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| **eMERGE Network: Manuscript Concept Sheet** | | |
| **Reference Number**  *(to be assigned by CC)* | NT447 | |
| **Submission Date** | April 14th, 2022 | |
| **Project Title** | Handling the differential performance of PRS by population group in clinical reporting | |
| **Tentative Lead Investigator** *(first author)* | Anna Lewis, MGB | |
| **Tentative Senior Author**  *(last author)* | Malia Fullerton, UW | |
| **All Other Authors** | Jodie Jackson (VU), Rene Sterling (NHGRI), Niall Lennon (Broad), Elizabeth Karlson (MGB), Eimear Kenny (Mt Sinai), Maya Sabatello (CU), Ingrid Holm (CHOP and CCHMC) | |
| **Sites Participating** | This is more about cross working group than cross site – Authorship team includes representatives from the PRS group, GIRA subgroup, ELSI group, Education group | |
| **Background / Significance** | The differential performance of PRS by population group is one of the major ethical barriers to the clinical implementation of PRS. It is also one of the main practical challenges for any such effort. How to address these challenges without exacerbating harms has been debated. We will share the experiences of the eMERGE IV consortium in handling this issue of differential performance, particularly in reporting results to patients and their providers. We will share insight from engagement in this conversation, outline why we used continental groupings despite the known ethical issues with their use, and explain how and why we aligned on using the language of “descent”. We will discuss remaining questions and the ways in which we hope the treatment of this issue will be improved in the future. | |
| **Outline of Project** | 1. Anna to draft outline of commentary, to be iterated upon with input from all co-authors 2. Anna to draft commentary based on aligned upon outline, comments to be sought form all co-authors 3. Final content agreed by all co-authors and commentary submitted | |
| **Desired Data - Common Variables\***  *(Available from the CC)* | **None** |  |
| **Other Desired Data *(Available from participating sites)*** | *Please specifically list out any data elements that participating sites would collect or extract from clinical or other sources for this project (i.e. not common variables above)*  **None** | |
| **Desired Genetic Data** | **None** | |
| **Does project pertain to an existing eMERGE Phenotype?** | ☐Yes, if so please list  X No | |
| **Planned Statistical Analyses** | None | |
| **Ethical Considerations** | One of the main focuses of the paper | |
| **Target Journal** | Nature Genetics, responding to this call: https://www.nature.com/articles/s41588-021-00965-1 | |
| **Milestones**  *(This section should include the key dates for completion of project, including approval, project duration, draft completion, and submission.)* | First draft of manuscript to be completed by June 2022.  Manuscript submission to be completed by July 2022. | |