Autism Registry

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| **Project Name:**  A Diverse Autism Registry for Effectiveness Studies |
| **Principal Investigator:**  Lisa Croen, PhD |
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| **Funder** NIMH |
| **Funding Period:**  08/2011 – 07/2013 |
| **Abstract:**  The overarching goal of this research proposal is to create a large, comprehensive and dynamic autism spectrum disorder (ASD) registry across several integrated health systems participating in the Mental Health Research Network (MHRN). This registry will enable rapid identification and enrollment of patients into future large-scale comparative effectiveness studies testing treatment, preventive and services interventions, as well as future pharmacogenomic and etiologic investigations. We will leverage the many unique resources provided by the MHRN, including: 1) the large and ethnically diverse population of children with ASD, who are representative of the communities served by the health plans, 2) comprehensive electronic medical records (EMR) systems which capture all patient interactions with the health plans, 3) the existing biospecimen repositories at some participating sites that will facilitate collection of genetic material from children and their family members, and 4) researchers with an established track record of engaging and enrolling patients in autism clinical research studies and extensive experience in conducting research using electronic databases. |
| **Grant Number:**  U19MH092201 |
| **Participating Sites:**   * Kaiser Permanente Northern California, Oakland, CA (Lead Site) * Harvard Pilgrim Health Care, Boston, MA * Kaiser Permanente Georgia, Atlanta, GA * Kaiser Permanente Northwest, Portland, OR * Kaiser Permanente Southern California, Pasadena, CA |
| **Investigators:**  Lisa Croen, PhD (Lead) Jeanne Madden, PhD Ashli Owen-Smith, PhD Frances Lynch, PhD Karen Coleman, PhD Virginia Quinn, PhD |
| **Major Goals:**   * Build a comprehensive and dynamic registry of children with an autism spectrum disorder receiving healthcare from one of the participating health plans * Collect survey data from a subset of these families regarding ASD services and treatments utilized and associated costs and perception of efficacy; quality of life; caregiver strain; coordination of care; and resource and educational needs * Establish a biospecimen bank for future research studies |
| **Description of study sample:** The initial sample for development of the ASD registry included all members aged 0-17 with any recorded ASD diagnosis.  1272 chart reviews were completed to validate ASD diagnogsis at 5 study sites, and 1155 families completed online surveys at 4 sites. |
| **Current Status:**   * Completed an ASD diagnostic validation study, ascertained children with ASD and built the registry * Completed the survey and collection of biospecimens * Currently, we are working on several manuscripts using registry and survey data * Work on this subject continues on a related MHRN project, “[Collecting Biospecimens from Families Affected by Neurodevelopmental Disorders**”**](http://hcsrn.org/mhrn/en/ResearchProjects/BiospecND.html) |
| **Study Registration:** N/A |
| **Publications:**  Coleman KJ, Lutsky MA, Yau V, Qian Y, Pomichowski ME, Crawford PM, et al[. Validation of autism spectrum disorder diagnoses in large healthcare systems with electronic medical records](https://www.ncbi.nlm.nih.gov/pubmed/?term=10.1007%2Fs10803-015-2358-0). *J Autism Dev Disord. 2015 Jul; 45*(7):1989–96. doi: 10.1007/s10803-015-2358-0.  Cummings, JR, Lynch, FL, Rust, KC, Coleman, KJ, Madden, JM, Owen-Smith, AA, et al. [Health Services Utilization Among Children With and Without Autism Spectrum Disorders](https://www.ncbi.nlm.nih.gov/pubmed/?term=10.1007%2Fs10803-015-2634-z.). *J Autism Dev Disord. 2015 Nov; 46*: 910-920. Doi: 10.1007/s10803-015-2634-z.  Madden, J.M., Lakoma, M.D., Lynch, F.L. et al. [Psychotripic Medication Use among Insured Children with Autism Spectrum Disorder](https://www.ncbi.nlm.nih.gov/pubmed/?term=10.1007%2Fs10803-016-2946-7). *J Autism Dev Disord.* 2016: 1-11. doi:10.1007/s10803-016-2946-7.  Owen-Smith, AA, Bent, S, Lynch, FL, Coleman, KJ, Yau, YM, Pearson, KA, Massolo, ML, et al. [Prevalence and predictors of complementary and alternative medicine use in a large insured sample of children with Autism Spectrum Disorders](https://www.ncbi.nlm.nih.gov/pubmed/26366192). Res Autism Spectr Disord. 2015 *Sept 1; 17*: 40-51. doi: 10.1016/j.rasd.2015.05.002.  Becerra, T, Massolo, M, Yau, V, Owen-Smith, A, Lynch, F, et al. A Survey of Parents with Children on the Autism Spectrum: Experience with Services and Treatments. *The Permanente Journal.* 2016. In Press. |
| **Resources:**  N/A |
| **Lessons Learned:**   * Health plan databases can be used to identify a large number of children with a valid ASD diagnosis * In order to achieve a high response rate to the survey, more resource intense and tailored contact strategies are necessary * Among families participating in the survey, a very high percentage agreed to donate a biospecimen |
| **What’s next?** Working on new manuscripts. |