

October 18, 2022

Submitted electronically to pcornet@pcori.org

Patient-Centered Outcomes Research Institute

Re: Comments in Response Request for Info. (Prioritizing PCORnet® Data Infrastructure Enhancements: Social Determinants of Health, Patient Reported Information, and Claims Data) (RFI # RI-2022)

To the Director,

We are submitting comments in response to PCORI's Request for Information (Prioritizing PCORnet® Data Infrastructure Enhancements: Social Determinants of Health, Patient Reported Information, and Claims Data) (RFI # RI-2022). We applaud PCORI's desire to improve data systems and write to express our strong belief in the need for tools to more comprehensively identify people with intellectual and developmental disabilities (IDD) in a manner that supports real-time clinical decision-making.

Institute for Exceptional Care (IEC) is a non-profit organization committed to transforming healthcare for people with IDD. IEC is working with broad coalitions of clinical organizations, payers, purchasers, regulators, consumer advocates, and social service professionals to improve systems and processes of care that support better health and life outcomes.

Currently, many people with IDD are poorly identified – not “visible” – in typical healthcare data, such as insurance claims or electronic medical records and charts. This is likely due to a combination of factors (under-screening and diagnosis, lack of self-disclosure among adults, and loss of clinical history during care transitions such as from adolescence into adulthood.). These data gaps pose a foundational barrier to (1) comparative effectiveness research that is inclusive, accurate, and generalizable; (2) addressing disparities in access and quality of care; and (3) effectively targeting services and supports (some unlabeled people with IDD hence currently manifest as “high-cost, high-need” patients because their underlying needs aren't being met); and (3) creating credible business cases for smarter investments in IDD care. People of color, females, those living in rural areas, and adults with IDD may be less visible than their white counterparts, due to inequities in access to accurate IDD diagnosis, particularly for those with less visible disabilities.

IEC's analyses of claims data from national insurers and electronic health record data from EPIC suggest that the observed prevalence of IDD is a fraction of that expected based on monitoring data from the Centers for Disease Control and Prevention, and surveys.

More comprehensive identification of IDD would improve research by supporting recruitment of more representative IDD study participants, which would enhance the validity of research conclusions and their generalizability to the broader IDD population. Providers would

gain better visibility into their patients and IDD prevalence and thus could target interventions that improve outcomes.

IEC applauds PCORI's interest in furthering the use of non-medical data, as socioeconomic factors are at least as, if not more, influential than clinical factors in a person's health outcomes. IEC supports the [May 2022 Expanding Social Determinants](#) of Health Data across PCORnet® Clinical Research Networks White Paper, which states social determinants of health (SDOH) as one of PCORI's "[three areas of interest](#) for data infrastructure enhancements." IEC agrees that more systematically SDOH would help "advance evidence-based approaches to improve health outcomes and health equity by informing healthcare decisions and care delivery."

[Health care service use only explains about 10%-20%](#) of the observed variation in health outcomes. The remaining 80%-90% is a combination of genetics (minor) and socioeconomic factors (major). They encompass many of the SDOH factors in the [May 2022 Expanding Social Determinants](#) of Health Data across PCORnet® Clinical Research Networks White Paper. [Higher socioeconomic status](#) (SES) is associated with better physical health. People with higher professional status are less likely to be exposed to health dangers. Individuals with higher incomes typically have better medical services. In addition, higher-educated people usually are more knowledgeable about health. [Lower SES](#) is correlated with decreased access to health care, poorer health outcomes, and more mortality and morbidity

However, IEC is concerned about the current state of SDOH data collection, which varies "[with regard to SDOH domains](#) collected, use of standardized terminology to capture SDOH in electronic health records (EHRs), and the data available for querying." Better data utilization can occur through collection of the same data using standardized language. Without standard terms and collection procedures, it would be very difficult to use the data to the fullest extent possible.

IEC also encourages PCORI to consider SDOH data that lies beyond what could feasibly and quickly be collected in electronic health records. More detailed socioeconomic data related to education, employment, income, family & social support, and community safety are currently available from commercial (e.g, home and car ownership, type of employer) and public sources (e.g., weather, commerce, and Census data), and could be linked to clinical data using privacy-preserving methods to support both more comprehensive identification of people with IDD, and more powerful research that might both direct interventions to specific subpopulations and better account for socioeconomic differences in treatment effects.

We encourage PCORI to invest in the development of data infrastructure and tools to more comprehensively identify people with IDD using novel combinations of clinical and non-clinical data.

Sincerely,

Hoangmai Pham
President & CEO
Institute for Exceptional Care