



**Joint HIT Policy and Standards Committee
JASON Task Force - Listening Session
Final Transcript
July 31, 2014**

Presentation

Attendance (See Below)

Operator

All lines bridged with the public.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Thank you. Good afternoon everyone this is Michelle Consolazio with the Office of the National Coordinator. This is a meeting of the JASON Task Force which is a combined Health IT Policy and Health IT Standards Committee Workgroup. This is a public meeting and there will be time for public comment at the end of the meeting.

As a reminder, if you could please state your name before speaking as this meeting is being transcribed and recorded. Also, as a reminder if you are not speaking if you could please keep your line muted it would be appreciated and I will now take roll. Micky Tripathi?

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative
Here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi Micky. David McCallie?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi David. Andy Wiesenthal? Arien Malec?

Arien Malec – Vice President Strategy & Product Marketing – RelayHealth Corporation

I'm here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Deven McGraw? Hi Arien.

Arien Malec – Vice President Strategy & Product Marketing – RelayHealth Corporation

Howdy.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Deven McGraw should be joining late. Gayle Harrell?

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

Here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi Gayle. Jon White?

P. Jonathan White, MD – Director, Health IT – Agency for Healthcare Research & Quality (AHRQ)

Here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi Jon. Josh Mandel? Keith Figlioli? Larry Garber?

Lawrence Garber, MD – Internist/Medical Director for Informatics – Reliant Medical Group

Here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Larry Wolf? Nancy Orvis? Tracy Meyer? Troy Seagondollar?

Troy Seagondollar, RN-BC, MSN, UNAC/UHCP – Regional Technology Nursing Liaison – Informatics Nurse – Kaiser Permanente

Here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Wes Rishel? Hi Troy.

Wes Rishel – Independent Consultant

Here, Wes Rishel here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi Wes. And from ONC do we have Kory Mertz?

Kory Mertz – Challenge Grant Director – Office of the National Coordinator for Health Information Technology

I'm here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi Kory and Debbie Bucci?

Debbie Bucci – Office of Standards & Interoperability – Office of the National Coordinator for Health Information Technology

I'm here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi Debbie. Are there any other ONC staff members on the line?

Kim Wilson – Health Communications Specialist – Center for Disease Control and Prevention – Department of Health & Human Services

Kim Wilson.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi Kim.

Kim Wilson – Health Communications Specialist – Center for Disease Control and Prevention – Department of Health & Human Services

Hi.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

And with that I will turn it over to David McCallie.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you, Michelle and welcome everyone to the first of two public hearings.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

I'm sorry, David, if people could please mute their line if they aren't speaking it would be appreciated. Thank you.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you. The first of two public hearings, virtual hearings on opinions regarding the JASON report. I appreciate everyone's ability and willingness to take time out of what I'm sure would otherwise be a relaxing summer afternoon to attend to these interesting and important questions and we will take your comments and your opinions very seriously as the Workgroup, the Task Force that Micky and I Co-Chair deliberate and summarize to make recommendations back to the Policy Committee and the Standards Committee, and of course to ONC.

I think the context of our hearing here is probably pretty well understood, but just to reiterate the JASON report was issued or was released to the public in April, this past April by ONC initially commissioned by AHRQ of the JASON's which is a group of scientists who anonymously advise the government on complex questions of interest to particular departments in government. This particular question addresses healthcare interoperability which we of course all realize this is the hot topic of the day.

The JASON report itself is quite sweeping in its scope and recommendations. I am not going to try to summarize it here because I think all of the salient points will come out in the course of today's discussions.

Our process, if you haven't done one of these before is pretty simple. We are going to have a series of panels today. I believe we have, what, three panels today, each panelist will be asked to just present five minutes of uninterrupted summary in response to specific questions that we ask and then in response to any of the general questions that they wish to take on.

We'll go through each presenter for each panel five minutes apiece and then at the end of the last presentation for that particular panel we'll open it for discussion with questions coming from the members of the Task Force.

You should feel free to deviate from your written remarks but use your five minutes wisely. We have asked Michelle to be the timekeeper and I'm warning you don't want Michelle to be mad at you so listen carefully when she tells you that your time is up. You'll have time during the discussion if you missed a point or something.

Rather than provide elaborate introduction since we have such a limited amount of time I will refer you to the document that was circulated with the materials accompanying the meeting that have more detailed biographical sketches for each of our presenters and so we won't go into detail you can read about these folks as you wish. Micky do you have any comments to add?

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative

No just want to join you, David, in thanking everyone and particularly the presenters. I mean, this is...we've had a couple of, you know, Workgroup meetings, Task Force meetings where we've, you know, sort of started to collect our thoughts on, you know, how to approach the JASON report review and this is our first outreach really out to the market to get the perspective of the market. So, we really appreciate the presenters for this meeting and the next one and you all taking the time to do it.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yes, absolutely. And I've seen a tremendous amount of interest in the JASON report both from ONC itself, Karen DeSalvo has made mention of it directly and indirectly on a number of occasions.

Our discussions on the Task Force, which are a public record you can go back and look at them if you care, have been really fascinating and have brought out a lot of really interesting issues, important timely issues particularly in the context of the imminent release of the NPRM for Meaningful Use Stage 3 and the relatively short period of time that we have to make decisions about course corrections if any that the JASON report would introduce into the Meaningful Use process, that will be obviously something of key concern to our Task Force as we synthesize what we hear today and in the next session.

So, barring other comments, Michelle, have I left anything out that I need to remind people of?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

No you did a great job, thank you, David.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, so let's start with panel one. I think I heard everyone's name in the call at the beginning of the call, but I know I heard most of them, so we'll go in the order that is listed on the agenda that will be David Horrocks from the Chesapeake Regional Information System first followed by Ted Kremer from Rochester RHIO, then Jitin Asnaani representing CommonWell Health Alliance and then finally Eric Heflin representing Healtheway. So, David if you're present and ready to start the floor is yours.

David Horrocks, MBA – President & CEO – Chesapeake Regional Information System for our Patients (CRISP)

I am thank you, David. My name is David Horrocks I'm the President of CRISP an HIE with 53 participating hospitals serving Maryland and the District of Columbia. We were chartered to improve health and wellness by deploying health IT solutions which are best done cooperatively. We have three services, a query portal, an encounter notification service and analytics and reporting.

Regarding the role of exchange service providers in a JASON-like architecture I have a few thoughts about the concepts of the new architecture. First it would be accurate to say that the service's CRISP now provides have been built in pragmatic, incremental and even opportunistic ways.

Our approach to gathering medical records for query is not particularly elegant, the records are not captured in a consistent format, many are not stored as discrete data and mechanisms for patient engagement are limited.

Our approach was chosen simply because it's what we thought we could pull off at the time. But the approach has also proven to be successful in that it's an incremental improvement over what existed before.

While we think that what we have is the right choice when we made it, we recognize our current approach should eventually be superseded. It should be obsolete. If a JASON-like architecture doesn't do that I think something else will, maybe it will be something non-JASON-like such as Health Record Banking.

On the secondary use and research front most of the work CRISP does today is based on records collected by regulation of state agencies. Records that resemble an all payer claims data set in that they are coded and structured. We find such data is very useful for population health management efforts but in contrast because the records we collect the discharge summaries, labs, radiology reports that we collect from providers is not structured it's much harder to use for secondary purposes and that is a weakness of our current architecture.

The second broad thought is that when members of our community asked us to become involved in an effort we generally go back to our mission statement and ask whether it's something that is best done cooperatively. If an initiative can be accomplished through a private investment or competition makes it better than it's probably not a good fit for an organization such as ours.

If the JASON authors are correct and APIs built into the EMRs can facilitate much of the exchange activity, which currently flows through CRISP and the business drivers...investment to make that happen can be marshaled without a governing entity such as ours then I'd say "so be it." Perhaps the role of CRISP should be narrowed away from what we do now...would be narrowed away from the technology operation we do today.

So, having said that, I must confess to having doubts about the ease of getting from here to there. We've seen how difficult it is to rollout secure messaging which is probably straightforward compared to building open APIs to access granular data.

As to the role of an organization like CRISP if a JASON-like architecture we're successfully to play I tend to think the community would still have use for an organization to facilitate cooperation but that we'd be doing less technology operation.

As I imagine how the world would operate with ubiquitous, well-documented and functional APIs in every medical record system I think it would be similar to a world in which a single vendor solution was in place for every healthcare provider.

The basic interoperability challenges would be off the table. But I'm struck that...and we have some experience with that, but I'm struck that even in such a scenario where interoperability is solved participating organizations would still struggle to establish rules of the road, it wouldn't automatically solve questions of allowable data use, patient consent and control of data and patient matching.

You'd still have tensions between competitors who need to know that the information they provide isn't used inappropriately and that privacy and security of such an architecture would still need to be managed. Someone needs to audit access and provide accountability when there's bad behavior.

A similar set of issues exists when it comes to secondary use. I suspect the community will still need trusted entities to consolidate whole and manage access to such data even in a world where gathering the data in the first place is much easier.

Perhaps in a JASON-like architecture those are the things that would be done by organizations such as ours. So, in closing if policy making...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Thirty seconds.

David Horrocks, MBA – President & CEO – Chesapeake Regional Information System for our Patients (CRISP)

If policy makers think a push toward a JASON-like architecture is pragmatic and incremental and that it can be pulled off then I say "go for it." But if that's too ambitious I'd suggest more incremental approaches for now such as steps to make Direct secure messaging truly ubiquitous and easy to use. Thanks.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you, David. Let me interject here before the next presenter to just remind folks if I didn't say it before, and I don't think I did, that the specific questions that we asked the panelists are at the bottom of the agenda that was passed out and then there is a series of more general questions below that and I think I failed to mention that and didn't notice it myself the first time through, so, if you're having a hard time figuring out what questions the panelists are responding to just scroll down on the agenda.

Okay, Ted are you here? Ted Kremer?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

I am.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay you're next.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Well, very good, well first of all thanks so much for allowing me to have an opportunity to provide feedback on something that I think is potentially a really significant national undertaking. As a health information exchange provider we really welcome efforts that sort of simplify or look to simply the interoperability landscape.

And as someone who has been involved in clinical trial software systems and healthcare information exchange for about the last 10 years now I'm really supportive of those efforts that look to sort of leverage those two domains. So, it's pretty exciting leveraging HIE and biomedical research.

I should point out if I get tongue-tied or I hit the 30 second delay or warning message I did also include some written testimony as well.

So, as a health information exchange provider our experience has been that as standards are promulgated across a sort of heterogeneous environment there's always a degree of interpretation and significant effort in working through implementation deals...these details between various health IT vendors. Given the scope that the JASON is really proposing and the architectural changes I would expect there would still be some significant effort to engage in that same sort of brokering.

Also as a health information exchange provider we've done a significant amount of regional semantic mapping and data normalization and provide patient identity services across our region and it isn't really clear that the semantic mapping and patient identity services occurring at the edges as envisioned by the JASON report would necessarily be the best solution or really even obviate the need for the sort of broader more coordinated efforts.

So, I think where there is a recommendation that JASON would tie this approach to the new Meaningful Use Program I think there is a much larger health IT ecosystem that we have to think about and I would really recommend that that larger IT ecosystem be considered.

I think one of the things that really stood out for us was the concept of the atomic level data segmentation with patients controlling secondary use of this data which would really help a lot of the privacy and policy issues that we sort of struggled on over the years. Again, not just with EHRs but lab systems, radiology, home care, long-term care. I mean, the list goes on. And when you start thinking about the exploding world of patient contributed data it's just going to be more important I think to wrestle down this data segmentation issue.

When you add on top of that the increasing global nature of clinical trials and research it seems crucial that we have to consider better support for secondary use of healthcare data in a broader sort of international context and that's where I think leveraging things like HL7 and other data standard bodies would be really crucial for this to really scale nicely.

The report calls out in, I think section 3.1, something like 15 issues beyond technology that would sort of frustrate the vision of better support for biomedical and clinical research and yet all 15 of those really have to get resolved.

The report also sort of talks about, you know, first order of business "do no harm" and so I think one of the things to keep in mind is that the JASON report is...or recommendations are occurring during this historic of competing healthcare reform initiatives and there is this national IT staffing shortage.

So, beyond the software development requirements there would be testing, quality assurance, but there is also adoption work that's going to have to go on with physicians. And the other thing that sort of...one of the policy things we'll need to wrestle through is how do we really make this so that patients have a better way of establish and manage access rights to their data so that they can change their choices over time and not necessarily burden healthcare providers to managing those granular permission levels across every care setting.

We spend a lot of time within the RHIO sort of building our HIE services a lot of time educating patients about what an information exchange is such that we now have 1 million patients having provided consent. When you think about these secondary uses and downstream uses of data I think it's going to be an even heavier lift to really educate patients about what they are granting permissions to or denying permissions to.

You know in context President Bush challenged us, what I think 10 years ago, to move to electronic health records by 2014 and I think looking at the report and the recommendations giving the multi-faceted nature of the work it looks like it would not be unreasonable to think that the effort is somewhat comparable in scale.

And that's where...sort of when I look as an HIE or as a clinical software research person, you know, I think are there may be ways that we could peel this a little differently such that...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Thirty seconds.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Yes. Such that we could really use the Meaningful Use interoperability capabilities that are there today and explore other market-based opportunities to get to this same sort of building clinical research and biomedical use case. I think there is a lot of opportunity with MU and what MU is doing today to support the same goals that the JASON report has and I'll stop there.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Excellent. Thank you, Ted. Jitin Asnaani are you present?

