

POSTER PRESENTATION

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Informatics methodology for the rapid, validated development of clinical research forms in CARRAnet: incorporating user-centered design into the Delphi technique

CJ Inman^{4*}, Marc Natter¹, Robert W Warren³, CARRA Investigators²

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Purpose

CARRAnet is a multicenter and multiple disease national registry in pediatric rheumatology with up to sixty sites participating. The CARRAnet registry is designed as a

framework from which to drive clinical research and creation of evidence based treatment protocols. Success of the project relies on the continued participation of the clinical sites. User centered design is an informatics technique for

Proposed Question:

Total number of joints affected since last report:

< 5 joints ≥ 5 joints

User Synopsis:

Issue: All physicians felt strongly that there should be a 0 joints affected

Propose: Add data field to capture 0 active joints

Revised Question:

Total number of joints affected with arthritis since last study visit:

None 1-4 joints ≥ 5 joints

Figure 1 Example of question, synopsis and change

⁴University of Utah, Salt Lake City, UT, USA

Full list of author information is available at the end of the article

creating an effective and efficient system that creates positive attitudes among the end users¹. We describe a methodological approach toward incorporating user centered design into the traditional Delphi process for data-element development as an approach for testing and validation of case report forms (CRF) for clinical registries.

Methods

Common and disease specific data elements sets were created using a modified Delphi Technique by expert panels of pediatric rheumatologists². Site Principal Investigators and study coordinators were contacted via email to participate in User Testing. Each user was sent a data element set, encompassing an initial and follow-up visit form along with a User Survey. A semi-structured interview was conducted over the phone by a researcher (CJI), qualitative information about missing, inaccurate or confusing data elements were recorded. The results of the user testing were recorded in a synopsis allowing anonymity to participants. The synopsis was a standardized summary of responses, in 3 domains and on a graded scale: who was providing feedback (attending, fellow or study coordinator), strength of opinion, and degree of agreement. This was presented to an executive panel and revisions to the data elements and instructions were made at their discretion. The accepted set of data elements and instructions were used for the registry CRFs.

Results

A common and 7 disease specific data element sets each with an initial and follow up visit form were created. The common and 5 disease specific data element sets underwent user testing. There were a total of 44 participants including 27 physicians.

Conclusion

We describe a methodology of incorporating user centered design into the Delphi Technique for creation of CRFs for the CARRAnet clinical registry. We propose that User Centered Design will encourage participation and provide more accurate data collection. Future research involves in-depth analyses of the content of the accepted versus rejected data elements based on user testing.

Disclosure

C.J. Inman: None; Marc Natter: None; Robert W. Warren: None; CARRA Investigators: None.

Author details

¹Children's Hospital of Boston, Boston, MA, USA. ²Stanford, CA, USA. ³Texas Children's Hospital, Houston, TX, USA. ⁴University of Utah, Salt Lake City, UT, USA.

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