ENVIRONMENTAL-RISK (E-RISK) LONGITUDINAL TWIN STUDY
CONCEPT PAPER FORM

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Provisional Paper Title: Current Prevalence, Time Trends, and Gaps in Diagnoses in Child and Adolescent Mental Health Services: A Clinical Record Study

Date: 23 June 2019

OBJECTIVE OF THE STUDY AND ITS SIGNIFICANCE:

Objectives:
As part of a larger study, we aim to describe the prevalence of psychiatric disorders in young people based on electronic health records at the South London and Maudsley NHS Foundation Trust, the time trends in the prevalence, and the proportion of psychiatric disorders in the population that is identified by clinical services (or diagnosis gap). We will use E-Risk data at age 18 years to provide the population prevalence of psychiatric disorders to estimate the diagnosis gap. E-Risk data on the prevalence of psychiatric disorders has previously been published. To illustrate how the diagnosis gap varies by gender and neighbourhood deprivation, we request here E-Risk data on the prevalence of psychiatric disorders by gender and neighbourhood deprivation.

Evidence on diagnosis gaps:
Population-based research using self and parent-reports has provided important information about gaps in young people's service use. For example, studies have found that, of those who meet criteria for a psychiatric disorder, about three in four English young people,[1,2] and one in two American young people,[3,4] have not accessed mental health services. Service use is more common in those with externalising disorders or comorbidity, and is associated with certain sociodemographic factors such as male sex and higher-income families.[4-7] Inevitably, not all young people with psychiatric disorders who do access services will have their disorder recognised and diagnosed, so diagnosis gaps are likely to be larger than these service use gaps. Self-reporting methods may not accurately determine whether those who do access services go on to receive a diagnosis, because subjective reports about clinical details are prone to errors.[5] Therefore, research comparing population-based data with clinical record data is required to gain an accurate understanding of diagnosis gaps, in order to indicate unidentified mental health needs in the population. Some previous studies have assessed diagnosis gaps of individual disorders. For example, in the Avon Longitudinal Study of Parents and Children, of 18-year-olds who met criteria for depression, 93.0% did not have a clinical diagnosis of depression documented in their primary care records.[8] In addition, in the Child and Adolescent Twin Study in Sweden, of 9-year-olds who met criteria for attention deficit hyperactivity disorder (ADHD), 81.5% of boys and 87.9% of girls did not have a clinical diagnosis of ADHD documented in their health records, highlighting possible gender differences in the ADHD diagnosis gap.[9] However, no previous studies have determined and compared diagnosis gaps in a wide range of psychiatric disorders in young people. Additionally, no previous studies have investigated diagnosis gaps in young people who have accessed health services. In order to address this lack of evidence, we plan to compare population-based estimates from the E-Risk Study with clinical record data from SLaM.

STATISTICAL ANALYSES:

To estimate the proportion of young people who meet criteria for a psychiatric disorder but are not clinically diagnosed – the diagnosis gap – we will compare estimates of the prevalence of psychiatric disorders in the community with the prevalence of clinical diagnoses of these disorders. First, using E-Risk Study data, we will estimate the 12-month community prevalence of depressive disorder, generalised anxiety disorder, post-traumatic stress disorder, conduct disorder, and ADHD. Second, we will estimate

the 12-month prevalence of clinical diagnoses of these five psychiatric disorders in South London 17-year-olds, by comparing SLaM patient data (numerator) with Office for National Statistics (ONS) population counts (denominator). Finally, to estimate the proportion of young people who meet criteria for a psychiatric disorder and use health services but are not clinically diagnosed – the diagnosis gap in health service users – we will compare estimates of the community prevalence of psychiatric disorders and health service use (using E-Risk data) with the prevalence of clinical diagnoses (using SLaM/ONS data). We will compare the size of diagnosis gaps by disorder and by number of disorders, using X^2 tests. Additionally, we will test whether gender and level of neighbourhood deprivation are associated with the size of diagnosis gaps, using X^2 tests.

In order to undertake this analysis, we require E-Risk estimates of the prevalence of psychiatric disorders. E-Risk prevalence estimates for the overall cohort have previously been published, however we require these estimates by gender and level of neighbourhood deprivation, and therefore would like to request these variables.

VARIABLES NEEDED AT WHICH AGES (NAMES AND LABELS):

Age 18:

Disorders, in past 12 months:

Major depressive episode, dsm4 - P18 - Elder	DXMDEE18
Gen Anxiety Disorder, dsm4_based - P18 - Elder	DXGADE18
PTSD Current dx, dsm5 - P18 - Elder	DXPTSD5CUE18
Moderate Conduct Disorder (>=5 count) - P18 - Elder	CDMODE18
DSM-5 ADHD Dx (based on >=5 Symp) [incl 4 NEET & meds] - P18 - ET	DXADHD5X_18E

Health service use, for mental health problem in past 12 months:

Medical doctor, GP	SER1E18
Psychiatrist	SER2E18
Psychologist, counsellor, psychopatherpist	SER4E18

Neighbourhood deprivation:

Index of multiple deprivation (IMD) for lower-layer super output area (LSOA11), rank within country	???

Study:

Sex	SAMPSEX
Standard variables	

REFERENCES CITED:

1 Lewis SJ, Arseneault L, Caspi A, *et al.* The epidemiology of trauma and post-traumatic stress disorder in a representative cohort of young people in England and Wales. *Lancet Psychiatry* 2019; **6**: 247–56.