Jitin Asnaani, MBA – Director, Product Innovation – athenahealth

I am.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, the floor is yours.

Jitin Asnaani, MBA – Director, Product Innovation – athenahealth

Great, thank you very much. So, I'm Jitin Asnaani and I'm here on behalf of the CommonWell Health Alliance. Thank you very much for this opportunity to provide testimony.

As you may know the CommonWell Health Alliance is an independent not-for-profit trade organization devoted to the simple vision that health data should be available to individuals and providers regardless of where care occurs. We believe that access to this data must be built into health IT at a reasonable cost for use by a broad range of healthcare providers and the people that they serve.

The alliance currently consist of 10 health technology vendors who collectively represent more than 40% of the acute EHR and 20% of the ambulatory EHR markets, as well as major participants in the lab, pharmacy and post-acute care markets.

The alliance plans to define and promote a national infrastructure with common standards and policies. The early core components of this infrastructure include identity management, record location, consent management and trusted data access.

Our view is that the CommonWell Health Alliance can fulfill the vision of interoperability as outlined by the JASON report in terms of both intent and architecture.

From the intent perspective CommonWell provides a practical piloted solution that enables a query approach across thousands of healthcare IT systems. While the writers of the JASON report were more oriented towards research and population health, with which we agree, such focus does require data of sufficient granularity and an interoperability platform of sufficient quality to facilitate improved patient care and as such that is the use case that CommonWell is first addressing.

From an architecture perspective CommonWell is already enabling JASON-like functionality among its member companies. For example, CommonWell provides a set of centralized services that are designed to interact through APIs with technology systems in a variety of healthcare settings. Vendors in these environments are opening up their systems to data exchange and providing accessible authorized data access. This architecture is highly flexible. It can, for example, be incrementally extended for new use cases or new models of usage such as pub/sub model for authorized data subscribers.

There are also other natural extensions of the CommonWell service that enable the JASON vision. For example, the JASON report zeroes in specifically on the concept of discrete data. While today's document centric chart data approach certainly leaves a number of use cases inadequately addressed, swinging the pendulum to the other extreme of discrete atomic data can create unnecessary performance overhead and needless rip and replace in the use cases where documents are actually sensible. Plus a low level of...can of course result in loss clinical context and so pose a higher patient safety risk.

The CommonWell approach then is to leverage the existing Consolidated CDA document specification and XDS service end points to facilitate meaningful exchange today. And this can be very easily extended to extend to for example a FHIR service end point that enables discrete data access tomorrow.

CommonWell also solves some of the real world implementation issues that JASON did not address. For example, the challenge of patient matching and disambiguation is a prerequisite for the JASON vision. In reality it's not solved today.

CommonWell creates a scalable solution to patient identification, matching, consent management and record location. The key difference I would say between CommonWell and the architecture outlined in the JASON report is that CommonWell explicitly employs a modular, that is a non-model, monolithic architectural approach by providing elements of the stack that are amenable to the deployment in multiple configurations.

For example, the JASON report suggested the creation or instantiation of centralized data storage to be queried and/or enabled by APIs but this may not be acceptable to a range of effective stakeholders, at least that's the battle that we'll face today including providers and consumers.

We think that there is a glide path to getting there, a glide path to getting to a learning healthcare system by separating the way data should be structured for interchange, which is salient interoperability from the way data is stored internally by the EHR or HIT implementation which is less relevant.

As such CommonWell's identity, discovery, authorization and secure transport are separate from the storage layer enabling a variety of future configurations. In our more extensive submitted comments we provided there again to illustrate how the CommonWell architecture maps to the referenced architecture posted by the JASON report.

But on the whole the CommonWell Health Alliance is bringing together the rights of the software services architecture that can enable search and index of both core screened charts and fine-grained atomic data. We recommend...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Thirty seconds.

Jitin Asnaani, MBA – Director, Product Innovation – athenahealth

Thank you. We recommend that ONC practice watchful waiting as industry innovators like CommonWell evolve while paving the way for the JASON vision by convening and encouraging complimentary efforts such as, and especially the FHIR standards, to meet new use cases enabled by atomic data. Thank you very much.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you Jitin. I'm sorry I mispronounced your name you think I would know it by now. And then finally for panel one, Eric Heflin, are you on?

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

Yes I am.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, great, Eric, go.

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

Thank you. So for my testimony I'm presented both written testimony with a little more detail as well as my verbal testimony today and my written testimony has also some references to aid readers.

So, to hit the highlights of this more comprehensive written testimony I'm going to provide some additional perspective on just some of the key JASON report topics and some specifics regarding the viability in particular of these topics.

And thank you very much for the opportunity to provide feedback on these two today and my focus will be largely from the perspective of the eHealth Exchange.

I believe the single most important topic though that would probably need an extension that's not really covered much in the JASON-like architecture is not a technical topic it's a legal policy and operational and trust framework topic. Specifically, the eHealth exchange has a legal and trust framework called the DURSA which enables a common trust and operational framework through all participants all the way from the highest level all way down to the edges of the operational entity.

And what this avoids is the need to create point-to-point business relationships and legal agreements between all participants within a unified, you know, JASON-like or other similar architecture because point-to-point agreements really do not scale up.

The JASON report also suggests that there is a need for common market language to be created to facilitated interoperability. Today we actually do have a market language called the CDA, Clinical Document Architecture, which is an industry standard specification specifically the Consolidated CDA.

The C-CDA or Consolidated CDA does a really good but not yet complete tagging of clinical data indeed as envisioned by PCAST and JASON. Capabilities include, today, include highly structured data exchange at the discrete level, controlled vocabularies are referenced using C-CDA, the ability to test this for conformity is also largely included within the C-CDA standard, Meaningful Use has sanctioned and pointed to C-CDA.

There is also...another strength is increasing vendor support over time. There are good patient demographics information which helps assist on the problematic patient matching aspects of our industry. In addition the C-CDA does have gaps though and I've detailed those more in my written testimony.

A new effort called FHIR, Fast Healthcare Interoperability Resources, is currently gaining some significant interest as was mentioned earlier and that may become a successor for Consolidated CDA in the future.

My recommendation is for us to globally invest in C-CDA, remediate the known gaps, create some tooling to author, manage and test it, and also to monitor FHIR to see if it will be a successor.

JASON recommends a semantic translation layer but envisions this layer as lying between the data and the users of this data. I would believe there is actually a role for this to be determined statically rather than dynamically by doing the semantic translation at the data source which is often the only place it can be done reliably.

In addition, we have a number of vocabularies already in existence that are not necessarily acknowledged by JASON directly that could be leveraged such as for problems, medications, allergies and tests.

The JASON report advances idea of interoperability or a privacy bundle. Many of these concepts have actually been looked at and addressed by some existing or current initiatives such as data segmentation for privacy.

The eHealth exchange is currently in production today with another standard called BPPC which allows a patient to express authorization for Social Security Administration, claims, disability termination and that request is included along with the request. This allows the disclosing party to determine if they will honor the request.

My recommendation is to select a single national target for computable or automatable consent and then to leverage existing standards to convey that.

JASON recommends an API application per the interface to allow exchange data from EMRs. I too feel that is important. We do have some positive examples already though. Many EMR and other EHR vendors have taken to market products that are interoperable today including open standards such as IHE XDS and XCA.

There also is an initiative from the ONC called the data access framework which is really a meta-initiative of other underlying standards and that's nearing completion and has already been published and I provide a reference to that.

Today the eHealth exchange has 72 organizations live using an API already that represents close to one third of all patients within the United States.

Finally, JASON briefly mentions patient matching as a concern. I too feel this is a looming issue. Many inside the...matching patients inside of a hospital organization is hard but matching across them is much more difficult.

The solution I feel, in the absence of a national identifier, is to clarify patient matching best practices and my recommendation as we continue as an industry to include minimal patient matching practices and best practices within our guidelines and specifications.

The JASON has envisioned a middleware architecture...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

I'm sorry, I didn't give you a 30 second warning, so if you could please wrap up.

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

Okay, well very good, so the JASON middleware architecture, I just want to mention, has actually been already addressed to an extent by one standards body called IHE International and their ITI technical committee. So, with that thank you very much for the opportunity to present to you and I refer you to my written testimony for more information.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, thanks Eric, Jitin, Ted and David. Now we have about 30 minutes or so for questions from the Task Force members that can be addressed to individuals that have presented to us or to the group.

And to the panelists, I would urge you to reply if you have something valuable to add. Don't feel like you have to reply to every question just to have a reply. So, limit your replies to contributions that you think make it worth the time.

I want to start with just a broad question that I know has been the subject of considerable discussion on several of the Standards Committee Workgroups, which is the adequacy of the clinical document architecture as a way to move discrete data around. Compare and contrast to FHIR has been raised by several of you. I don't necessarily want you to address that.

And some of you talked about the CDA, but if you wouldn't mind, what kind of problems and/or successes are you seeing with using the C-CDA to move discrete data around?

Because that was the subject of considerable criticism from the JASONS. So, I'll just open that up to anyone who wants to respond.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Can I just ask if any of the presenters before speaking if you could please restate your name it would be appreciated and also just for the Workgroup if you could use the hand raising feature to put yourselves in the queue for questions. Thank you.

David Horrocks, MBA – President & CEO – Chesapeake Regional Information System for our Patients (CRISP)

This is David Horrocks. David, I'm not sure about the adequacy but I can say that our experience moving the documents they sometimes arrive, I guess the format is not as consumable by the clinicians on the far side as we would have liked and maybe that's surmountable but that was one of our observations.

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

This is Eric Heflin, we're seeing similar behavior in that the discrete elements within a CDA document which are there and they don't seem to be recognized by the JASON report are working relatively well.

The key problems we're seeing is it's not necessarily complete, you know, a lot of times the clinical document doesn't have problems, medications, allergies, and very interesting information. Also, the location of where data can be stored is not clear. In some cases there are multiple locations where it can be stored so organizations have to hunt for it.

And then the final issue is that there is actually very interesting clinical content in the unstructured text block that also is required to accompany CDA documents or C-CDA documents. And right now there is no standard in terms of how that text is formatted or laid out. The result is organizations have to have custom translation logic to make sense of that really valuable textual information.

And my recommendation regarding that is I think it's time we actually make a standard statement around the text blocks so it's actually indeed also interoperable.

Jitin Asnaani, MBA – Director, Product Innovation – athenahealth

Hi, this is Jitin Asnaani, what I'll contribute on top of those comments is that I think it's well known that the C-CDA and the CDA architecture in general is a little heavy for processing and transmission, etcetera, when it comes to maybe small pieces of data that want to be transmitted.

But what is also true is that the C-CDA is being produced by a large number of vendors in accordance with Meaningful Use Stage 2 which also required certain sections. And, so I think it's actually sort of natural that at this point there are a number of vendors producing C-CDAs where you can't actually issue a C-CDA with only discrete sections it tends to be sort of all or nothing and that's one of the issues that we see as we try to look at what could be some of the more leading edge use cases where it could make sense to have a discrete piece of data without necessarily the full document.

And of course one of the big risks is if you go down that route of even trying to go there, you don't know if you're losing important clinical context and so creating a patient safety...so I think it's both the standard and the fact that there are no profiles around discrete data that make it a standard to use for discrete data today.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Michelle, how are we...do you want me to identify the next questioner from the hand raising?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Yes. So, we have a number of people in the queue. So, Arien Malec.

Arien Malec – Vice President Strategy & Product Marketing – RelayHealth Corporation

Hello, so, I will probably inappropriately summarize the testimony in general as "don't get distracted" and I'd like to...that may or may not be fair, but I would like to challenge the panelists to think about if there were one API or some set of APIs that EHRs universally offered either that were more standardized than they currently are or don't currently exist and yet are needed that would expand your ability to achieve your mission. What APIs would you wish to be available and why?

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

So Arien this is Eric Heflin, I've put a lot of thought into this over the years and I keep coming back to the point of "let's make this as simple as possible but not simpler" to quote Einstein and I think that may be one of the challenges we're facing with Direct is it does provide transport but there are limitations on other things it can do as far as automated patient matching.

So, if you actually look at all of the real requirements we have as an industry, you know, patient matching, making sure consents are in place, discrete data that's parsable, narrative text that can be displayed to users, security and so on, those requirements essentially dictate a fairly heavy lift even if the transport itself is simple like FHIR or Direct.

And so one of my fears, and I don't know if this is true or not, just watching to see, with FHIR will be that for example whenever you add on all the other necessary elements for secure exchange that you may indeed essentially almost end back where you are with something like Consolidated CDA and web services over SOAP instead of using REST.

So, I think it's difficult to say. So, what I would...I think the ultimate answer to the question would be let's identify something like JASON has started to do are true national requirements for key use cases including security and threats to IT security and from there let's determine what architectures would meet those requirements.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Anyone else to Arien's question or do we move into the next question?

