July 29 2014 Written Testimony Regarding JASON Report Ted Kremer, MPH

Thank you for the opportunity to provide feedback on what could be a very significant national undertaking. As a health information exchange provider I welcome efforts that propose to simplify and enable a more robust interoperability landscape. And as someone who has been involved in both clinical trial software systems and health information exchange services for the last ten years, I am very supportive of efforts that look to leverage our expanding health information exchange capabilities to improve bio-medical research.

As a Health Information Exchange (HIE) provider, our experience in working with both state and national technical standards, is that as standards are promulgated across a heterogeneous environment there is always a degree of interpretation and significant implementation details that need to be managed between various health IT vendors. And while a recommendation was made in the JASON report to tie this new architecture to the meaningful use EHR program, there is a much larger healthcare IT ecosystem that should be a part of such systems evolution. As an HIE that has provided regional semantic mapping and data normalization and patient identity services to healthcare providers across our region, it is also not clear that semantic mapping and patient identity services occurring at the edges within each EHR, as proposed by the JASON report, will be the best solution or obviate the need for broader more coordinated efforts.

Adding to this larger health care ecosystem, we may also want to consider the ability of patients to establish and manage access rights to data in such a way that they can change their choices over time while not burdening healthcare providers in managing granular permission levels in every care setting. HIEs or other organizations might represent a useful place for patients to manage such access rights across various care providers and across time. In building out our health information exchange services, supporting informed patient choice has always been an overarching concern and obligation. Regionally we conducted significant marketing and educational outreach to ensure that patients understood health information exchange services, such that today over a million patients have now consented to our services. We would expect a significantly bigger lift to educate patients about the possible downstream uses of their data as envisioned by JASON.

Section 3.1 of The Report enumerates 15 issues beyond technology that could frustrate the vision of better support for bio medical and clinical research, and yet all 15 of the issues raised will still need to be addressed for this vision to be realized. As pointed out in the report, the first order of business for promoting such an evolutionary migration is “To Do No Harm”. And yet the work envisioned by the JASON report will be occurring during a historic period of competing healthcare reform initiatives and a national health IT staffing shortage. Beyond the software development necessary there will be significant testing, quality assurance and adoption work that will be required not only of health IT vendors but for all healthcare providers. These considerations would seem to argue for a more measured approach that takes into account the demands currently being placed on both health care providers and health IT vendors.

One of the cornerstones of the Report’s recommendation is the concept of atomic level data segmentation with meta-data controlling a patient’s wishes regarding secondary use of their information. This data segmentation would address a number of the privacy and policy issues that sometimes challenge current interoperability efforts focused on improving healthcare treatment and operations. Such a data segmentation capability becomes even more valuable if it is facilitated and coordinated across the larger healthcare ecosystem, not just in electronic health records but also in lab systems, radiology systems, home care, long term care, care management, pharmacy and pre hospital care systems as well as the soon to be exploding world of patient contributed data. When you add this to the increasingly global nature of clinical trials and research it becomes crucial that we consider better support for secondary use of healthcare data in a broader international context and leverage existing international health IT data standard bodies such as HL7 as part of this effort.

President Bush challenged us some 10 years ago to move to electronic health records by 2014. Given the multifaceted nature of the work necessary to move the entire health IT ecosystem to a JASON like architecture it is not unreasonable to expect these efforts may be comparable in scale.

As such, a more measured approach, that initially seeks to solve some of the data segmentation challenges facing us, might serve us better. At the same time we could explore other business and patient engagement models that leverage existing meaningful use patient engagement requirements. Such models could provide improved support for clinical research in the near term, while not necessarily facing all the hurdles as outlined in the JASON report. Paralleling some of these broader market or patient centric approaches we could also move to piloting some of the proposed JASON architectural components and learn from these efforts in order to better chart a path forward.

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