Global Information for Public Health Transformation (GIPHT) Pilot Project:
A Person-Centered Approach to International Health Record Interoperation for Refugees from Ukraine and Other Countries
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We believe refugees fleeing their home countries, and leaving so much behind, carry with them the inalienable human right to health. This requires that they take their health information with them wherever they may go. Doing so ensures that they can be more confident of receiving safe and effective healthcare - which refugees often need urgently – and empowers them to advance their health and the health of others, while also supporting public health agencies in their missions.

We are proposing a pilot demonstration project addressing the need for interoperable health information for Ukrainian refugees who are dispersing across the world, enabling these people to safely and securely take their important and trusted medical information with them. This pilot project would initially focus on the numerous Ukrainian refugees who are already in Spain, in anticipation of many of them coming to the United States via New York. Madrid and New York City are sister cities, so there is a basis for cooperation. Although starting as a point-to-point effort, the sociotechnical infrastructure underpinning this effort could easily scale to help refugees around the world.

In pursuit of this goal, a team of experts has assembled under the umbrella of the Learning Health Community, a not for profit organization grounded in a set of inclusive *Core Values* and seeking to improve health through the appropriate use to data to drive innovation. The proposed collaborative effort draws on expertise, experience, and technology of MITRE Corporation, the Linux Foundation for Public Health, the Clinical Data Interchange Standards Consortium, the Health Record Banking Alliance, the European Institute for Innovation through Health Data, Indra Minsait of Spain, and Elligo Health Research. Members of the team bring additional experience in government agencies focused on health information technology in the U.S. and Spain, and in global data networking. The leadership of the New York Health + Hospitals Corporation has expressed significant interest in this project.

The pilot project we propose would create a secure personally-controlled health record databank, based on the model developed by the Health Record Banking Alliance and populated with health records of selected Ukrainian refugees currently in greater Madrid. Each individual's record in the bank would contain a core body of trustworthy health information, based on international standards, that is generally recognized to be necessary to support safe and effective care for that individual wherever they may go. Open-source technology developed by MITRE Corporation would ensure that authorized persons will have access to this health information, and others would not.

The project will populate the databank with health information of consenting Ukrainian refugees who express intent to relocate to New York City. Out of 25,000 Ukrainian refugees currently in Spain, we expect that at least 100 would have intentions to relocate to New York. We will enroll 50-100 individuals in the pilot project. As these individuals emigrate, we will demonstrate the feasibility of using the record bank information to support their health care in New York, and we will investigate the interoperability of these records with the EHR systems deployed in the city. Using synthetic data, we will also demonstrate the scalability of the personally

controlled health records and their applicability to support Ukrainian refugees in other nations with possible further extension to refugees anywhere in the world.

Because all of the core technical components of the envisioned record banking system exist, we believe we can carry out this project over 12 months in three phases--a 3 month requirements analysis, 6 month technical integration, and 3 month deployment—with an estimated direct cost budget of $250,000. Although this is an ambitious timeline, we recognize that time is of the essence in meeting these humanitarian needs. We believe this timeline is realistic because we would be implementing a resource for which the architecture, interoperability specifications and privacy protection measures are all well-defined through existing standards.

In summary, we believe individuals have a fundamental human right to access and control their health data, as well as to utilize it and knowledge derived from it to advance their own health and the health of others. To these ends, the proposed pilot project will produce scalable, repurposable, freely available, open source sociotechnical infrastructure. By creating a digital public good, we are pursuing the humanitarian goal of helping some of the world's most distressed individuals to exercise that fundamental right.

We would be happy to answer questions and provide further details on request. Please direct all inquiries to:

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