Jitin Asnaani, MBA – Director, Product Innovation – athenahealth

This is Jitin and maybe what I would add over here is...and I think about this largely from a content perspective, I think Eric hit the services and the transport perspective really well. But as I think about a content perspective and sort of the mission that we're all on and certainly we are on individually as well, not the entire world trades clinical documents and there are more and more participants outside of health IT vendors and particularly outside of both acute and ambulatory care who want to participate in health IT and particularly in interoperability and cannot today because either Meaningful Use doesn't apply to them, their health IT vendors don't support it, it is a big and expensive lift. There are a variety of reasons.

And for those participants of which, you know, I'm talking about post-acute care, pharmacies, others who these are great sets of participants for whom there is a valid role in the care of the patient but not necessarily the type of investment that the rest of...sort of the core set of providers are used to and I would love to see, over time, simple APIs that allow them to transfer the same sort of really core data that comes in let's say a C-CDA document today problems, medications, allergies the types of things you find let's say a discharge that can come in a discrete format or at least a lighter weight format, light load relative to what we have today and I think that's what those types of players need that does not exist today and prevents us from building the learning healthcare system that we want.

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

This is Eric, if I could...

David Horrocks, MBA – President & CEO – Chesapeake Regional Information System for our Patients (CRISP)

This is David Horrocks...

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

I'm sorry, go ahead.

David Horrocks, MBA – President & CEO – Chesapeake Regional Information System for our Patients (CRISP)

Yeah, this is David, I would like to be able to get out of ambulatory EMRs I'd like to be able to get the equivalent of an ADT feed so we could see when a patient has visited their doctor and that would allow us to provide sort of a gaps in care service and then if those ambulatory docs could very easily send a summary of their care as a CDA those two things would be huge for us. I don't know Arien if that's API changes or user interface changes, but those are the two things that come to mind.

Arien Malec – Vice President Strategy & Product Marketing – RelayHealth Corporation

Okay, thank you.

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

So, this is Eric Heflin, to briefly build on Jitin's comment. The only thing I would offer is a caution which is to make sure that we first have a discussion about requirements in use cases and agree to those. Without those it's going to be very difficult to judge any architecture of any API as being sufficient to meets its requirements.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Let's move onto the next person in line. Thank you for those answers, excellent answers. Michelle?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Micky Tripathi.

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative

Yes, great, thanks. So this question is a little higher level and directed first at Ted Kremer because you had mentioned it, but certainly to any of the panel members.

So, the JASON report makes, you know, sort of an implicit, well it's, you know, it's actually an explicit assumption that the theme architecture and approach that one would use for research is also adequate or optimal for clinical care as well.

And Ted you had kind of alluded to health information exchange and biomedical research and the bringing together of, you know, those two strands. I'm wondering if you could elaborate on that. Is a single architecture appropriate for both and what's been your experience there?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Well, again, you know, I have this sort of toe in both worlds so I've been kind of looking at this for a while trying to figure out how to bring them together. And I think the way I've been looking at it more is how to leverage the interoperability that we've been building and I think based on the conversation it is important to keep in mind that, you know, limitations of CDAs today we've really only been starting to use them for the last year or two in a lot of cases.

So, where I've been sort of very excited is where we could take some of those Meaningful Use capabilities whether it's the content of the CDAs or Direct, or just EHR sort of services in general, view the, you know, the view, download, transmit and connectivity with patients and start using that as a way to inform biomedical research platforms.

I'm not...you know, I still think it's kind of a big sea change to try and get one architecture to support both of them out of the gate today because we're really still working on trying to get transitions of care working better.

So, I still see sort of a market-based approach where you could leverage those things that we've built today and let patients control where they send through the view, download, transmit their data out to those clinical research efforts that they're really excited about and I think there is sort of a business and a patient engagement model there that we could leverage pretty quickly while we work through the more nuanced use case and architectural issues that I think we're all a little concerned about.

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

And this is Eric, to very briefly build onto that, the other part to the answer is that most clinical systems are not designed to be research platforms in terms of their underlying database schema and capacity, you know, they're designed to officially store a patient's lab results. They're not designed to officially return a list of 1 million patients, sorted and organized by ways that researchers may find valuable.

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative

I guess that's why the JASON report calls them all legacy systems.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

I didn't take too much offense to that by the way.

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative

You're over it, I know, you're over it.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Speak for yourself. Okay, Michelle, why don't we go to the next question?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Yeah, Wes Rishel.

Wes Rishel – Independent Consultant

Thanks, building on Micky’s last comment, one definition that is presented frequently of a legacy system is any system that’s actually in production. And it strikes me that a comment we’re hearing right now is that the interfacing functionality of EHRs and related clinical systems that the panelists have appropriate with are generally, frequently document oriented and frequently inconsistently implemented and they see a role of HIE as effectively providing the shims that make interoperability happen, anyone who would disagree with that please comment.

But the related question is, based on what you’ve seen of the evolution of the participating systems in your HIEs is it in fact a case of just some incremental improvements in those systems or is the cost of getting to JASON completely, literally fully replacing the EHRs that are in the field now?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Ted Kremer, I don’t see that the JASON approach would really replace the EHRs that are out there and I think what we’ve been hearing from some of the other panelists is that I still think that there is a series of services that HIEs are performing today that would still need to exist in that framework whether it’s patient attribution or larger order aggregate somatic normalization, or, you know, provider attributions things like that. I mean, I think there’s definitely an opportunity for increased incremental improvement on the standards that we’ve all been working on.

Wes Rishel – Independent Consultant

So, Ted just to be clear you’re saying that most or many of the EHRs that are out there now are capable of providing discrete data throughout the realm of data with provenance if only they had been given an API to use to offer? Is that...

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

No, I think...

Wes Rishel – Independent Consultant

I’m stating this a little dramatically just to try to hone in on a point here.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

No, I think what I’m saying is that first of all I don’t see JASON replacing EHRs because I think there are still some requirements that need to go on for connectivity.

I think in terms of the data and the semantic or the granular level of data as much as EHRs are, I think really in a lot of ways, just now, and you’ve heard a lot of people say this, just now starting to send C-CDAs that are a little more complete, you have to work with them, there are some standards, but while those are documents they have discrete fields in them. So, I think it’s important to clarify that even though...if they’re sending a CDA document you can still burst those things apart as much as they build them out.

So, I think there is an incremental learning and sort of standardization that could go on or whether it’s policy guidance what have you to get people to fill things out in a certain way. So, I think there is still some incremental value in the system that we’ve got.

Wes Rishel – Independent Consultant

Just to be sure you're answering the question that I am asking. I hear you saying that there are reasons not to run to JASON because there's a lot of value in what we have now. I think that many people would agree with that statement.

The question I'm asking though is, if we are to get to JASON and the vision in the architecture diagram of JASON will it be done by retrofitting EHRs or will it be done by a new generation of EHRs that have been architected internally to meet the specific requirements of JASON?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

So, I think there is sort of one of those classic design challenges where, you know, in a world where you've got a couple of hundred EHR vendors some would, in fact, set up little skunk teams and reconfigure their systems or rebuild from the ground up, but you would have market entrants that would say, look we can get to this quicker without thinking about things the old way.

So, I think you would have both. I mean, this is really a function of the company's capabilities, the organizations capability to be creative given a given design challenge.

Wes Rishel – Independent Consultant

Thanks.

Jitin Asnaani, MBA – Director, Product Innovation – athenahealth

This is Jitin Asnaani, I would like to jump in on this question if that's okay as well?

Wes Rishel – Independent Consultant

Sure.

Jitin Asnaani, MBA – Director, Product Innovation – athenahealth

My view on this is that in a world where we get to a JASON-like functionality what you would have needed is that the current generation of EHRs have completely replaced themselves with EHRs that are more open and have more open API. I think there are a number of companies who can and will have taken that approach and then a number of them who would have deemed this intermediate or defunct because they did not take that approach.

But I do see us getting to that place with a new generation of EHRs and again some of them provided by the current generation of companies have taken that foothold.

It's not just a function of the EHR's technology that is a piece of it. It's also a function of the organizational focus and capacity and talent, and the like of the company that is building the EHR that in turn...technology turns out to be just a great manifestation of the company's philosophy and principal and I think that is what's going to...that's where you will find that some EHRs will either turn over or reinvent themselves.

Wes Rishel – Independent Consultant

Thanks.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Michelle...

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

Wes, this is...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Oh, go ahead.

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

I was going to briefly say that, this is Eric Heflin, we actually do have evidence to us that it's possible to uplift existing technologies rather than replace them. For example, XDS.b did not exist 10 years ago, but a lot of the vendors are supporting it and have added that onto products that did exist 10 years ago. So, we have evidence that vendors can uplift their products and add personal capabilities to open them up.

Wes Rishel – Independent Consultant

Eric, I'm sorry, adding a document exchange mechanism or a document retrieval mechanism onto systems is a level of challenge but I don't find it comparable to providing detailed structured data with full provenance in terms of the challenges of adapting the API to the underlying systems.

Julia Skapik, MD, MPH – Medical Director, Office of the Chief Medical Officer – Office of the National Coordinator for Health Information Technology

This is Julia Skapik from ONC. I would argue that there are a lot of systems out there that are in serious need of a platform rebuild already and I think that if we do a good job of really creating buzz and announcing the direction we're moving that people will be more strategic about the way that they implement interoperability along with other standard upgrades and potentially get towards more crowd-based systems.

David Horrocks, MBA – President & CEO – Chesapeake Regional Information System for our Patients (CRISP)

This is David Horrocks. Hi, Wes, I'm not sure what it would take on the EHR side but the jump from where we are to a JASON-like architecture would require a lot of changes on my side that we're not prepared for and wouldn't be easy. Whereas the move to CDAs and making it easier to get those out of the systems that is incremental and more accomplishable.

Wes Rishel – Independent Consultant

Okay, so, I'm going to cut my answers to my question off now and let somebody else have some attention.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Thank you, Wes, sorry, David.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Wes, this is David, just...we will have a vendor panel on the next session. So save some of those vendor specific questions in your mind for the next session.

Wes Rishel – Independent Consultant

David, I would just like to comment that it's also end user. I mean, the cost of...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, yeah.

Wes Rishel – Independent Consultant

The cost of replacing an EHR is nontrivial.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, no I agree. I'm just saying don't forget we will have vendors who you can ask directly...

Wes Rishel – Independent Consultant

Yeah.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

How they plan to respond to something like this. Michelle, who's next? We have about, what 7 minutes left on this panel?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Yeah, we have Larry Garber, he's the last person in the queue.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, great, Larry?

Lawrence Garber, MD – Internist/Medical Director for Informatics – Reliant Medical Group

Thank you. So, the JASON model from an end user's perspective is predominantly a query for information and I wanted to get a feel from each of you on how important you feel the ability to use push or a subscription to have the information automatically flowing to the end user is?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

In Rochester...

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

Well...I'm sorry, go ahead.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Okay, yeah, I think we have a huge user demand from care providers for the sort of alert and notification model. We do a lot of push-based exchange as well. So, I think to your answer, whatever architectural solution needs to come up there needs to be support for multiple information models.

Eric Heflin – Chief Technology Officer – HealtheWay, Inc.

And this is Eric Heflin. I concur, we have needs today in the eHealth exchange to provide push type content. Right now we're exchanging around 27 million messages a year, last year, that were mostly push messages related to quality data and then also we have new use cases we're in the process of helping our participants to work through to push data on a pub/sub model for example, immunization information from the public health to interested federal agencies.

David Horrocks, MBA – President & CEO – Chesapeake Regional Information System for our Patients (CRISP)

This is David Horrocks. We have about 1500 queries of our system a day but we push about 7000 notifications. And when you talk to a clinician who is say coming into our system to check a drug list or the PDMP system, they say “well could you just tell me when I really ought to go look.” They want some basic computer decision support that would then push them a message to say “hey there’s an issue now, now come look at it.” So, you know, how that gets put in place I don’t know but we certainly feel like pushing information is...there will be more of that in our future.

Jitin Asnaani, MBA – Director, Product Innovation – athenahealth

Hi and this is Jitin Asnaani I’ll also jump in. I think there can be no doubt that a push based model, a pub/sub model, a model that gives you real time information when it changes is critical. It’s going to be...it’s so critical to, you know, several different types of stakeholders in the community. If you think about the caregivers and the care team that sits around the patient they need to know when things are changing with that patient and that’s sort of the delivery of care level.

If you take it sort of a slightly different model, a different set of players, so for example the CDC or any other body that is monitoring syndromic issues, having that sort of data allows you to actually be able to counter bioterrorism or other syndromic threats much more actively than you can through today’s current set of models and much more real time than you can get and I think there are...I’m sure there are several other models where this just becomes a critical and an important piece of the total solution. There has to be multiple types of modes and models for usage.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Great, Michelle, should we go to the next panel or do we...you said there is no one left in the queue? I think we’re just about out of time for number one anyway.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Yeah, there is no one left in the queue so it’s perfect timing to move to panel two.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, excellent. Micky do you want to run panel two or do you want me to keep going?

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative

I think you’re doing great, David.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, on a roll, Micky says I’m on a roll. Okay, panel two the subject is research as several of our first round of panelists commented the JASON report really elevates the need of the research community to be a sort of first-class citizen in their architecture. I heard one person describe it as, you know, secondary use should really be primary use because research ought to have the same priorities as clinical care. I’m not sure those are the exact words in the report but I think that’s the spirit to some degree of some aspects of the report.

So, this panel we’re looking forward to get some perspective from the research community on the recommendations from JASON, how it either does or doesn’t fit with the way that community sees their needs as part of a robust healthcare interoperability architecture.

