

The Clinical Data Linkage Service (CDLS)

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What is the Clinical Data Linkage Service?

The CDLS acts as a ‘*trusted third party*’ to facilitate secure data linkage to improve the secondary uses of clinical and administrative data for observational research. The service is jointly managed by the BRC’s Clinical Informatics team and the South London and Maudsley (SLaM) Information Governance (IG) team. The CDLS provides a range of services designed to support researchers throughout the life-span of their data linkage project, from IG advice and approvals, through to data extraction and processing.

What is Data Linkage?

Data Linkage is the joining of two or more independent databases that share common unique variables at an individual record level, for example NHS number.

Most linkages facilitated by the CDLS have involved case-matching mental health records from SLaM’s pseudonymised electronic patient record system (CRIS) with other external data sources.

Linkage between data sources improves the quality and reliability of data, enabling deeper analysis than would otherwise be possible from either dataset in isolation.

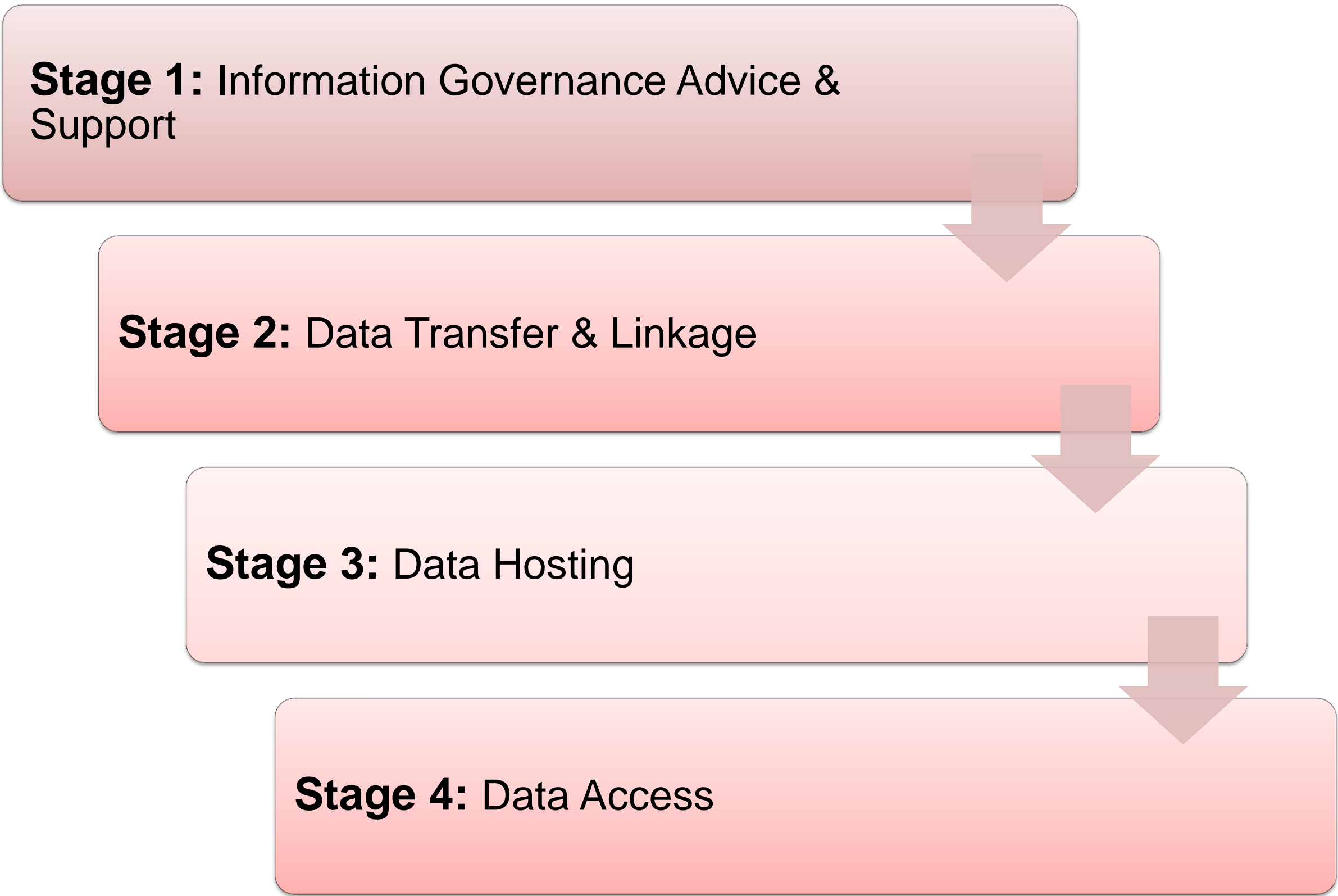


Fig. 1 The CDLS project process.

