**eMERGE Network Proposal for Analysis**

Manuscript Concept Sheet

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| **Submission Date** | 3/7/2017 |
| **Reference**  | NT219 |
| **Project Title** | MyResults.org, Phase 3 Expansion  |
| **Tentative Lead Investigator (first author)** | John Connolly  |
| **Tentative Senior Author (last author)** | Hakon Hakonarson |
| **All other authors**  | Margaret Harr, Elizabeth Bhoj, Avni Santani |
| **Sites Involved** | CHOPAny interested sites/workgroups  |
| **Background / Significance** | More than 80% of Americans report using the internet as their primary source of scientific or medical information1. Paradoxically, while consumption of online health resources continues to rise, reported trust in these resources continues to fall. More than 86%2 of the general public report concern about getting health information from online sources, while approximately one-third of Americans have little or no trust in health information found on the internet3. This mistrust is in large part justified – numerous studies have shown that online health information is either incorrect, inaccurate, or biased4,5. Authoritative media developed by universities, hospitals, and science centers can help to address this problem.A large consensus in the scientific community favors the free dissemination of information as widely as possible6,7. The NHGRI, NSF, and a range of other foundations such as the HHMI have been instrumental in supporting a wide range of resources for informal education, but areas important to eMERGE, such as return-of-results procedures and reporting, remain under-served in terms of high-quality, authoritative resources. In August 2013, we launched *MyResults.org*, a public-facing website to inform patients about genomic results and the goals of the eMERGE consortium. Under Phase III, we propose to revise and expand *MyResults* with updated content, media, and external resources, relevant to diseases covered on the eMERGE-Seq panel. |
| **Outline of Project** | The goal of this project is to provide patients with the requisite tools for making sense of genomic testing and results. This phase of the project will focus on developing: 1. A workgroup of representatives from interested eMERGE sites
2. A hit-list of desired resources from respective sites, including:
* Developing/reviewing a catalog of relevant diseases and required resources
* Developing a hit-list of 2-3 flagship projects
* Incorporating existing resources from eMERGE and external sites
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| **Desired****Variables (essential for analysis****indicated by \*)** | None |
| **Desired data** | None |
| **Planned Statistical Analyses** | Google Analytics  |
| **Ethical considerations** | None |
| **Target Journal** | Genetics in Medicine |
| **Milestones\*\*** | 1. 4/3/17: Finalize workgroup
2. 4/17/17: Distribute survey of individual site priorities
3. 5/30/17: Finalize content-development strategy
4. 11/17/17: Site re-launch
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**References**

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4 Kortum P, E. C., & Richards-Kortum, R The Impact of Inaccurate Internet Health Information in a Secondary School Learning Environment. *Journal of Medical Internet Research* **10** (2008).

5 Abbott, V. Web page quality: can we measure it and what do we find? A report of exploratory findings. . *. Journal of Public Health* **22**, 191-197 (2000).

6 De Castro P, M. D., Poltronieri E & and Calderón CA. Dissemination of public health information: key tools utilised by the NECOBELAC network in Europe and Latin America. *Health Info Libr J* **119-130**, 2 (2012).

7 Hartz, J. & Chappell, R. *Worlds apart: How the distance between science and journalism threatens America's future*. (First Amendment Center, 1997).