Using participatory design to optimize capture of information needed for public health reporting processes

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**Objective.** To engage public health end-users in the participatory design of Communicable Disease Report (CDR) forms that are pre-populated with HIE-derived clinical data (patient demographics, laboratory results, and treatment) and transmitted via the HIE.

**Background.** Prior research demonstrates a need to improve public health (PH) agencies’ ability to more completely and accurately capture routinely collected CD case information from clinical providers. Traditionally these processes involve manually completed paper forms by providers and/or clinic staff. In settings that utilize electronic health record systems, one proposed pathway for improvement is deploying CDR forms pre-populated with electronic data derived from clinical care settings.\textsuperscript{1} Participatory design (PD) principles advocate including real users and stakeholders when designing an information system to ensure high ecological validity of the product, incorporate relevance and context to the design, reduce misconceptions designers can make due to insufficient domain expertise, and ultimately reduce barriers to adoption of the system.\textsuperscript{2} Prior to deploying a pre-populated CDR form, we engaged PH users and stakeholders as co-designers.

**Methods.** Over a 9-month period, we engaged stakeholders in a multi-phase PD process as follows:

1. Initial Focus Groups: Focus groups (5-6 participants/group) were held with PH health stakeholders representing communicable and infectious disease investigation in two PH agencies to review the list of existing CDR form data elements and identify data elements that PH routinely request from clinical reporters and are desirable for inclusion on a CDR form, focused on high priority conditions previously identified by PH: Chlamydia; Gonorrhea; Hepatitis B, acute; Hepatitis C, chronic; Histoplasmosis; Salmonella; and Syphilis.
2. IT Input: Project staff held meetings (n=4) with IT staff to categorize and document the technical feasibility of extracting both existing and additional desirable data elements.
3. Survey: Practitioners and investigators from the two PH agencies prioritized data elements feasible for extraction with regards to data needed to close a CDR case.
4. CDR Form Mock-ups: Based on survey data, IT staff developed a modified, pre-populated CDR form mock-up for each high-priority condition.
5. Closing Focus Groups: The original PH stakeholders reconvened to review and achieve consensus on the collated list of final prioritized data elements and provide feedback on the CDR form mock-ups.

**Results.** By involving PH users in a PD process, we made significant improvements to the layout and functionality of the forms. Focus groups with PH stakeholders identified a number of state-mandated fields that are not highly used or desirable for disease investigation and their elimination allowed engineers to focus on re-purposing form space to capture higher priority data elements. Establishing appropriate user expectations is a critical factor with respect to adoption and receiving early input through PD methods provided new insights into PH workflow and allowed the team to quickly triage user requests while managing PH user expectations within the realm of engineering possibilities. A final CDR form for each condition was designed to meet the needs of PH stakeholders and the technical capabilities of the HIE to automatically pre-populate the forms with available, prioritized data elements. Deployment of the modified, automatically pre-populated CDR forms is in process in pilot clinic settings and evaluation of these improvements on CDR data quality and reporting rates is ongoing.\textsuperscript{3}

**Conclusions.** Innovative IT strategies must be aligned with the requirements and expectations of their users. Engaging PH as a co-designer not only ensured the new CDR forms will meet real-life needs, but also will support development of a product that will improve CDR reporting.

**References**


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