58, 1.09) | 0.151 |
| | | | 1324 (99.9%)* | | |
| Charlson Index (Mean± SD) | 0.17±0.66 | 0.13±0.50 | 0.15±0.62 | -0.04(-0.11, 0.03) ^c | 0.225 ^a |
| Passports Intervention | | | | | |
| - No | 480 (51.3%) | 180 (46.3%) | 660 (49.8%) | | |
| - Yes | 456 (48.7%) | 209 (53.7%) | 665 (50.2%) | | |
| | | | 1325 (100.0%) | 0.82(0.65, 1.04) | 0.097 ^b |

^aIndependent t-test, ^bUnadjusted logistic regression, ^cMean difference(95%CI).

*Total sums to less than 100% due to missing data. ID: Intellectual Disability; OR: Odds Ratio; SD: Standard Deviation; TBI: Traumatic Brain Injury; 95% CI: 95% Confidence Interval

Table 2 – Baseline cohort characteristics overall and by ID status.

| Characteristic | No ID N (%) | ID Not-identified N (%) | ID Prior-identified N (%) | All participants N (%) | p-value ^b |
|--|----------------|----------------------------|------------------------------|---------------------------|----------------------|
| Gender | 728 (77.8%) | 125 (13.3%) | 83 (8.9%) | 936 (100.0%) | |
| - Male | 539 (74.0%) | 113 (90.4%) | 79 (95.2%) | 731 (78.1%) | |
| - Female | 189 (26.0%) | 12 (9.6%) | 4 (4.8%) | 205 (21.9%) | <0.001 |
| Age (Years ± SD) | 33.4±11.2 | 34.0±12.4 | 30.9±10.0 | 33.3±11.3 | 0.183 ^a |
| Indigenous Status | | | | | |
| - Non-Indigenous | 603 (82.8%) | 83 (66.4%) | 61 (73.5%) | 747 (79.8%) | |
| - Indigenous | 125 (17.2%) | 42 (33.6%) | 22 (26.5%) | 189 (20.2%) | <0.001 |
| Stable Relationship at Baseline | | | | 936 (100.0%) | |
| - No | 394 (54.1%) | 68 (54.4%) | 55 (66.3%) | 517 (55.2%) | |
| - Yes | 334 (45.9%) | 57 (45.6%) | 28 (33.7%) | 419 (44.8%) | 0.109 |
| Years of School | | | | 936 (100.0%) | |
| - ≥ 10 Years | 480 (65.9%) | 56 (44.8%) | 24 (28.9%) | 560 (59.8%) | |
| - < 10 Years | 248 (34.1%) | 69 (55.2%) | 59 (71.1%) | 376 (40.2%) | <0.001 |
| Social Visits in Prison | | | | 936 (100.0%) | |
| - No | 347 (47.7%) | 70 (56.0%) | 44 (53.0%) | 461 (49.2%) | |
| - Yes | 381 (52.3%) | 55 (44.0%) | 39 (47.0%) | 475 (50.8%) | 0.175 |
| Participation in Transitional Programs | | | | 936 (100.0%) | |
| - No | 597 (82.0%) | 95 (76.0%) | 65 (78.3%) | 757 (80.9%) | |
| - Yes | 131 (18.0%) | 30 (24.0%) | 18 (21.7%) | 179 (19.1%) | 0.238 |
| Released on Parole | | | | 936 (100.0%) | |
| - No | 452 (62.1%) | 73 (58.4%) | 46 (55.4%) | 571 (61.0%) | |
| - Yes | 276 (37.9%) | 52 (41.6%) | 37 (44.6%) | 365 (39.0%) | 0.332 |
| Juvenile Incarceration History | | | | 936 (100.0%) | |
| - No | 583 (80.1%) | 84 (67.2%) | 59 (71.1%) | 726 (77.6%) | |
| - Yes | 145 (19.9%) | 41 (32.8%) | 24 (28.9%) | 210 (22.4%) | 0.002 |
| Adult Prison Sentence | | | | 936 (100.0%) | |
| - First | 269 (37.0%) | 40 (32.0%) | 25 (30.1%) | 334 (35.7%) | |
| - Repeat | 459 (63.0%) | 85 (68.0%) | 58 (69.9%) | 602 (64.3%) | 0.306 |
| TBI / Lead Poisoning History | | | | 936 (100.0%) | |
| - No | 681 (93.5%) | 110 (88.0%) | 75 (90.4%) | 866 (92.5%) | |
| - Yes | 47 (6.5%) | 15 (12.0%) | 8 (9.6%) | 70 (7.5%) | 0.069 |
| Pre-release Mental Health Diagnoses | | | | 936 (100.0%) | |
| - None | 355 (48.8%) | 48 (38.4%) | 35 (42.2%) | 438 (46.8%) | |
| - Mental illness | 62 (8.5%) | 9 (7.2%) | 8 (9.6%) | 79 (8.4%) | |
| - Substance use disorder | 167 (22.9%) | 30 (24.0%) | 20 (24.1%) | 217 (23.2%) | |
| - Dual diagnosis | 144 (19.8%) | 38 (30.4%) | 20 (24.1%) | 202 (21.6%) | 0.164 |
| Hepatitis C exposure | | | | 936 (100.0%) | |
| - No | 629 (86.4%) | 102 (81.6%) | 68 (81.9%) | 799 (85.4%) | |
| - Yes | 99 (13.6%) | 23 (18.4%) | 15 (18.1%) | 137 (14.6%) | 0.243 |
| Charlson index (Mean± SD) | 0.16±0.65 | 0.23±0.72 | 0.16±0.72 | 0.17±0.66 | 0.609 ^c |
| Passports intervention | | | | 936 (100.0%) | |
| - No | 368 (50.6%) | 67 (53.6%) | 45 (54.2%) | 480 (51.3%) | |
| - Yes | 360 (50.4%) | 58 (46.4%) | 38 (45.8%) | 456 (48.7%) | 0.701 |
| Days spent in community (Mean± SD) | 174.4±64.0 | 176.4±61.7 | 183.6±62.4 | 175.5±63.5 | 0.234 ^d |