The Data Linkage Service User and Carer Advisory Group

The CDLS, in collaboration with colleagues in the CRIS team, have set up a Data Linkage Service User and Carer Advisory Group. The group is a regular meeting of people with lived experience of mental illness, all of whom have an interest in mental health research involving data linkage.

The group meet quarterly and researchers are invited to present their data linkage projects, where they receive feedback and advice from members.

The group encourages the incorporation of Patient and Public Involvement in data linkage research, helping to ensure the legitimacy of data linkage practices and governance systems whilst also improving the quality and appropriateness of the research being conducted.

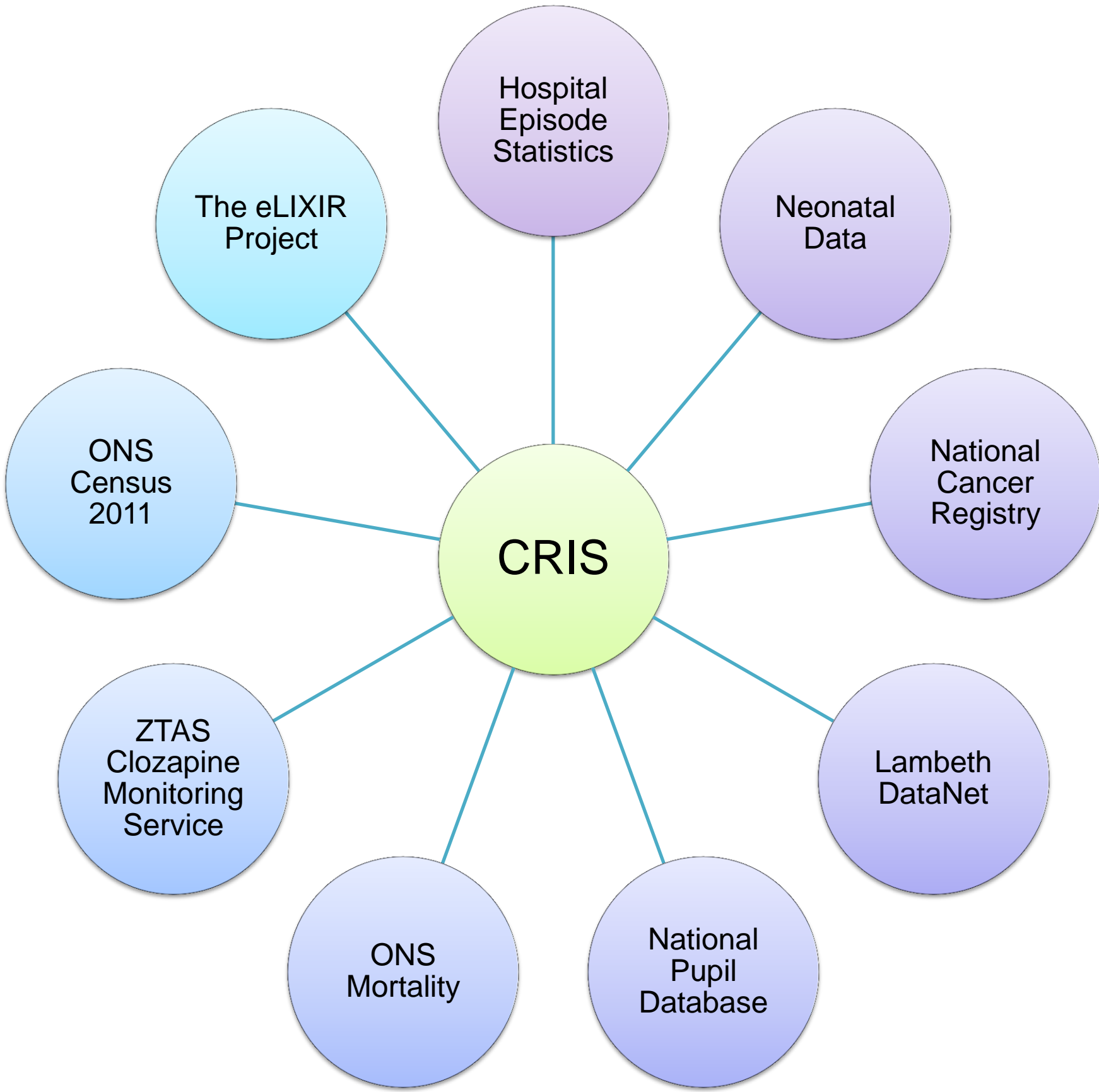


Fig. 2 Completed CRIS Data Linkages.

CRIS Data Linkage Research Findings

- Data from CRIS were linked to ONS Mortality data to provide estimates of life years lost in different mental disorder groups; data which remain the only UK source of information on this topic¹. More recently ONS mortality data were used to estimate the contributions of different causes of death to life expectancy loss; a wide range of causes of death were responsible for the life-expectancy loss, indicating that public health interventions need to focus on factors with multiple health benefits².
¹Chang, C-K., Hayes, R.D., Perera, G., Broadbent, M.T.M., Fernandes, A.C., Lee, W.E., Hotopf, M. and Stewart, R. (2011) Life Expectancy at Birth for People with Serious Mental Illness and Other Major Disorders from a Secondary Mental Health Care Case Register in London. *PLoS One*, 6(5): e19590. ²Jayatileke, N., Hayes, R.D., Dutta, R., Hotopf, M., Chang, C-K. and Stewart, R. (2017) Contributions of Specific Causes of Death to Lost Life Expectancy in Severe Mental Illness. *European Psychiatry*, 41:109-115.
- The CRIS linkage to Hospital Episode Statistics (HES) has been used to investigate health inequalities at the level of hospitalised disorders, including a recently published demonstration of the high risk of respiratory disease admissions in patients with learning difficulties, as well as longer durations of hospitalisation and higher risk of readmission. Chang, C-K., Stewart, R., Chen, C.Y., Broadbent, M. and O’Hara, J. (2017) Hospital Admissions for Respiratory System Diseases in Adults with Intellectual Disabilities in Southeast London: a Register-Based Cohort Study. *BMJ Open*, 7:e014846.