2 Mandalia D, Ford T, Hill S, *et al.* Mental health of children and young people in England, 2017: professional services, informal support, and education. NHS Digital, 2018 https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017.

3 Merikangas KR, He J-P, Brody D, Fisher PW, Bourdon K, Koretz DS. Prevalence and treatment of mental disorders among US children in the 2001-2004 NHANES. *Pediatrics* 2010; **125**: 75–81.

4 Merikangas KR, He J-P, Burstein M, *et al.* Service utilization for lifetime mental disorders in U.S. adolescents: results of the National Comorbidity Survey-Adolescent Supplement (NCS-A). *J Am Acad Child Adolesc Psychiatry* 2011; **50**: 32–45.

5 Ford T, Goodman R, Meltzer H. Service use over 18 months among a nationally representative sample of British children with psychiatric disorder. *Clin Child Psychol Psychiatry* 2003; **8**: 37–51.

6 Ford T, Hamilton H, Meltzer H, Goodman R. Child Mental Health is Everybody's Business: The Prevalence of Contact with Public Sector Services by Type of Disorder Among British School Children in a Three-Year Period. *Child Adolesc Ment Health* 2007; **12**: 13–20.

7 Haines MM, McMunn A, Nazroo JY, Kelly YJ. Social and demographic predictors of parental consultation for child psychological difficulties. *J Public Health Med* 2002; **24**: 276–84.

8 Cornish RP, John A, Boyd A, Tilling K, Macleod J. Defining adolescent common mental disorders using electronic primary care data: a comparison with outcomes measured using the CIS-R. *BMJ Open* 2016; **6**: e013167.

9 Mowlem FD, Rosenqvist MA, Martin J, Lichtenstein P, Asherson P, Larsson H. Sex differences in predicting ADHD clinical diagnosis and pharmacological treatment. *Eur Child Adolesc Psychiatry* 2018; **15**: i15–9.

Data Security Agreement

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Proposing Author	Stephanie Lewis
Today's Date	23 June 2019

Please keep one copy for your records
(Please initial your agreement)

_SL_ I am familiar with the King's College London research ethics guidelines (https://www.kcl.ac.uk/innovation/research/support/ethics/about/index.aspx) and the MRC good research practice guidelines (https://www.mrc.ac.uk/research/policies-and-guidance-for-researchers/good-research-practice/).

_SL_ My project has ethical approval from my institution.

_SL_ I am familiar with the EU General Data Protection Regulation (https://mrc.ukri.org/documents/pdf/gdpr-guidance-note-3-consent-in-research-and-confidentiality/), and will use the data in a manner compliant with its requirements.

_SL_ My computer is (a) encrypted at the hard drive level, (b) password-protected, (c) configured to lock after 15 minutes of inactivity, AND (d) has an antivirus client which is updated regularly.

_SL_ I will treat all data as "restricted" and store in a secure fashion.

_SL_ I will not share the data with anyone, including students or other collaborators not specifically listed on this concept paper.

_SL_ I will not merge data from different files or sources, except where approval has been given by the PI.

_SL_ I will not post data online or submit the data file to a journal for them to post.
Some journals are now requesting the data file as part of the manuscript submission process. The E-Risk Study cannot be shared because the Study Members have not given informed consent for unrestricted open access. Speak to the study PI for strategies for dealing with data sharing requests from Journals.

_SL_ Before submitting my paper to a journal, I will submit my draft manuscript and scripts for data checking, and my draft manuscript for co-author mock review, allowing three weeks.

_SL_ I will submit analysis scripts and new variable documentation to project data manager after the manuscript gets accepted for publication.

_SL_ I will delete the data after the project is complete.

_SL_ **For projects using location data:** I will ensure geographical location information, including postcodes or geographical coordinates for the E-Risk study member's homes or schools, is never combined or stored with any other E-Risk data (family or twin-level data)

____ **For projects using genomic data:** I will only use the SNP and/or 450K data in conjunction with the phenotypes that have been approved for use in this project at the concept paper stage.

Signature: ...Stephanie Lewis.....

CONCEPT PAPER RESPONSE FORM

A. To be completed by the proposing author

Proposing Author:

SL I have read the E-Risk data-sharing policy guidelines and agree to follow them

Provisional Paper Title: Current Prevalence, Time Trends, and Gaps in Diagnoses in Child and Adolescent Mental Health Services: A Clinical Record Study

Potential co-authors: Andrea Danese, Tamsin Ford, Alan Meehan

Potential Journals:
Intended Submission Date (month/year): November 2019

Please keep one copy for your records and return one to Louise (louise.arseneault@kcl.ac.uk)

B. To be completed by potential co-authors:

☐ Approved ☐ Not Approved ☐ Let's discuss, I have concerns

Comments:

Please check your contribution(s) for authorship:

☐ Conceptualizing and designing the longitudinal study

☐ Conceptualizing and collecting one or more variables

☐ Data collection

☐ Conceptualizing and designing this specific paper project

☐ Statistical analyses

☐ Writing

☐ Reviewing manuscript drafts

☐ Final approval before submission for publication

☐ Acknowledgment only, I will not be a co-author

Signature: .....