^aUnadjusted linear regression (F(1, 934)= 1.77), ^bPearson chi-square test, ^cUnadjusted linear regression (F(1, 934)= 0.26), ^dUnadjusted linear regression (F(1, 934)= 1.42)

*Total sums to less than 100% due to missing outcome data

ID: Intellectual Disability; SD: Standard Deviation; TBI: Traumatic Brain Injury

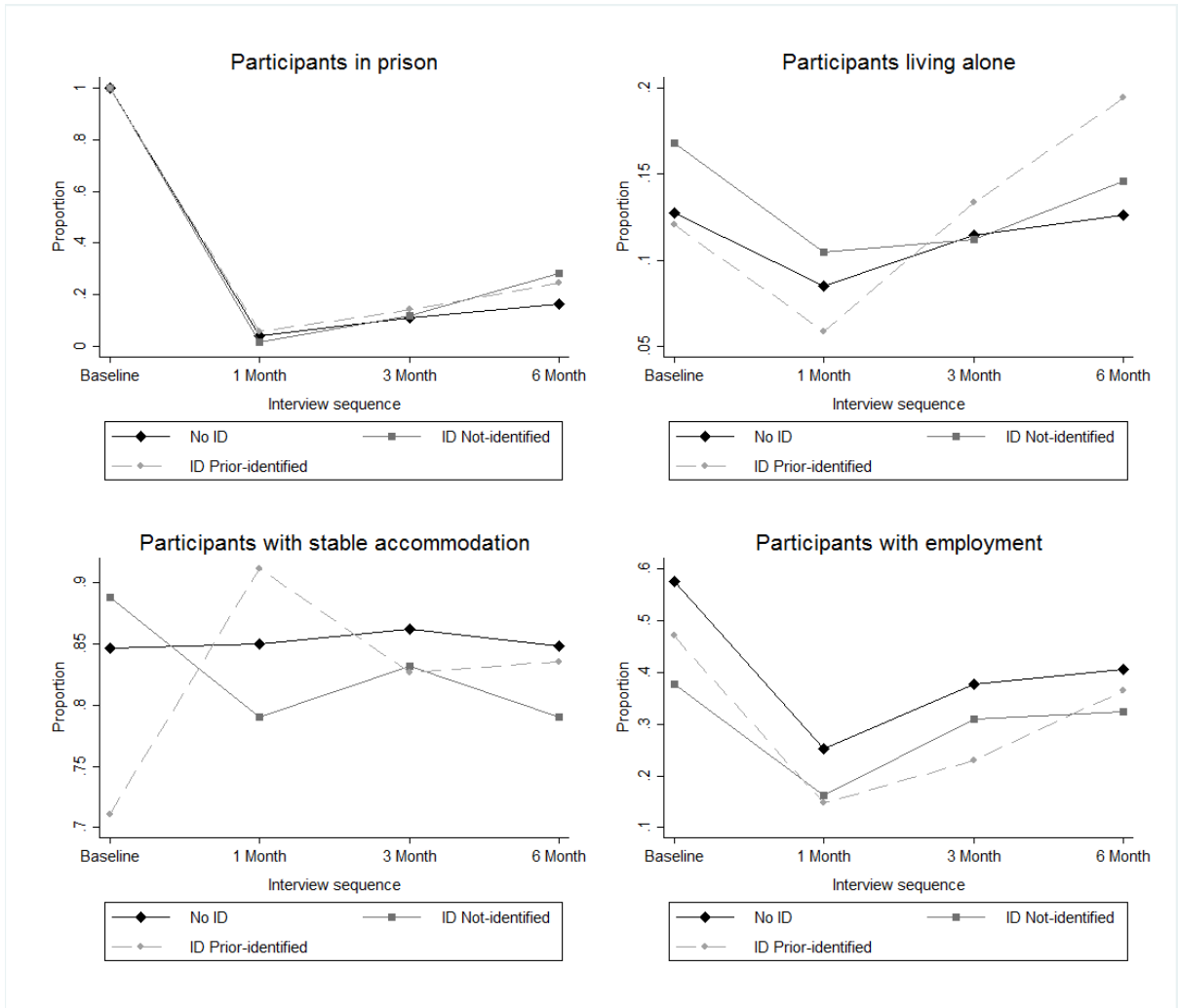