So, our three, our four panelists will go in the order of the agenda if they're present. First will be William Tierney from the Regenstrief Institute, then Sarah Greene from PCORI, then Landen Bain representing CDISC, and then finally Gwen Darien representing Cancer Support Community. Bill, are you here?

William M. Tierney, MD, FACI – President & Chief Executive Officer – Regenstrief Institute, Inc.

I'm here.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, the floor is yours.

William M. Tierney, MD, FACI – President & Chief Executive Officer – Regenstrief Institute, Inc.

Okay, hi, I'm President and CEO of the Regenstrief Institute which is an academic research organization and I'm pleased to provide this testimony, and I submitted written comments in more detail.

Overall, I found the JASON report to be somewhat unrealistic and not really responding to its charge of recommending means to collate EHR data for analytics. Instead it recommends a much more big step radically different broad architecture for EHRs in the US that is, at this time, impractical and unworkable. Details about that are in my comments and I'm going to focus really on the five questions that we were asked.

The first one is, what do I think about patient control of data sharing?

In 2011 the Regenstrief Institute with NIH as the PI received funding from ONC's Challenge Grant Program to first capture patient's preferences for accessing their EHRs and second to modify the data viewer of a large health information exchange, the Indiana Network for Patient Care, to invoke patient's preferences when displaying data to healthcare providers. This project concluded a few months ago with a demonstration study in one primary care clinic.

Granular control requires that each item of information be separately tagged with appropriate metadata and although this is not typical for discrete data with numbers and codes it is currently impossible for free text note and reports where a lot of patient information is recorded.

For example, a primary care doctor's note could say the patient had an abortion age 18 and postpartum depression after her first child. That sentence contains two categories of sensitive data, mental and reproductive health and yet the note would be tagged as primary care.

So, complete granular control of EHR data will not be possible until natural language processing can tag every important concept within free text notes and then redact those notes based on patient's preferences. Currently this is just not possible but we and others are working on it.

So, what do I think about patients being able to do this?

Although JASON discusses risks associated with patient granular control of EHR to access it, it focuses entirely on losing confidentiality by sharing data and ignores harms that could come from patients hiding their data from their providers. Healthcare is an information business and healthcare delivery depends on knowing what's happening with your patients.

Restricting provider access to information will undoubtedly pose risk to patient safety and result in errors and harm. JASON completely ignores this issue but healthcare providers know this and in our study many physicians had strongly negative feelings towards patients being able to hide data from them. We need to understand and balance health care needs and risk before invoking such data segmentation.

Next the question was, what do I think about unbiased data and research? I'm sorry, biased data and research.

Bias data yields bias results that cannot be relied upon to tell the truth about a topic being studied. Truly unbiased studies must have full access to all available data and only unbiased results can be used for clinical decision making.

The third question asked about, what we felt about opting in or opting out?

The question of opting in or out can be asked about both data segmentation and access to data for research. For our ONC funded data segmentation study we took an opt out approach. Our patient's showed that they expected healthcare providers to have access to their records and in healthcare providers have always had such access and expect it...into an opt out approach or data segmentation...for data segmentation would be much more difficult to implement culturally, technically and organizationally.

As for opting in and out of data for research I believe health systems should have access to patient data for quality improvement research unless patients opt out such studies are necessary and patients directly benefit.

Academic researchers using identified data should be required to get consent thus opting in. Researchers should be able to use de-identified data unless patients opt out.

JASON states that de-identification is impossible and I believe that statement is just wrong. In every study I've found where a de-identified patient had been re-identified the re-identifiers had access to the patient's identified health system data. If all 18 HIPAA identifiers are removed from a research data set it is truly impossible to trace it back to individual people.

The fourth question asked about consent and that was really covered under the answer to question three.

The fifth question says, what are your experiences compiling EHR data?

For more than 25 years I and my colleagues have worked with data from the Indiana Network for Patient Care which currently includes 103 of Indiana's 120 hospitals and 20,000 physicians along with Indiana Medicaid, the State Department of Health and Surescripts and uses established data format and coding standards to capture more than 5 billion observations for more than 14 million patients including 11 million patients from last year alone.

The architecture JASON recommends would not help the INPC. In fact moving to new standards would place a substantial burden on the INPC and all other HIEs. It doesn't mean that standards don't need to evolve, but incremental steps would really be needed.

And then finally, I've also been involved in an operation called open MRS which is an open-source EHR platform that's been implemented in more than 40 countries mostly in the developing world using architecture that's actually very similar to what JASON recommends, but this is because these countries have centrally controlled healthcare delivery systems and few pre-existing EHRs where dictating structure is easier. This is not the situation in the US and so I think a more incremental approach to enhancing data collation for analytics is the most appropriate near-term solution. Thank you.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you, Bill. Sarah, I believe you're next if you're here? Sarah Greene?

Sarah Greene, MPH – Senior Program Officer, Methods & Infrastructure Program – Patient-Centered Outcomes Research Institute (PCORI)

Yes, yes, hi I'm here.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay.

Sarah Greene, MPH – Senior Program Officer, Methods & Infrastructure Program – Patient-Centered Outcomes Research Institute (PCORI)

Okay, thank you. Great. Well, I'm Sarah Greene, I'm the Senior Program Officer with the Patient-Centered Outcomes Research Institute or PCORI and PCORI is an independent nonprofit organization that was authorized by congress in 2010. Our mission is to fund research that will provide patients, their caregivers and their clinicians with the evidence-based information that they need to make better informed healthcare decisions. And so I'm pleased to be able to provide our broad perspectives on the JASON report as it relates to research using health data.

As I mentioned, PCORI's research is designed to answer questions that patients and their providers face every day. Patients facing illnesses have a desire and a need to know which treatment is right for them based on their personal characteristics and preferences. So ensuring that reliable evidence-based information is available when patients and those who care for them are making those critical health decisions is predicated on the availability of highly reliable, high-quality data from real-world clinical settings. And so to that end PCORI supports a robust health data infrastructure with equally robust privacy and security protections.

And as PCORI's name suggests we involve patients in every aspect of our research from the identification of research topics to the conduct of studies, to the dissemination and implementation of the results. And to support this mission PCORI recently began constructing a health data infrastructure for research of our own called the National Patient-Centered Clinical Research Network which we also refer to as PCORnet.

PCORnet is comprised of 29 individual research networks that are working together as a national alliance. Patients are involved in every one of these 29 networks and in fact 18 of them are governed and operated by the patients and their academic partners and collectively they've been instrumental in helping us think through the complex issues around data privacy and security.

I think the JASON report describes several privacy principles from the broad institute of MIT and Harvard that I think are very pertinent and resonated with PCORI and especially our PCORnet activities. These include respecting patient's data sharing preferences, maintaining transparency in our research operations, holding research collaborators accountable for upholding best practices in both technology and ethics including all stakeholders to build trust, collaborating and innovating to accelerate progress, and these principles would happen all the while and moving very swiftly to render furthering improvements to the health data infrastructure.

So, we were also asked to comment on consent which is another issue of great concern to us. I would say that a considerable volume of research is conducted through secondary use of health data that had previously been collected and stored, and this kind of research is overseen by ethics committees or institutional review boards and at times if a particular study adheres to certain regulatory criteria it may be conducted through a waiver of informed consent.

And such waivers mean that relative to the benefits of the research, the potential risks of the study are considered by the institutional review board to be extremely minimal and that the study would be impossible to conduct if individual level informed consent were required.

A waiver consent is not taken lightly by IRBs and we know that many influential and important studies have been conducted through such waivers that could not have been done had individual informed consent been required. As two examples, first the data we rely on to support Pap smear screening for cervical cancer are from a large multinational study that showed marked reductions in cervical cancer mortality in countries that had introduced Pap smear screening compared with countries that did not.

And the second example a study at Kaiser Permanente shows that the commonly prescribed blood thinner warfarin, as it is used in community care, reduced the occurrence of stroke in patients with atrial fibrillation without increasing their bleeding risk even in elderly persons and those with relative contraindication, patients who had never been included in previous clinical trials.

So, in our view, in low risk big data studies where direct consent would be impractical if not impossible a worthy alternative to consider is routine notification by health systems and providers for patients making them aware of the research uses that are in place that might utilize their data, the patient's data.

Currently, these frank conversations with the patient community only happen rarely. Greater use of the HIPAA disclosure accounting process would further strengthen patient trust that health data are being used responsibly and for important purposes.

And finally, we must work with the public to convey the value of research and to ensure that the public has a say in what research is conducted by including their voices in the governance of the research process and in the studies, in the governance of the studies.

PCORI is working with the partner networks of our PCORnet initiative to develop robust privacy and consent processes and policies. It is a very careful and deliberate process and it involves patient's workings side-by-side with researchers.

So, in conclusion, this report lays an important foundation for the key considerations in a robust health infrastructure but we think it could go even further with respect to patient-centered outcomes research by endorsing the direct and meaningful involvement of patients in that research.

The direct involvement of patients in research is the key to a sustainable ecosystem that will truly leverage the potential to health data to improve health and healthcare. Thank you very much.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you, Sarah. Landen Bain from CDISC are you on the call?

Landen Bain – Healthcare Liaison - Clinical Data Interchange Standards Consortium (CDISC)

Yes, I am.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Good, you have the floor.

Landen Bain – Healthcare Liaison - Clinical Data Interchange Standards Consortium (CDISC)

All right, thank you. I appreciate the opportunity to speak to this group. I'm representing CDISC the standards development organization for the medical research industry and I would just like to make a few sort of general comments about research and a couple of specific comments about the JASON approach section on enabling research.

First of all, let me say that I think the JASON document is very useful. It provides a departure, point of departure for some very important conversations that we need to have. And just on a personal note, I find it to be an outstanding compendium of sort of history of all the different things that are going on in the federal world especially.

I have a blank spot in my head for a lot of acronyms so just to be...I'm going to use this document as a reference document to keep straight all of these various acronyms HITECH, FACA, HITPC, HITSC, PCAST, MU1 and 2. I think the JASON document does an excellent job of sort of sketching out the whole array of activities that are going on.

In terms of the specific section on research I was gratified to see there was a section on research and it was given a lot of press. I certainly agree with the recommendation that says we ought to convene a group of people who are familiar with research to delve into this further. Certainly agree that research is an international initiative. Agree that research is going to rely on a bunch of new types of atomic data types.

But there are a few things that I would point out that I think are perhaps given a little bit shorter shrift in the JASON report. I emphasize...I grew up in the healthcare IT sector and came to the research industry later. One of the things that I learned with some difficulty is that research, especially regulated funded research is actually a separate industry from healthcare. It has its own business drivers, it has its own standards development organizations, CDISC.

The standards that come out of CDISC are driven by sophisticated but somewhat alternative view of data from what you find in healthcare and the distinctions are important, they're not arbitrary. I think this points to the fact that a JASON-like architecture can be of use to this research industry but that a lot of care has to be given as the report itself acknowledges to what this use looks like

The next thing that I would mention is that most research is driven by a protocol. And a protocol is a formal document that defines steps that have to be executed. Study execution is a process and the approach of JASON is very much focused on data. The word data is used 511 times in the document. The word process is used 27 times in the document.

I think that the JASON architecture ought to take more into consideration workflow, integration across systems and process integration. The research use of data, inert data, and de-identified data is very important. But keep in mind that EHRs can also be useful to research in terms of automating activities, study execution.

We have, and CDISC has worked with IHE and developed profiles one of which is called retrieve process for execution and what this does is say what activities does the EHR have to initiate to be able to execute a study, enroll a patient, discover patients, schedule patients visits. These are things that are not primarily data-driven they're activities that need to be automated. So, I would urge JASON to also broaden its scope to include more activity automation and coordination across systems.

In terms of the...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Thirty seconds.

Landen Bain – Healthcare Liaison - Clinical Data Interchange Standards Consortium (CDISC)

C-CDA I agree with Eric Heflin and many others that the C-CDA is useful today. We use it to export data in a just in time way to populate patient report forms for research and that the roadmap route that was assembled by ONC recently emphasized the need to continue to refine C-CDA and to enable its use. So, with that I'll end my remarks.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you Landen. Gwen Darien you're next.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

Yes, thank you very much and thank you for inviting me to give testimony on this panel and in this session. My name is Gwen Darien I am an Executive Vice President of Programs and Services at the Cancer Support Community.

And the Cancer Support Community is the largest provider of psychosocial services through an integrated suite of programs for people that are impacted by cancer both people who are diagnosed with cancer and those who care for them, caregivers, family and non-health care caregivers.

We deliver programs through on the ground affiliates, through telephone services and online. And the three pillars that really inform what we do are research, service delivery and policy. And under my preview is research, education and outreach, and program development and delivery.

I'm also a long-term cancer survivor and have worked close to 20 years as a patient advocate putting a patient voice and what has been the unifying team of everything I've done is to put the patient voice at the center of all of these conversations.

And I think, you know, to build a little bit on what people have said before and build a little bit on what Sarah said, when I read the JASON report, and I'd like to just pull back a little bit from some of the technical issues, the underlying value of the report seemed to be to focus on the patient, elevate the patient as the primary beneficiary of health outcomes of course and really focus on the patient as the owner of the data as well as the sharer of the data increasing control of the patients in terms of how their data is used.

