

FasterCures

Health Data Basics

CONCEPTS V4

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PATIENT ORGANIZATION TRAINING



SUMMARY

This initiative would involve training representatives from patient organizations on major topics around health data. These representatives would then provide this information to patients and families from a trustworthy source. A reliance on patient organizations also provides an opportunity for tailored feedback for provider and regionally specific information.

AUDIENCE

Representatives from patient organizations will be trained to conduct lessons. Individuals who may attend training include caregivers, patients, or family members. One reason to focus on this group of end users is that individuals will be intrinsically motivated to retain the information provided.

ENVIRONMENT

Training would likely occur at the meeting location of the patient organization, or at an agreed upon venue. Trainings generally require an indoor meeting space, chairs and presentation equipment.

SCALABILITY / DURABILITY

Changes in guidance, as well as updated training material, can easily be disseminated to representatives of patient organization particularly if this is done through digital means.

FASTERCURES TRAINING FORCE

Training workshop

Support staff to field questions from patient organizations

Resource portal - a place for trainers, deputies, and patients/families/caregivers to come and get up-to-date information and materials, ask questions, and request sessions



PATIENT ORGANIZATION MATERIALS

Health Data Deputy training workshop

Techniques for disseminating information to patients and families efficiently

Resources to set up patient workshops, individual sessions, Q&A sessions



PATIENT MATERIALS

In clear, plain language (6th grade reading level)

“What is health data?” primer

Health data rights

Info packet on how different entities use your data, risks and benefits of them having this data / your sharing with them

Tips or resources to help retrieve health data with as little effort as possible

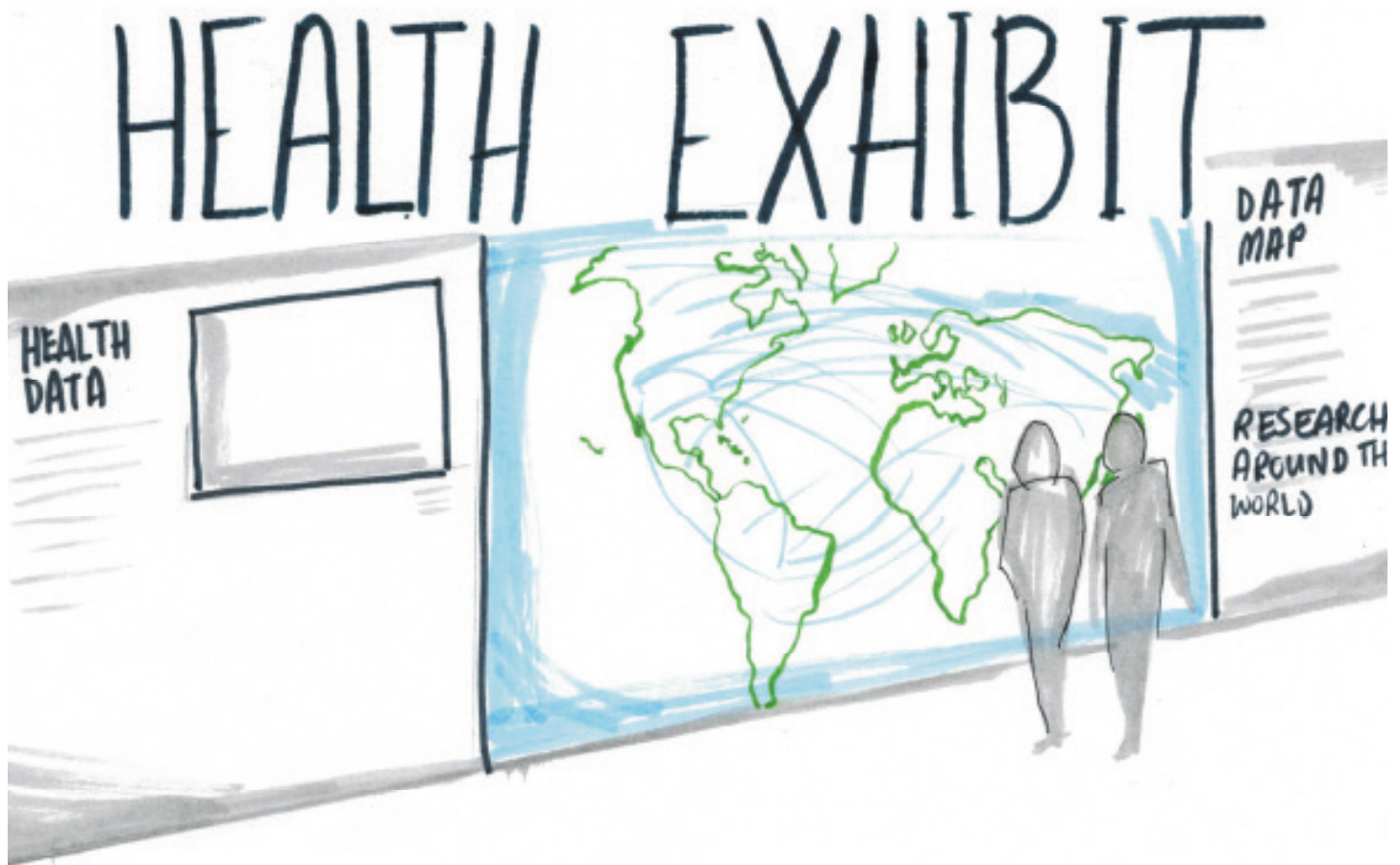
Other ways to collect health data and share it with providers

Resources to help manage day-to-day wellness using the power of health data

Patient / Caretaker checklists for inpatient and office visits to ask questions, improve communication, prevent medical or record errors

Research organizations or charities that use donated data to find cures for specific relevant conditions, or provide access to citizen scientists to learn more about the condition

Bonus: How to be a health citizen, list of health demands, who to talk to to make ripples in the health/political world



SUMMARY

A health exhibit would captivate the curiosity of visitors while deepening their understanding of health data. An exhibit would allow individuals to discover and browse relevant topics in an immersive environment that could include visualizations, participatory activities, and text.

AUDIENCE

A desire for information may draw caregivers and patients to this exhibit, while curiosity will entice the general public. An exhibit would hold particular relevance to healthcare providers and individuals concerned about privacy.

ENVIRONMENT

This exhibit may reside in a permanent physical location, or take the form of a portable exhibit. Options for a permanent location include, a studio space in major metropolitan area, appended to an existing healthcare related exhibition, accessible inside a healthcare facility, or near a high density area of care providers. Showcase locations for a temporary exhibit include at conferences, community events, and workshops.

SCALABILITY / DURABILITY

Ease of updating the exhibit will depend on whether the display is digital or physical. Digital experiences may will likely be easier to update.

Exhibits may be appended to include new sections as sentiments and challenges evolve.

Exhibition Map

