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Re: JASON Report "A Robust Health Data Infrastructure", JSR-13-700 – Approved for publication 4/09/2014

Humetrix has a 20 year history of developing consumer facing mobile solutions which have been deployed around the world. In the U.S., Humetrix has capitalized on the transformative patient engagement policies and initiatives – Meaningful Use and Blue Button - to build the iBlueButton smartphone apps to help patients bring critical health data to the point of care.

In analyzing the JASON report, we have focused on portions of the report which we find especially important to emphasize to the JASON task force and have included them throughout these written comments starting with:

"When faced with decisions about how to implement systems for exchanging health information, one should ask: "What is best for the patient?" The answer usually provides clarity to help cut through the debate about these matters." JASON Report section 4.2

We live in a time when the Institute of Medicine has estimated that 100,000 patients a year die due to preventable medical errors and some have estimated this number may be as high as 440,000 per year¹. It further appears that up to 20% of these of preventable catastrophic outcomes are tied to the lack of medical information at the point of care². None of these deaths are likely to be caused by the lack of big data or analytics which may in the future define new ways of more effectively caring for patients. Instead, these deaths are caused by a lack of small data: often the simplest of things like a list of medications, problems, and allergies.

"One lesson to draw is that the US health data infrastructure should not eliminate the possibility of smartcards or their equivalent, patient-controlled cloud storage, or some other future technology from being used in conjunction with traditional storage for medical data" JASON Report section 3.4.3

Even though the JASON report here recognizes the importance of consumer-mediated health information exchange in Taiwan, it overlooks the importance of the ONC-led Blue Button initiative which aims to provide the

1. James JT. J Patient Safety September 2013 Vol 9, No 3

2. Fickenscher KM. J Am Med Inform Assoc May 2013 Vol 20 No 3

tools needed for patients to effectively exercise their new rights to receive electronic health records under HIPAA. By capitalizing on the existing Blue Button records and the recently published Blue Button⁺ implementation guide which specifies the use of C-CDA content and the Direct protocol for transport, millions of Americans can today receive medical records which can be lifesaving. While we agree that Direct is not the solution for building scalable interoperability between providers, we believe it serves a very important purpose in providing the means for patients to securely receive their summary medical records. Humetrix has made available the iBlueButton smart phone apps that millions of American can use today to obtain, parse, display and aggregate clinical record summaries in diverse structured formats including C-CDAs produced by multiple EMR vendors transmitted by Direct, as well as VA & DoD CCDs and the Medicare Blue Button ASCII text file pulled by the app to ensure that their physicians will have access to their key medical information whenever and wherever care is provided.

- The important finding overlooked in the JASON report is that a nascent app ecosystem has been built around the Blue Button initiative, and it would be a cardinal error to withdraw support for the existing MU2 standards which have provided the foundation for this private sector innovation which is so badly needed in building a sustainable nationwide health information exchange sector.

“HHS asked JASON to address the nationally significant challenge of developing comprehensive clinical datasets, collected in real world environments and accessible in real time, to support clinical research and to address public health concerns.” JASON Report section 2.2

The JASON report aims at the creation of an HIT architecture which is designed to support clinical research and public health, and we believe this is an important national priority even if the design of this system has yet to be defined, and even if the challenges to implement this system will be considerable and the process lengthy and uncertain. We would like to underline that this is a separate goal from getting actionable clinical information into the hands of patients and their families as soon as possible so that this information can be shared at the point of care. The considerable progress which has been made, and is being built on as every day passes, due to the Meaningful Use 2 certification requirements for EMR systems to produce C-CDAs and enable Direct transport should in no way be delayed or compromised by planning for the implementation of a national HIT architecture as proposed in the JASON report.

“...priority should be given to services that make it possible for health care providers to rapidly access patient clinical information in the near term. The use of patient data for research purposes would become a priority only after significant exchange of health records for clinical purposes is established” JASON Report section 5.2

We fully endorse this statement and urge the Task Force and the HIT Policy Committee to maintain and extend existing MU2 requirements in order to enable eligible providers and hospitals to transmit C-CDAs to third party apps used by patients by including in the 2015 EMR Edition criteria the use of the Blue Button trust bundles, as some EMR companies have already done. The ONC should also consider making the use of the Blue Button trust bundles part of the mandatory MU Stage 3 standard and certification criteria. Taking these steps will ensure that a viable, self-sustaining ecosystem of innovative third party apps can thrive and provide patients and providers the tools needed to ensure safer and more cost effective care. These measures should be undertaken as a first priority while the ONC is considering a JASON report-inspired HIT infrastructure to support clinical research and to address public health concerns.