But while the patient is elevated to the top of this whole report the patient's voice seems invisible in this report and perhaps, as I was looking at who had participated in the development of the report I couldn't find the patient voice there and I think this is leading to some of these questions that we're asking and some of the challenges in terms of the questions that you have asked us and some of the tensions that are in the report.

Over the years I've often been asked to represent the patient voice in many different venues and often another colleague and I are or just I alone are the only people that really represent that and of course we represent some perspectives, we certainly don't represent all perspectives.

But if this is to be truly useful to patients and if patients are truly to be elevated to the level of controlling the sharing of their data and controlling their data they have to be part of this conversation and they have to be part of the development of this conversation.

So, just to sort of give a background or a framework for my response to this which is I wanted to just emphasize that and I think Sarah Greene certainly talked about the work that PCORI is doing.

So, in terms of the tension in the JASON report around consumer control of data sharing versus unfiltered data I think the other issue that comes out here and it comes out in a lot of the work that we've done at this organization and the other organizations of which I've been a part is that there is a very big difference between a consumer of healthcare and somebody who has been diagnosed with a life-threatening or chronic disease. And there's a big difference in how they respond to the sharing of data. How they respond to what is being asked of them and how much they understand about things like the research enterprise.

I mean, doing work in...there's been a lot of work and a lot of educational work around clinical trials in the cancer research community in particular and I think that it's astonishing that people don't actually understand, often don't understand, that the therapies from which they're benefitting have come through clinical trials and cancer research.

So, I think there are...I think one of the challenges is inherent in a large-scale adoption of something like JASON is that we're talking about multiple different patient communities.

The other thing that struck me and I think this just unscors it; that patients were used in some cases and consumers were used in other cases and I think they can often be two very different groups of people as I just said.

I think most people who are patients are very, very willing to share their data. They're very, very willing to participate in research. They're very willing to be part of something that will help people that come after them or help themselves.

I mean, everybody approaches everything with multiple points of view and with multiple goals, nothing is black and white, nothing is...nobody is doing anything for a wholly altruistic reason and nobody is doing something for...engages in research for a wholly selfish reason or self-involved reason.

So, I think that this is another issue that...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Gwen if you could please wrap up, thank you.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

Sure, let's see where do...let's see, where I can wrap up here, sorry. You know, so I think for example if you look at...I just want to continue the theme of kind of the patient versus the consumer, I think if you look at informed consent and you look at sharing of data for example, I don't care who knows that I'm a cancer survivor, you know, I'm a "public cancer survivor" but I do care if it leads to discrimination for my family and I think that understanding where people's concerns are and where are the barriers to consent and where the concerns of privacy is critical to moving this forward. Thank you.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Good, thank you Gwen. So, we had four quite different viewpoints from four different perspectives I think and a lot of overlap in viewpoints. So, let's turn to some questions. Michelle, is anyone in the queue yet?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Yes, there are people in the queue, Wes Rishel.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, go.

Wes Rishel – Independent Consultant

Always the first one with my hand up. So, Gwen, I just wanted to especially note your distinction between the patient and the consumer and thank you for that I think it's something that we often lose track of and argue without being aware we're making the distinction.

I have a question for you Gwen and then another one for Landen. In your case, it has been written by some privacy people that there is no real ability to protect data that the appropriate public policy is to punish its use that sort of resonates with your comment about you don't care if people know if you're cancer survivor but you care if that information is used to discriminate against your family.

Do you think that one of these groups, patients or consumers is ready to embrace that particular view on privacy or do you think that for all practical purposes people who are making policy need to be continued to defend the walls at the point of access to medical data?

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

I think it's very difficult to answer that definitively. I think there is a very wide range of where people are comfortable in terms of privacy.

I think the more important question and the more important challenge is to be able to be transparent and to have a real discussion around the risks and benefits. You know there is...it was talked about in the report and through some of the advocacy work I've done, you know, it's clear that there have been a lot of discussions in the genomics community around privacy and the ability around privacy.

I think the other aspect of it, in terms of people sharing data, and this is slightly off of what you said, but I think it's also important is that, you know, when you participate in research the person that is asking you to participate in research, the researcher, your healthcare provider is making a social compact with you. And if the results of that research are returned and the results of research that would impact you either positively or negatively I think that would also incentivize people to participate in a more, probably in a larger...probably in larger numbers.

I mean, the number one reason people don't participate in research is because they aren't asked not because they're concerned with privacy, not because they're concerned with other things, it's because they're not asked.

Wes Rishel – Independent Consultant

Thanks.

William M. Tierney, MD, FACI – President & Chief Executive Officer – Regenstrief Institute, Inc.

Can I respond to that question a little bit, this is Bill Tierney?

Wes Rishel – Independent Consultant

Sure, go ahead.

William M. Tierney, MD, FACI – President & Chief Executive Officer – Regenstrief Institute, Inc.

I'm a cancer survivor too and also I agree that I'd like to have my data used for research so that the long-lasting side-effects I had from my chemotherapy can be prevented in somebody else. So, you want to get the most benefit from any bad things that happen to you.

Having said that, the study that we did actually asked patients with whom would they be willing to share their data and essentially, 100% of their patients were willing to share their data with their primary care physician, only 15% were willing to share their data with researchers.

And so as much as I would like to be optimistic and agree with Gwen that patients have warm and fuzzes for researchers that's not what our data showed and so I think there is some educational track work yet to be done, especially since I don't think we do a good job of defining what research is.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

Right.

William M. Tierney, MD, FACI – President & Chief Executive Officer – Regenstrief Institute, Inc.

There is kind of little "r" research which is how does my healthcare institution do a better job of serving it's patients versus big "R" research where I'm a pointy-headed academic and I want to be able to say what are the risk factors for developing, you know, peripheral neuropathy with vincristine and so I think there is a lot of spade work that needs to be done.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

But, I think, Bill just...sorry, just to add a little nuance into this is that I think that's part of the issue, part of the issues around education, because, you know, there is a whole range of researchers and many, many people interact with what, you know, what would be called physician researchers, so they would be their physicians and I think that is...I think it is a question of bringing...I mean, I think one of the solutions to this is to bring all of these voices to the table together.

And, you know, this is...I ran a program...I started the Department of Survivor and Patient Advocacy at the American Association for Cancer Research and one of the programs that I ran was bringing together patients, researchers, physician researchers, survivors, survivor advocates to really understand each other's point-of-view perspectives, experience, goals and so I think that's really critical.

So I agree with you that people don't understand research, but I think that there are also many nuances and many different kinds of researchers that they work with and they may not know their physician is also engaged in research.

Wes Rishel – Independent Consultant

Thanks, I would argue that I hear the two of you violently agreeing with one another that there is a big job there and we need to work on it.

William M. Tierney, MD, FACI – President & Chief Executive Officer – Regeneron Institute, Inc.

And not assume it's going happen passively.

Wes Rishel – Independent Consultant

Right, right, yeah.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

Yeah.

Wes Rishel – Independent Consultant

And I would just add the comment that there is big "R" research and bigger "R" research if you will in the sense that there are very focused clinical trials with clear hypothesis and there is an increasing interest, as expressed in the JASON report, at using big data either to discover testable hypotheses or to go all the way through to proven results all of which creates a more diffuse use of the data from the point-of-view of the patient/consumer.

I think Landen spoke to the difference between clinical trials and the broader view of research that includes clinical trials but is, as he said, a different industry to a certain extent.

I did want to go back and focus on your comment Landen on the usefulness of the CDA. As we look at the question of how much retrofit versus replacement of EHRs would it be necessary in order for the JASON architecture to deliver the results, the benefits that are blatant or potential in it?

In particular, as I understand it from our own conversations, one of your uses, one of CDISC uses of CDA is to automate certain steps in data collection that are generally done on paper or through spreadsheets now in order to meet clinical trial protocols and the question that I have is, is there an upfront cost in terms of individualizing the way you map data from the CDA into your forms or has CDA reached that level of sort of multi-study, multi-source system interoperability that could reduce the design time or the pretrial implementation time?

Landen Bain – Healthcare Liaison - Clinical Data Interchange Standards Consortium (CDISC)

So, we have a couple of ways that we use the C-CDA in one scenario the EHR pushes the C-CDA to the research system, which is typically called an electronic data capture EDC system. And the EDC system is responsible to pick through the CDA and apply the data through the questions in the form and then the form is displayed for the EHR user to complete.

One of the fundamental assumptions here is that for clinical study execution, especially for investigational new drug trials, the EHR is not going to have all the data necessary for the research. There are good reasons for that, not bad reasons for that. You're investigating the effects of a new agent so historic data from the electronic health record are not going to be there and in some cases data about that shouldn't be there.

But what the C-CDA does have the ability to pre-populate, especially some historical parts of the research need. So, we found that demographics, vital signs, labs and what we would call concomitant medications are very useful and immediately applicable or extractable let's say from the C-CDA.

There are issues around problems and what the EHR is typically interested in terms of adverse events that become trickier and more semantically difficult. But the beautiful thing is that we don't really have to know anything about the EHR other than ask it a question and it pops the C-CDA back to us and we can use that in the best way we know how to use.

The next phase of that mapping is going to be, instead of using what we do today where we just take a C-CDA and push it through a transform in XSLT and map it into a CDISC standard called CDASH.

In the future what we hope to do is get to a much more atomic granular level, somebody earlier said that C-CDA even though it's a document it does contain atomic data elements, to get to that data element level and to map them using a metadata repository to...in a more fine-grained way by referring to this sort of mapping in the cloud which is something that CDISC is developing called SHARE.

So, I hope I answered your question Wes, I might have got a little off track there, but yeah, we find, again the C-CDA gets a lot of criticism because it's not canonic. I'm not interested in it being canonic I'm interested in it being useful and it is.

Wes Rishel – Independent Consultant

Thanks.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Michelle, let's go with the next questioner.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Arien Malec.

Arien Malec – Vice President Strategy & Product Marketing – RelayHealth Corporation

Great, thank you. One concern that I haven't heard discussed, and I'm I guess a little surprised by given the focus of JASON on a more universal approach to getting data out of EHRs for research purposes, are twin concerns of pharmacovigilance and then other natural history trials particularly in smaller or the experiences of patients in smaller or non-academic institutions.

And I'm wondering whether the panelists could comment on both the state-of-the-art relative to those two concerns and then secondly what kind of approaches the Standards Committee should be looking at whether JASON-like or others to encourage or provide more access to data for pharmacovigilance and natural history? Thanks.

William M. Tierney, MD, FACP – President & Chief Executive Officer – Regenstrief Institute, Inc.

This is Bill Tierney from Regenstrief. I can take a first stab at that. I think that you could...at least I can characterize that the research for pharmacovigilance and natural history as looking for keys under the lamppost.

That we use the data that we have and we try to get the information we have out of it, but the data are often incomplete and biased by the kinds of institutions for which you get access to data and often academic institutions and we're as guilty as anyone of that, but getting hands on drug use data, in other words, prescription fill in information is difficult because it resides in a bunch of different commercial pharmacy systems that all have unique data, unique databases.

Now, we've actually interfaced with them in the past and interfacing with them is not a technical issue it's an organizational, it's a social issue and for all of these things discussions of the interfacing of these systems it's not a technology issue for the most part, because the large HIEs have been able to interface with these systems and be able to draw in data, but it's a degree of access that you have and a degree of difficulty to have to overcome these things.

So, I think that the studies that are being done are being done predominantly in systems where there is a little bit greater capture of data. For example, the HMO Research Network because the data come from prospective payment systems that have both the providers and the payment within one organization that then have more complete capture of information so their studies may be a little bit more complete but still most of them are academic, much of them are academically focused.

So, there are tradeoffs there that hopefully by the broader use of both the current standards and evolving standards, the capture of data can be more complete and therefore you get less biased results.

But it's mostly getting the health systems to provide the...the different components of the health system to provide data. It's not really, as far as I'm concerned, these aren't...the technical barriers are much lower than the organizational social barriers.

Sarah Greene, MPH – Senior Program Officer, Methods & Infrastructure Program – Patient-Centered Outcomes Research Institute (PCORI)

Yeah, this is Sarah Greene from PCORI, I mean, I think Bill summed it up beautifully. I think, you know, there are initiatives like the FDA's Mini-Sentinel Initiative that has been able to work with the systems to get at the data that can shed light on pharmacovigilance.

So, I think the efforts are out there I just...you know, there is...each access request, unless you have a system in place such as a sentinel initiative might be treated de novo and that, you know, creates a lot of inefficiencies.

I think the other aspect of this might be worth considering is that, simply understanding prescription pills do not get at the notion of patient behavior and adherence.

William M. Tierney, MD, FACP – President & Chief Executive Officer – Regenstrief Institute, Inc.

This is Bill Tierney I have one other thing to add and that is the biggest challenge is actually in how to use the data in that the naïve user will say there is a billing record out there or a visit record out there with a diagnosis that this patient had heart failure therefore I'm going to put this patient in the category of heart failure.

We've done studies looking at those things and in heart failure in particular 57% of the time that a patient has a diagnosis of heart failure it's wrong that if you look at subsequent imaging, left ventricular imaging that patient does not have left ventricular dysfunction and most times they have COPD and on the large right ventricle but a large heart shadow and junky lungs and then they come in when they're sick. So, the EHRs just have what the provider's store it's not necessarily truth.