- Data from CRIS linked to Neonatal data from two local hospitals were included in an international meta-analysis investigating the association between in-utero lithium exposure and risk of pregnancy complications. Munk-Olsen, T., Liu, X., Viktorin, A., Brown, H.K., Di Florio, A., D’Onofrio, B.M., Gomes, T., Howard, L.M., Khalifeh, H., Krohn, H., Larsson, H., Lichtenstein, P., Taylor, C.L., Van Kamp, I., Wesseloo, R., Melterzer-Brody, S., Vigod, S.N. and Bergink, V. (2018) Maternal and infant outcomes associated with lithium use in pregnancy: An international collaboration combining data from 6 cohort studies using meta-analysis covering 727 lithium expose pregnancies and 21,397 bipolar or major depressive disorder reference pregnancies. *Lancet Psychiatry*, 5(8), p.p. 644-652.
- Breast and cervical cancer screening uptake in woman with serious mental illness (SMI) has been examined using the CRIS linkage to local GP records (Lambeth DataNet). Findings indicate that woman with SMI are less likely to receive breast and cervical cancer screening than woman without SMI, highlighting an important area for improvement. Woodhead, C., Cunningham, R., Ashworth, M., Barley, E., Stewart, R.J. and Henderson, M.J. (2016) Cervical and Breast Cancer Screening Uptake Among Women with Serious Mental Illness: a Data Linkage Study. *BMC Cancer*, 16:819.
- A large programme of work has used the CRIS-HES linkage to investigate medication and medication changes during pregnancy in women with severe mental illness. This is one of the world’s largest investigations of this question and highly relevant for services caring for women with SMI and the treatment decisions required around pregnancy. Taylor, C.L., Stewart, R., Ogden, J., Broadbent, M., Pasupathy, D. and Howard, L.M. (2015) The Characteristics and Health Needs for Pregnant Women with Schizophrenia Compared with Bipolar Disorder and Affective Psychoses. *BMC Psychiatry*, 15:88.