Figure 1 – Time varying covariate proportions displayed by interview sequence, according to ID status.

ID: Intellectual Disability; PAM: Patient Activity Measure

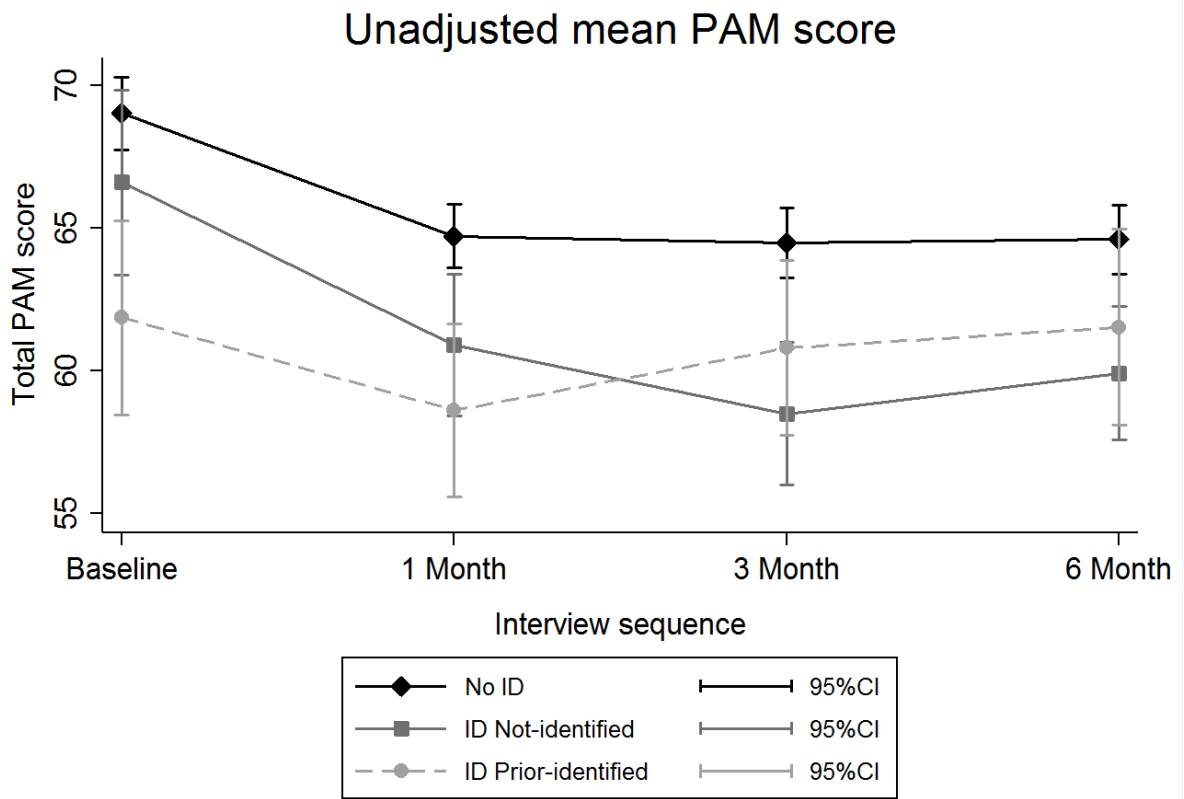


Figure 2 – Unadjusted mean PAM score over the six month follow-up period, according to ID status. ID: Intellectual Disability; PAM: Patient Activity Measure; 95% CI: 95% Confidence Interval