And so, there are groups, eMERGE is one of them, but there are groups out there beginning to look at database epidemiology and saying, how can we...we know that there's information in here because people use these data for care all the time, but how do we sort through it in a way that I know what to believe and know what not to believe. I know how to combine data in a way that allows me to get a reasonable sensitivity and specificity trade-off for definitions.

Because, you know, you can have diet controlled diabetics with no medication and with normal blood sugar values they don't look like a diabetic and so you've got to have ways of being able to define these things that are useful to the epidemiologist or the clinical trialist using these data and it's not trivial.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

So this is Gwen Darien just to build on of what Bill and Sarah, we have a cancer experience registry in which we have 7000 participants who answer questions about their experience with cancer. We have sub-registries and one of the registries where we've just cut the data is in people who have been diagnosed with CML and it is...and to the point of not knowing...we know what's been prescribed but we don't know what people have taken and we don't know what the effect of it is.

When we asked people about their CML medication, which they have to take every day, the number of people who skipped medications at different points in time was quite large and quite astonishing and some of it...some of the times they shared it with their doctors and also back to Bill's point about what patient's share with their doctors and some of the times they didn't share it with their doctors, sometimes it was recommended by their doctors.

So, just because they've been prescribed a medication doesn't mean that they are going to take it and so it does bias the outcome there and there is a lot of discussion among the CML community about drug holidays just like there was a lot of discussion around the HIV AIDS community around drug holidays. I just wanted to re-enforce that point.

Arien Malec – Vice President Strategy & Product Marketing – RelayHealth Corporation

This is been really helpful and if I'm maybe reading between the lines I'm hearing that if there is one thing that one could focus on rather than getting more access to discrete information out of individual EHR information it would be generally getting more access to fill and other information out of pharmacy systems. Am I hearing that right?

William M. Tierney, MD, FACP – President & Chief Executive Officer – Regenstrief Institute, Inc.

It certainly is a big missing hole in a lot of clinical data repositories.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

And you also have to have patients be willing to talk about whether they are adhering to the prescription instructions and the protocol instructions which is often not the case.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

We need those little tracking devices in the pills it sound like.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

Yeah, well and, you know, it doesn't even matter whether it's something that's very, you know, that isn't as critical or if it's something that is very critical like CML, I mean, so it doesn't matter if it's allergy pills or if it's an acute cancer.

Sarah Greene, MPH – Senior Program Officer, Methods & Infrastructure Program – Patient-Centered Outcomes Research Institute (PCORI)

Right the prescribing data does not tell the whole story.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, this is David. There are certainly lessons that have been learned the hard way in the tuberculosis resistant tuberculosis treatment community that you actually need to watch the patient take the pills certainly in areas where communication is perhaps difficult. Gwen, why, I'm sorry, Michelle, why don't we move onto the next question.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Deven McGraw.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Thanks a lot Michelle. Thanks to all of you for really great testimony. When I first read the JASON report and the emphasis on patient control I think my initial concern was to be a little bit worried about how you could...it seemed to be a bit of a switch from the way the law generally permits data sharing in general which is to sort of default to not necessarily requiring consent in circumstances where information is being shared for treatment purposes.

Requiring consent for research uses, but subject to, as Sarah did a really good job of explaining, subject to opportunities for waivers in circumstances where the benefits outweigh the risks and consent would be hard to get. And in other circumstances data can be shared without consent as well such as for public health reporting.

So, I just wondered what they were getting at. But I've recently been thinking more about circumstances where data doesn't get shared even when the patient wants it to be shared because of other barriers at the institutional level, anti-competitive concerns, concerns about data as an asset, uncertainty on the part of some of these organizations about whether or not they can share based on a multiplicity of laws.

So, I'm curious about whether there's a way to sort of turn that patient consent piece that is so much a part of the JASON report into one that helps us eliminate the barriers to sharing when patients want data to be shared versus looking at it as an absolute requirement in all circumstances.

Gwen Darien – Executive Vice President, Programs & Services – Cancer Support Community

So, this is Gwen Darien, Deven that was a really, really important and really good point. And I think one of the things that...and I think it goes back to something that I had said earlier about the social compact that we make with people who participate in research.

And so if the patient is being asked to share data, is being asked to participate in research I think that focusing on fulfilling the social compact from the researchers or the academic centers or the physician scientist's point-of-view is a really important lens to look through not just from the patient's lens.

William M. Tierney, MD, FACP – President & Chief Executive Officer – Regenstrief Institute, Inc.

This is Bill Tierney. When we first established our health information exchange 25 years ago the key was convincing the CEOs of the various health systems to share data. It took years, literally years to make that happen, but now the CEOs all sit on the board of directors of the health information exchange so they've gotten that message and recently, for various reasons, we had...I'm on the board of directors as well and we had a discussion about just the whole notion of health information exchange and what they said is 12 years ago when we did this it was with the promise that this would be a good thing for us to do. We're now convinced, we now can't turn it into value-based organizations since we have known that half of our patients are being seen in at least one other health system, we can't care for those patients without the data.

So, I think the tide seems to be changing. I think our CEOs were early adopters, but I think the tide is starting to change with the national movement towards ACOs, etcetera with the health systems beginning to have lower barriers to sharing data.

So, I'm encouraged to think that activities to enhance data sharing now for care and for secondary purposes because they have to squeeze as much value they can out of their health system and data is an asset for doing that, that there are fewer organizational barriers now than there were before, at least in our neck of the woods.

Sarah Greene, MPH – Senior Program Officer, Methods & Infrastructure Program – Patient-Centered Outcomes Research Institute (PCORI)

And this is Sarah Greene, I also echo that and thanks to Deven for the great question. I mean, I think that, you know, our experience in PCORnet really builds directly from what Bill was just saying.

We have partners in our PCORnet initiative that came to the table based on that premise that, you know, we can no longer...we need to collaborate more than we need to compete and population health is a responsibility that we all share.

So, if you take the City of New York where patients can go to any number of health systems. Those health systems are now working together and have the plans to share data in support of not only research but better health outcomes for their populations that they manage.

So, I do think we're getting there in terms of, you know, sort of the value proposition of a learning health system. I think we have a ways to go still but I'm optimistic.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Great, thank you.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

David, there is no one left in the queue so if you're ready we can move on to panel three.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay. Let me ask the group if there are any last-minute questions. We have just 5 minutes left that we could use, if not we will go to the next panel. Any last minute questions for this panel?

Hearing none let me say thank you again to Bill, Sarah, Landen and Gwen for a stimulating discussion and testimony, and then let's go to panel number 3.

The JASON report was very careful to describe a sort of functional perspectives on an architecture without specific standards other than the ones they chose to criticize and even there they didn't name too many standards. So we have some opportunity to explore the candidates that might fit some of the JASON requirements and that's the subject of panel number three.

We've invited Grahame Grieve to speak about FHIR, Thomas Beal to talk about openEHR, Steve Emrick from the National Library of Medicine and Stan Huff who will speak on behalf of the Healthcare Services Platform Consortium. Grahame, did you make it in from Australia?

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Hello I'm here, sorry I just had to get off mute.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, great, thanks for joining us from a long way away.

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Pleasure. Okay, so I had some slides. Did we display those slides?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

They're being displayed if you could just let us know when to move to the next slide.

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Oh, I see them, oh, okay, all right thanks. So, thank you David. I've been asked to talk about FHIR which is Fast Healthcare Interoperability Resources which is just a demonstration about how hard you have to try for local interoperability these days. Can we go to the next slide, please?

So, just bring the whole slide. So, I see it. FHIR was borne out of a re-extension of where HL7 standards were, recognition that existing standards did not meet the market need and in particular the standards that we had although they were widely identified as being too complicated they were too limited in scope to address the kind of use cases that the JASON report is interested in and believes it can be leveraged. If you look at the existing standards we had this didn't address that use case at all.

We held a Fresh Look Task Force a few years ago to reassess where we were going and out of that I drafted an example spec based on use of RESTful interfaces and I did that in July of 2011. And since that it's grown into became FHIR today. A draft standard was published in 2014. I'm planning a second draft in 2015 with a full normative version to follow. So, if you can go to the next slide.

So, the core parts of what the FHIR specification are we define a set of resources, the resources have a description in JSON and XML and there are small independent pieces of content that actually correspond relatively well to the molecules described in the PCAST specification or report.

And we have resources that have a clinical content, health administrative content and some infrastructure scored for the kind of things you need to do to support the other things. And we're aiming at the moment at the high value shared content that is shared across the different EHRs and other clinical support systems.

Then we offer a choice of ways to exchange those resources. The lead one that everyone focuses on is an API that allows you to interact with the application that corresponds remarkably well with the ideas of the JASON report.

And we have, between the API and the set of resources that we define we have the baseline for implementing, as a technical standard, the functionality described by the JASON report although it's still as a draft and developing.

The other thing that we have is a document form for packaging packaged exchange between clinical systems and the importance of integration of a document for packaged exchange with an API can't be underestimated.

With CDA, which is a speculum very familiar with our support conventionally here in Australia, we have a document form but we don't have a matching granular access methodology that uses the same syntax and the syntax conversion is quite expensive.

In addition with FHIR we have a bunch of implementation collateral that we provide as part of the specification schemas, other kind of implementation support, there's a bunch of open source code and servers so you can easily pick up a specification and start working with it straight away.

We hold regular connect-a-thons to help people connect up to the servers and to the community and to each other. So, those are the basic parts of the FHIR specification. If we go to the next slide.

The essential problem that we face with FHIR with any kind of healthcare data exchange, and the JASON report brushes over, is the question of dealing with the variability. The use cases are very, very variable across different parts of the healthcare system.

Some of the variance arises due to the standards, some of the variance arises because people's requirements are always different and there is no pressure for them to harmonize their requirements. In fact, use cases are fractal and that's a central problem that we struggle with every day and the JASON report brushes over this issue.

We can deliver data interoperability maybe one day, we're working towards that every day, but data interoperability is not clinical interoperability and unless the clinical consumers of the IT systems pursue their own version of interoperability then data interoperability will be limited and not very useful, to me that's the central problem that the JASON report doesn't or basic question is, how do you deliver clinical interoperability, it's a management 101 thing, curing an IT system and a management problem doesn't make any...you know, it doesn't solve the problem.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Grahame, if you could please wrap up, thank you.

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Okay, so just about there. So, we have a number of tools for dealing with variability. We define a common shared base and we allow users to define extensions that can do that where they can find agreement and they can do that within a common schema and then we define a way for them to describe variable usage. So, if you go to the next slide.

That's our manifesto focusing on implementers to focus common support to use word technologies to include human readability and I've got a joint statement coming out with Lantana about that and to make content freely available, so we want the content to freely move.

FHIR doesn't solve any problems but if we can make it easy to move data then people could start to address the clinical interoperability problem and I'll finish there, thanks.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you Grahame, appreciate that, especially coming from half way around the world.

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Pleasure.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Next we have Thomas Beal. Tom are you on?

Thomas Beal – Chief Technology Officer – Ocean Informatics

Hi there David, yes, I'm on, can you hear me okay?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yes.

Thomas Beal – Chief Technology Officer – Ocean Informatics

Well, I...thanks for having me on this hearing. I also had slides so I wonder if they can...yes.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

They're showing now.

Thomas Beal – Chief Technology Officer – Ocean Informatics

Next slide, I didn't tell you anything useful. Can someone just go to the next slide, please? Yes, that's it. There is a little plotted history of openEHR.

OpenEHR is a dialogue, a foundation that's producing both specifications and open source implementations, it's been doing that since 2000, its key task it's been trying to address or a problem it's been trying to address is an EHR architecture that's semantically enabled, so fine grained semantically marked data, although of course it accommodates large chunks of narrative because that exists all over the place as well.

It introduced something called archetypes, there are a few things on there, and it has developed to date about 400 of these archetypes of clinical content models. There is varying adoption in Europe and Australia, and New Zealand, and Brazil, and it's also used occasionally by certain national eHealth programs. Next slide, please.

So, I've listed out the key elements of the openEHR technical paradigm. One of the points with respect to this JASON report that I would point out is that the vast, well, I wouldn't say the vast, the majority of the semantics of the openEHR environment aren't in the software they're in terminology obviously and in these archetypes and terminology data sets, queries build based on archetypes which are portable queries and so one of the things I would...so with respect to the JASON report is that categorizing the solution that's required is, as a software architecture, is probably underestimating what the real solution is something bigger than that. In my written notes that I've provided I called it an open platform definition where substantial parts of the platform specification...software.

Anyway, so in openEHR there are these content models, there is a reference model, there are sort of open querying language and service architecture. Next slide, please.

It has a heavy emphasis on being able to specialize and customize models. The archetype formalism that's being used by various groups including CIMI, CDISC is looking at it as well as others through openEHR and either 13606 communities, so it works with difference reference models and the archetype formalism has also turned out to be a good basis for co-generation of normal developer usable artifacts like schemes and so on. Next slide, please.

So, that, I think if you press the button once again, because there was little doodles on that slide, yeah, that just gives a picture of what an openEHR-based architecture would look like. So the blue stuff on the right-hand side is a deployed one, the right-hand corner is a deployed system that started with applications and services and now health data and so on.

On the top right-hand side are tools which are the involved co-generation and a lot of that is coming from the models on the left-hand side and terminology. So, a large proportion of the semantics comes from outside the software and from models that are built primarily by clinical and clinical informatics people rather than IT people. Next slide, please.

So, that's just a picture of the openEHR.org archetype library and an archetype rendered as a...there are about 400 archetypes in that library or repository. There are about 4 or 5 other repositories around the world at the moment, Brazil has just decided to start modeling their health data in this way as well. Next slide, please.

We probably...the later part of the development of openEHR over and under review has been to develop APIs and service specifications some we've just stolen, unashamedly, like IHE Aetna and those kinds of things you can see them up there. We're working on how to integrate to FHIR and particularly how to integrate the content model...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

If you could please wrap up that would be great, thank you.

Thomas Beal – Chief Technology Officer – Ocean Informatics

Okay, yes...into FHIR that's one thing we're doing. So, next slide, please. So, just speaking in terms of the comments I made earlier with respect to JASON I think if you press the button again it's probably good, yeah, the amount of an overall system or environment which is software related is only a part of the totality of the things that need to be formed and specified, archetype terminology, archetype bindings, queries and templates are actually the main part which...that's where the clinical complexity and diversity is. Next slide, please.

So, this a list of things which potentially openEHR has developed and generated over the years which may be of use in the JASON conversation for ONC and provided in bullets. Some people are aware of this stuff like HSPC and a few other groups. So, I'll just leave it there. Thank you.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you, Thomas. Steve Emrick NLM, are you on the line?

Steven Emrick, B.Sc – Head Terminology QA & User Service – National Library of Medicine

Yes I am, can you hear me?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yes we can, go ahead.

Steven Emrick, B.Sc – Head Terminology QA & User Service – National Library of Medicine

Okay, great, I just wanted to say thanks to the panel for inviting me, for inviting NLM to participate and so I'll just start off, you know, NLM is the...we're the central coordinating body for clinical terminology standards within HHS and as such we support three major vocabulary standards that probably many of the panel are already aware of these SNOMED CT, RxNorm and LOINC and these are all major underpinnings of Meaningful Use.

SNOMED CT provides standard codes and name for medical condition, organisms, procedures and other aspects of clinical care. And NLM also is the US member representative to the International Health Terminology Standards Development Organization, IHTSDO, headquartered in Copenhagen in March and they own the rights to distribute the international edition of SNOMED CT.

NLM as the US member representative we give...we license SNOMED CT use within the US and as such the US taxpayer can use SNOMED CT within the US for free.

RxNorm provides codes and names for prescribed drugs and their ingredients and is published every month. We also provide what's called a current prescribable subset of RxNorm which is in the best approximation of what we think is currently prescribable in the US.

And then there is LOINC which is a standard for codes and names of test measurements, clinical reports and survey instruments.

NLM also participates in the development of many HL7 method standards and UCUM which the standard for developing computable units and measure codes.

So, all of these vocabulary standards have been around for a while and they're used in the real world and they've been essential for exchange of electronic clinical data. And the Meaningful Use, you know, requires them to be used in some degree.

More recently, in October of 2012, NLM developed and launched the Value Set Authority Center, this is considered the source of truth for value sets required to compute Meaningful Use clinical quality measures.

We also publish the unified medical language system which has been around for over 25 years and has helped EHR systems understand clinical meaning by showing linkages and relationships...between disparate vocabulary standards such as ICD-9 CM, CPM, CPT, SNOMED CT and others.

So, we feel that the above standards are essential for use in any kind of EHR systems across institutions and these are really architecture independent. So, any architecture could implement these standards. The HL7 method standards have been around...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Steve if you could please wrap up.

Steven Emrick, B.Sc – Head Terminology QA & User Service – National Library of Medicine

Okay. You know we feel that, you know, overall with the JASON report it didn't mention the vocabulary standards which we feel, you know, have been out there for a while and being used in the real world and one of the biggest impediments to adoption or base cost is mapping one institution's code to another when they're using local codes rather than standard codes.

There were also some gaps in the JASON report with...and I think that some of these have already been mentioned in previous meetings. They didn't seem to mention things like the Blue Button, SMART, DICOM has been around for quite a while for imaging and radiology.

So, you know, we would want to see, you know, increased adoption of those standards through more federal regulation for example in Meaningful Use Stage 3 to expand the requirements for LOINC to be used for things like radiology. Do I still have time?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Not really.

Steven Emrick, B.Sc – Head Terminology QA & User Service – National Library of Medicine

Okay. I'll stop there then. Thank you.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

You will have time if you want to add a little bit more when we have the discussion going but we'll move onto panelist number four Stan Huff from Intermountain and the Healthcare Services Platform Coalition. Stan?

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

Yes, if you could bring my slides up. Thanks a lot for the opportunity to speak. The Healthcare Services Consortium...next slide, please.

One comment first, this is a general comment rather than a specific comment. As a national strategy I think we need to develop truly interoperable data services and in saying that one of the things about the JASON report is it had very unrealistic timelines for adopting standards and mandating standards. I think that's been an error of things that we've been doing already and it would certainly be in error to continue to think that we could get to true interoperability within a year or even mandate the standards that would get us there in a year. There's too much work to be done fundamentally to do that.

It's an eight to ten year process would be my guess, but we could make incremental steps as we went along that for instance might standardize the exchange of lab data first and then standard patient measurements next, etcetera and get progressively more complex and get reasonably useful by, you know, the 8 to 10 years.

Certify message and services not applications and get away from mandating EHR functionality which I think is a big mistake. But mandate the use of standards and then hold people accountable for outcomes of healthcare rather than reporting process measures which has been sort of the focus. Next slide.

So, Healthcare Services Platform is directly aimed at what JASON talked about in terms of standardized APIs. The idea is that we would create specifications for standard APIs and that those standard APIs would be supported by existing vendors to make the data in their systems available through those standard APIs.

Current systems have almost all of the current leading vendors have their own libraries of APIs and what we're asking is that there would be work by those vendors to create standard APIs that would be offered as a supplement to the APIs that they currently have. And of course all of this and I get into it but is aimed at trying to improve the quality and decrease the cost of healthcare. Next slide.

There are three essential functions of the consortium and you might as well go ahead and build this slide. There should be three sections. We specify the standards and one of the key parts of specifying the standards is making standard models with tight bindings to terminology that tries to address the issues of optionality so that there is essentially no optionality in a given use case.

Once you specify that information then you need a way to test and make sure that services or applications actually adhere to that and I don't know whether it's testing or conformance or certification. But you need a way of knowing whether people are actually conforming in an inoperable way to the standards.

And probably the third and maybe the most important part of this is actually sort of the political and policy, and environmental work that makes a business case for why existing vendors would support these services and I think there is a business case for that. But I don't think any of this works if we don't have that support and we don't manage the business case appropriately. Next slide.

We've made some technology assumptions about what we're doing. We're using FHIR that Grahame already described. We're doing data models. Right now we're using data models that exist at Intermountain Healthcare but our goal is to use CIMI models as soon as those are available and, as Thomas Beal mentioned, there is an opportunity to use to our advantage the work that's already been done in openEHR and Thomas has been very helpful to the CIMI effort in the information modeling.

We're using LOINC, SNOMED, RxNorm and HL7 tables and other things but the key three big terminologies that we're using are LOINC, SNOMED and RxNorm.

And then a key part of the strategy is actually getting these applications so that they integrate into existing EHR systems. And we're using these SMART approach from the folks at Boston Children's Hospital that's been championed by Isaac Kohane and Ken Mandl, and Josh Mandel, and Ben Adida and others for the integration. Next slide.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Stan if you could please wrap up.

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

Okay, I'll just end there. I'll just say that it's a not-for-profit entity and we're allowing and supporting commercialization as well as open source contributors, small companies and large companies and want it to be a robust open marketplace for medical applications. Thanks.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you Stan. This is David and I'm going to sneak to the head of the line with the Co-Chairs prerogative and ask the first question and I'm going to steal a little bit from Wes's prior question and I just want to focus this specifically to Grahame and Thomas but obviously anyone can comment on it.

The JASON report refers to existing EHRs as legacy stovepipe applications, but makes the assumption that it would be possible to retrofit a data centric, a data element centric API on top of those legacy applications.

And I was wondering if the two of you could comment on your experiences, if there are any worth sharing anyway, with retrofitting FHIR or openEHR onto existing, you know, so called legacy applications, your thoughts about that, the feasibility, difficulty, relevance and so forth?

So maybe Grahame, do you want to start?

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Yeah, I'll go first, thank you. As a technology it's relatively straightforward to affix FHIR to existing products. The data mapping migration issues are substantial and they become even more so when you start imaging a writable API as well as just a readable API. The challenges are much steeper for that.

My experience with mapping external models onto an EHR is that it's a very difficult process. The fundamental question of legacy is the legacy better. If you're prepared to post your legacy data then it's straightforward. But real value legacy data vary, for obvious reasons, and so that will become a very become a very difficult process.

One way to do that, to handle it is to simply make the APIs very, very abstract and basically offload that problem to integrators at run time, but that's just moving the deck chairs around the Titanic.

However you approach this getting agreement around the fact there were use cases that's difficult enough but dealing with, you know, legacy data that's likely whatever you do is extremely expensive.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you. Thomas, do have some thoughts?

Thomas Beal – Chief Technology Officer – Ocean Informatics

Yes. I could just say what he said which is the fundamental question is the data, everything in this whole thing is about the data, the semantics of the data, the complexity of the data, the structure or not of the data.

Our experience is with...as a company we produce an EHR stack and it's been solid in a lot...well a number of places in Australia and also we've done some implementation in leads in the UK. So in all of those situations we're always doing data integration, we do it by using archetypes and templating the data sets that we want to integrate but then, as Grahame implied, there is still is this dirty work of digging out, you know, where is that blood pressure, where is this and where is that?

If you're trying to expose complex data or not even complex data a managed medication list is complex data if you're going to present it in a simple way, if you're including things like the current status of the drug, you know, is it suspended, is it still active and any other indicators of the part of the details of the drugs themselves of course, and, you know, when was the last administration, etcetera, etcetera. Just to make that available you've got to be able to bind the source elements for that in your source data.

Now in the UK GP data, let's take an example, and in Australia the data is not bad, but if the data is, you know, going to be hard to get the...if the source data is not very structured than that's going to create a problem.

One way of ameliorating this whole thing is to simply restrict or limit the scope of what data you're going to say that the system should try and share. You might say, well okay for the next couple years let's just stick to medication list, allergy list, problem list and that's it, you know, nothing more or maybe even less than that. So, that's one way.

But, at the end of the day there are just inevitable costs and it just has to be managed. I think just like what we've done in our archetypes and I think what the FHIR guys are doing will certainly help that, but I think just choosing to limit the scope carefully at the time to the highest value data and letting manufacturers slowly get there and providing little chunks of generated codes that's in the FHIR territory, we do a bit of that that's in itself useful.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, thank you.

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

This is Stan. Could I make a comment?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yes, I was going to ask you to. So, go ahead, please.

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

Well I certainly agree with what's been said. I would summarize it in this way. I think any strategy towards interoperability that assumes we can migrate all of the existing providers to some new technology, you know, fundamentally new databases and other things is doomed to failure.

I mean, that's a...I don't know it's certainly billions and it's more than all of the investment that we would have...you know, that we've put into Meaningful Use so far. So, I would say it's maybe in the order of magnitude maybe \$100 billion sort of or more endeavor.

So anything that, you know, starts with the assumption that we're going to get to interoperability by swapping out all of the existing legacy systems I think is a nonstarter.

And so I would just emphasize that then says if we want to do this feasibly we've got lots of work. It is hard work to map from local terminologies and local schemas to a standard schema, but that's the work that we have to do if we're going to get the interoperability and we should stage the work, as Thomas said, so we do the things that, you know, provide the greatest value for the least investment first, get successful and build on that success and as I said, you know, that's my way of saying that it's hard when I say it's going to take us 8-10 years to get to something that's starting to approach comprehensive use, you know, in this environment.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you. Michelle, how about the queue?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Actually there is no one in the queue.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Oh my goodness people must be tired how could that be? All right Task Force anybody out there awake still?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, I'm awake David, it's Deven.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, Deven.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I would love it if people could expand more on the point that they all were just making about the transition. I don't know that there is anyone who thinks, at least on the working group, although we haven't been polled, but certainly I don't think rip and replace is going to work.

But the JASON report did map out a transition strategy...your thoughts about that and if that doesn't make sense then what is it that we could or should be focusing on in terms of achieving greater interoperability, achieving some of the outcomes identified by JASON?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

And this is David. I want to offer a friendly amendment to...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes you can David, go right ahead.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Well, to your question and I'll again sort of start with Grahame and then go round the table. Grahame, you were talking about FHIR profiles as a way to scope down to specific use cases and I think you had to rush through those slides at the end of your presentation.

And I wanted to just wonder if you had in mind something that would fit Stan's notion of sort of incrementalism?

Is there a set up profiles or a scope of profiles that would make sense as a place to get started?

I know you've thought about this so I'd just see if you have thoughts to share on that?
If you're talking you're on mute.

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Thanks for reminding me, yeah, I was on mute. There certainly is a set of things that we can do. I generally agreed with the JASON Task Force, the JASON report plan, it's the timelines that are the problem and the need to attend to details.