Table 3 – Association between ID status and PAM score for six months post-release: a multilevel mixed-effects linear regression model.

| PAM Score | Univariate B(95% CI) | p-value | Multivariable B(95% CI) | p-value |
|--|----------------------|---------|-------------------------|---------|
| <i>Marginal Effects</i> | | | | |
| ID Status | | | | |
| - No ID | 0 | - | 0 | - |
| - ID-Not Identified | -4.96(-7.01, -2.90) | <0.001 | -4.24(-6.28, -2.21) | <0.001 |
| - ID-Prior Identified | -4.91(-7.37, -2.45) | <0.001 | -4.41(-6.84, -1.98) | <0.001 |
| Sex | | | | |
| - Male | 0 | - | | |
| - Female | -1.72(-3.40, -0.04) | 0.045 | -1.71(-3.42, 0.01) | 0.051 |
| Age (per year increase) | 0.08(0.02, 0.14) | 0.012 | 0.06(-0.01, 0.12) | 0.086 |
| Indigenous Status | | | | |
| - Non-Indigenous | 0 | - | 0 | - |
| - Indigenous | -3.06(-4.83, -1.29) | <0.001 | -0.83(-2.62, 0.96) | 0.365 |
| Interview Location (TVC) | | | | |
| - Community | 0 | - | 0 | - |
| - In prison | 5.26(4.27, 6.25) | <0.001 | 5.25(4.21, 6.30) | <0.001 |
| Living Alone (TVC) | | | | |
| - No | 0 | - | 0 | - |
| - Yes | 0.60(-1.10, 2.31) | 0.489 | 0.55(-1.14, 2.25) | 0.523 |
| Accommodation (TVC) | | | | |
| - Stable | 0 | - | 0 | - |
| - Unstable | -1.87(-3.36, -0.38) | 0.014 | -1.56(-3.03, -0.09) | 0.037 |
| Employment (TVC) | | | | |
| - Employed | 0 | - | 0 | - |
| - Unemployed | -3.61(-4.73, -2.50) | <0.001 | -1.30(-2.46, -0.14) | 0.029 |
| Stable Relationship at Baseline | | | | |
| - No | 0 | - | 0 | - |
| - Yes | 2.24(0.83, 3.64) | 0.002 | 2.03(0.65, 3.41) | 0.004 |
| Years of School | | | | |
| - ≥ 10 Years | 0 | - | 0 | - |
| - < 10 Years | -1.97(-3.41, -0.54) | 0.007 | -0.24(-1.69, 1.21) | 0.749 |
| Social Visits in Prison | | | | |
| - No | 0 | - | 0 | - |
| - Yes | 2.95(1.55, 4.35) | <0.001 | 1.36(-0.08, 2.80) | 0.064 |
| Participation in Transitional Programs | | | | |
| - No | 0 | - | 0 | - |
| - Yes | 1.87(0.08, 3.65) | 0.040 | 2.23(0.49, 3.97) | 0.012 |
| Released on Parole | | | | |
| - No | 0 | - | 0 | - |
| - Yes | -0.37(-1.81, 1.07) | 0.614 | 0.52(-0.88, 1.92) | 0.464 |
| Juvenile Incarceration History | | | | |
| - No | 0 | - | 0 | - |
| - Yes | -3.19(-4.88, -1.49) | <0.001 | -2.28(-4.01, -0.55) | 0.010 |
| Adult Prison Sentence | | | | |
| - First | 0 | - | 0 | - |
| - Repeat | -2.34(-3.79, -0.90) | 0.002 | -1.02(-2.56, 0.52) | 0.192 |
| TBI / Lead Poisoning History | | | | |
| - No | 0 | - | 0 | - |
| - Yes | -2.64(-5.31, 0.02) | 0.052 | -1.90(-4.43, 0.64) | 0.143 |
| Pre-release Mental Health Diagnoses | | | | |
| - None | 0 | - | 0 | - |
| - Mental illness | -1.10(-3.68, 1.47) | 0.415 | -0.73(-3.20, 1.74) | 0.582 |
| - Substance use disorder | -3.18(-4.94, -1.41) | <0.001 | -1.95(-3.72, -0.18) | 0.031 |
| - Dual diagnosis | -4.18(-5.99, -2.37) | <0.001 | -2.58(-4.43, -0.72) | 0.006 |
| Hepatitis C exposure | | | | |

| | | | | |
|-------------------------|--------------------|-------|---------------------|--------|
| - No | 0 | - | 0 | - |
| - Yes | -1.37(-3.38, 0.64) | 0.204 | 0.48(-1.49, 2.44) | 0.635 |
| Charlson index | -0.05(-1.08, 0.97) | 0.918 | 0.02(-0.97, 1.00) | 0.972 |
| Passports intervention | | | | |
| - No | 0 | - | 0 | - |
| - Yes | 0.30(-1.11, 1.70) | 0.679 | 0.38(-0.95, 1.71) | 0.580 |
| Days spent in community | -0.01(-0.02, 0.01) | 0.245 | -0.01(-0.01, 0.01) | 0.834 |
| <i>Random Effects</i> | | | | |
| - Intercept | - | - | -28.1(-41.1, -15.2) | <0.001 |

B: Beta Coefficient; ID: Intellectual Disability; PAM: Patient Activation Measure; TBI: Traumatic Brain Injury; TVC: Time-Varying Covariate; 95% CI: 95% Confidence Interval

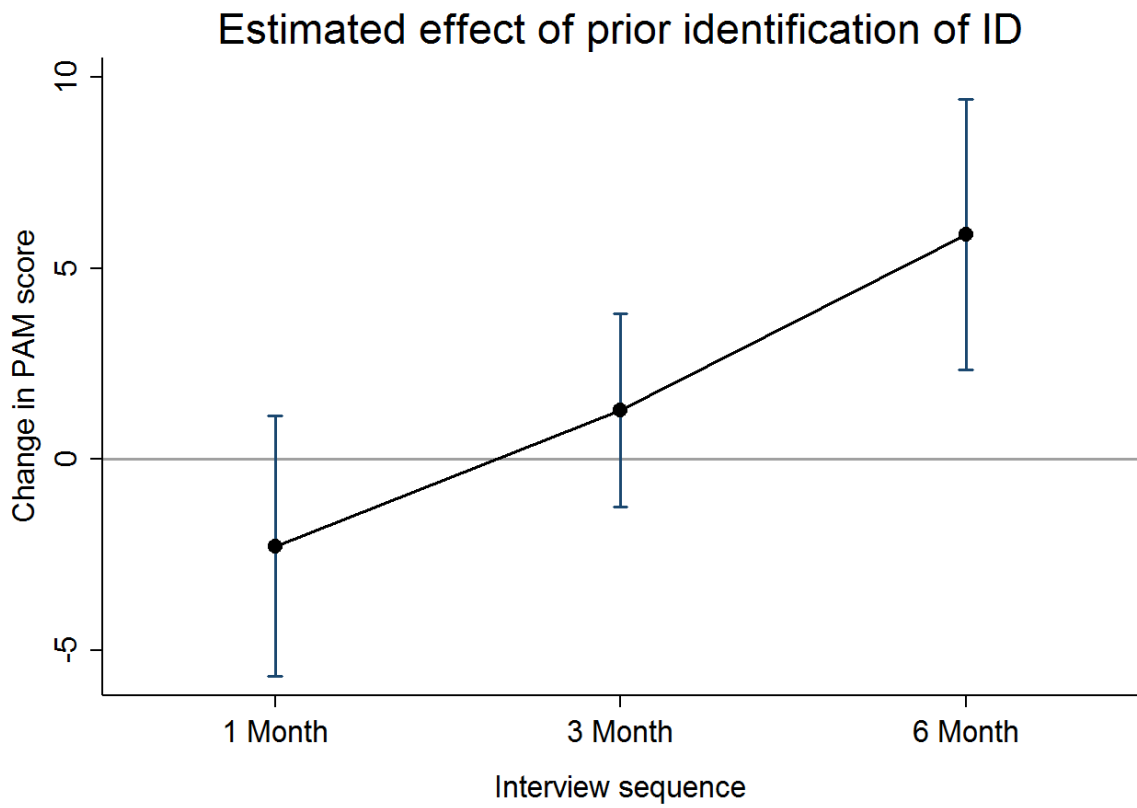


Figure 3 – Estimated mean effect of pre-incarceration identification of ID on post-release PAM score from a propensity score-matched logistic regression analysis.
ID: Intellectual Disability; PAM: Patient Activation Measure

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