There are certainly areas in clinical practice where there is more agreement than other areas and there are areas where there is less and generally that's where...where there's more agreement is also where there is more value in exchanging data rather than narrative.

However, I want to get back to my point about clinical interoperability. I thought that the missing thing from the JASON plan was to focus on addressing, you know, you could make data available but unless you address clinical interoperability blocks then the data might not be that useful.

So, I thought that the general technical roadmap made sense to develop those things and to do so collaboratively but also to pay more attention to the workflow aspects of it.

Profiles certainly are a tool that you can use to express those agreements once you can get the community together and agree to them and then they're leveragable along those lines. But if the amount of agreement that you can get is limited then the use that you'll get out of the data that's exchanged will be limited in the same form. So those agreements and creating the community consensus around them will remain, you know, a critical part of the overall process.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Any other thoughts on that topic from Thomas or Stan, or Steve?

Thomas Beal – Chief Technology Officer – Ocean Informatics

I can't remember what the original question was David?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Is there an incrementalism approach that would...

Thomas Beal – Chief Technology Officer – Ocean Informatics

Oh, yes.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

You know help get moving towards the granular API without requiring boiling the ocean before you could expose some of it?

Thomas Beal – Chief Technology Officer – Ocean Informatics

I could make a very long answer, but to try and be very quick. Stan's horizon of 10 years that's the kind of mental horizon I have and I see a growth of progress that, you know, maybe it's just a sort of triangular shape, you know, like a ramp.

The thing to do I think is to carefully think of the overall architectural paradigm and like I said before it's more than just a software architecture it's an information architecture and a semantics architecture. I think to work out at least the main ingredients of the paradigm as it would be at the 10 year mark, in other words, the kind of paradigm that is actually going to get you 10 years and just use it in potentially simplistic ways early on which is sort of what we haven't done that well in openEHR, we belatedly realized we should have been, you know, making more easily available things that many programs could use early on.

I think FHIR is doing a better job of, you know, making useful things available early on, but I think just doing, you know, fix XML schemas or something like that I mean people will think of why don't we just do that. Of course that's not scalable so it's about scalability to the architecture.

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

So, this is Stan. Focusing even more specifically, you know, my experience would be that the easiest domain to attack first and is always sort of...and the reasons why it's sort of been automated the longest is laboratory data, standard old laboratory data, you know, hematocrits and hemoglobin, and glucose levels, and all that sort of stuff, you know, that...because of the long presence of commercial vendors in lab systems and adherence to earlier HL7 standards in that area I think we're a lot closer to having sort of the business support around those use cases that Grahame mentioned and I think we have standards that are closer to being ready for use.

The next thing that our clinicians ask for are medications and that's two things. Typically they care about prescriptions and orders for medications. But in other situations it's actually administration that you would use for like immunization and closely related to that are, you know, the medication allergies.

And then almost everything requires you to know something about the...you know, you want to know which diseases are involved and so it's diagnoses or problem list, or health issues whatever you want to talk about next.

And then the fourth category in fact are all of the narrative documents, operative reports, chest x-ray reports that we wish were coded but are extremely useful in guiding therapy today and so, you know, having...in that case probably the only value we're adding is getting to the documents so that you have some expectation about the content when you exchange.

So, those are specific domains lab data, medication data, you know, allergies and, you know, adverse reactions, text documents and then, you know, I could go on from there but that's where I would start, you know, that would be my suggestion.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you. Do we have other questions or other...

Wes Rishel – Independent Consultant

Yeah, Wes here.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Yeah, Wes has a question.

Wes Rishel – Independent Consultant

So, I'm going to first throw this one to Grahame and others are welcome to comment too. And I need to give just a bit of background.

We are all familiar with what my old employer called the hype cycle where new technological ideas reached the peak of interest long before they're ready for practical rollout over a large group or percentage of the industry and we had some recent experience in that regard with CDA which essentially, you know, could be described as an XML way of describing data that is both textual and structured.

And we found lots of issues around inoperability when one tried to interpret the structured data. We found issues about usability that are really related to how the documents are created and what the now mandated content and so forth, but even just getting two different vendors or two different implementations of the same vendor product to generate the same structured data has been a significant challenge and we found that out when we tried to do it.

So here's FHIR, another XML-based standard for administrative and clinical data, less tried out at this point, than the CDA is. Why is there any reason to believe that we won't go through the same cycle of it all looks good until we try to interoperate across vendors or implementations with FHIR?

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Well, Wes, thanks for the question we have reason to be confident that at the technical level it's a better choice than CDA that it's more usable that people can more rapidly and safely move data in and out of the format that FHIR provides.

However, that doesn't deal with the heart of the question. The problem which is actually doing integration faithfully moving the data well, dealing with all of the data differences that we've talked about there is no reason to think that FHIR will make a substantial difference there. It's a technology. It's not a solution and so...

Wes Rishel – Independent Consultant

Grahame, I'm sorry to interrupt, but you would say the same about virtually any standard right, that the issues are...the real issues are sort of less about how the data is represented as it's exchanged and more about how it's created and used in processes. Is that my understanding of what you are saying?

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

Yeah, pretty much. I mean, FHIR is empirically suitable for the kind of role mentioned by JASON where once you have described the data there are all sorts of ways you can leverage it and that's where it's easy to leverage it once you've described it better and that's where I think FHIR really excels.

Wes Rishel – Independent Consultant

So that's what I'm trying to get to Grahame, you said we have reason to believe and then you said FHIR excels at that.

Can you explain to someone who is not an implementer and who doesn't necessarily know much about XML other than it's got funny characters in it and the same for JSON, could you explain at that level to people what is the evidence, what are the reasons that you believe that implementing of FHIR will be less problematical than the implementation that the CDA has been?

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

So the main issue, the main reason is that the CDA is based on a pretty abstract grammatical language called the RIM which was created to ensure consistency of data. We don't actually have consistency of data so it was solving a problem that doesn't really exist the same way in the real world.

And the language, the grammar is imposed on the data that's exchanged by the users. So, the users need to learn a really arcane grammar as a part of their implementation and exchanging of data.

With FHIR we've moved the abstract grammar out of the picture, it's still there in the background but it's not explicit we just express the content in the language, it's the domain that's being exchanged, and so it users find out in order of magnitude it's easier to deal with the data that's being exchanged because it's their natural language as much as we can make happen.

There are still lots of problems with factorial use cases and so forth but that's the fundamental notion. And so that level of difficulty goes away and we've got plenty of evidence that that's the case and the best evidence of course is we have a specification, a standard in its first...which we expected to have a few uses primarily in a central web healthcare data exchange space playing with because it's still a very elite detail but we're having these kinds of discussions those are driven by the difference in usability, but it still doesn't deal with the data mapping problem.

In terms of the hype cycle in 10 years' time I'll be able to share with you where we are. In the hype cycle the evidence suggests that we're still in the early stages of the hype cycle going off like a rocket.

Wes Rishel – Independent Consultant

Yeah, I agree with that completely. I'm just looking...given that, to a certain extent, the fact that the hype cycle requires people to try to second-guess it, I'm looking for what we can point to, to say that FHIR is different rather than more of the same. It certainly has...where it is in the hype cycle indicates that a lot of people find it appealing and they must have a reason.

But from the point-of-view of people who have made a lot of investment in existing systems, why should they believe that it's worth doing anything different and I appreciate you're being conservative and not just giving the company line, but that's what I'm trying to get to.

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

This is Stan if I could make a comment?

Wes Rishel – Independent Consultant

Sure.

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

You know...I mean, I think another reason for me projecting the 10 year timeline is the fact that in spite of how excited I am about FHIR and grateful for, you know, the work that Grahame has done there. We're going to learn things when we try to implement at scale.

And so I think it would be naïve to say that, you know, that the hype cycle doesn't apply here. I think it does. Hopefully, it's maybe flattened a little bit so that our expectations are closer to what we're realizing, but, you know, my 10 year timeframe is allowing for us to learn as we implement at scale and I think, you know, it's going...we're going to learn some things and there are going to be some things that as we implement we will learn.

Wes Rishel – Independent Consultant

Yeah.

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

Absolutely and people should expect that.

Wes Rishel – Independent Consultant

Yeah, I'm not trying to goat anyone into saying anything differently. I guess the question I'm asking is why bother?

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

Yeah.

Wes Rishel – Independent Consultant

I mean, why not just continue down the CDA course?

Stanley M. Huff, MD, FACMI – Chief Medical Informatics Officer – Intermountain Healthcare

So, my answer would be an additional one and it comes back to things that people have already said. In spite of the fact that CDA has been implemented I haven't heard anybody say they thought that was simple or straightforward. Everybody I've talked to said it was complex.

And the other thing that I heard from previous testifiers was that CDA is, you know, because it's coming from the document paradigm is clunky and has a lot of overhead and has a lot of ambiguity when you're trying to do really sort of query response activity as opposed to creating summaries that you, you know, send at a point in time.

And you can get into the architecture of CDA to look at that but what it really amounts to is that CDA is set up to send individual and, I grant that you have provenance associated with individual elements in that document, but it's primarily set up to set a snapshot of time of data that, you know, you have and unless you do other kinds of things around it what happens is the same data gets sent again and again and there is no recognizable easy way to know whether what you received before was, you know, sent now.

And we're looking at I think the use of these discrete data services to say something like don't send me a C-CDA of lab data or of something else but send me, you know, hematocrits for this patient in the last two weeks or in the last three months. That kind of transaction I think is not what CDA was set up to do.

And furthermore, you need to do what Thomas said or what Grahame said, or Thomas has a lot of experience with, you need a query language to be able to frame the query to ask for what you want to ask for and that's a part that again, in the 10 year time frame we need a query language that's based on the logical models not based on, you know, a CDA template tag.

So I think there are a lot of...and there are more detailed things we can say I think if we had time, Wes, but those are the things at the front of my mind that say, you know, CDA is useful and we're going to keep using CDA and it's probably have the same kind of lifetime as HL7 version 2 but I don't think it's the solution that we want to work toward that would meet the goals of the JASON report.

Wes Rishel – Independent Consultant

Thanks.

Nancy J. Orvis, MHA, CPHIMS – Director, Business Architecture & Interoperability – Department of Defense

Wes and Stan Huff this is Nancy Orvis and I'd like to make one suggestion or ask a query on this. I've just been...you know I'm in a position as a provider and a payer where we are very much looking at the next 10 years and I'm also looking at the fact that, you know, like this what would fundamentally show an improvement in the next five years possibly for all of us as consumers and for the clinical organizations who are trying to implement this and help getting these suggestions better from this report.

And the one thing that keeps coming back to me is since I've had one knee injury I've had six new user name patient portals open up to me in the last six months one a month depending on where my procedure was done for my knee and I had a health administration clinical degree. I can't deal with.

If I could remove, as a consumer for US patients, the ability to have a continuing care, some patient care summary that would keep me from having to fill out the same paperwork on the same medications, the same conditions, the same allergies are on seven or more organizations that to me...anything that we could do with helping the US infrastructure to say the original goal of continuing care summary was this transition of care that the patient didn't have to carry everything with them, the doctor didn't have to call the other originating provider, that they had something they can look at that would give a snapshot of somebody's health.

So, whether it's FHIR or better APIs, or something that we could say what would fundamentally help this piece of the infrastructure, I think would be a benefit that everyone...the consumer could see and the provider could see. It is there one time that they would not have to mandate that the patient come in and refill out everything just to make sure that nothing was missed.

That is the point of it I think and it's the point of the provider being able...the family practitioner or the care provider being able to send this information when they get queried to any other specialist or somebody who is requiring that information.

I know we have other issues on more detailed queries, but if that piece...if that's what we want to focus on can the data infrastructure be changed enough to help simplify that maybe there are some ways we can go forward. I mean do any of the things that we've been looking at help that?

Because, so far the early implementation I'm seeing now there is not one change for almost any patient in the United States they're still being required to do this. They're still being asked for it and there isn't something that would change that data infrastructure where each new specialist didn't automatically require the patient to fill out everything again is one of the things I would be saying, what we could do that would do that?

Thomas Beal – Chief Technology Officer – Ocean Informatics

FHIR...

Grahame Grieve, B.Sc, MAACB, FACHI – Principal – Health Intersections

So, I'll speak to this regarding FHIR. FHIR includes by virtue of inheriting from the web infrastructure, FHIR includes for and integrates really well with the standard web browser solving those kinds of problems, but there are a bunch of policy and procedural, and liability issues to go with that which we don't address and need addressing and that gets back to what I was talking about with regard to clinical interoperability rather than really data interoperability they are a bunch of things around that I didn't discuss and security as well. Sorry, Tom.

Nancy J. Orvis, MHA, CPHIMS – Director, Business Architecture & Interoperability – Department of Defense

So, maybe that's another piece is to go back and re-address the business, the clinical policies or the business policies that would reduce each new practitioner seeing that patient from having everyone redo the same thing that has been done redundantly several times before on the same patient.

Thomas Beal – Chief Technology Officer – Ocean Informatics

Tom Beal here, just a couple of comments on both that, Nancy's comment and Wes's original thing, the reason we still have to keep filling out these forms again is simply that basic interoperability just isn't working in a routine way...when the next place that we go to, if you're referred into the hospital.

So, making...the thing that's going to get any solution whatever it is, make it have a different story on the hype cycle, which was Wes's original question, in my view a little bullet missed of things that are going to make a tension to make interoperability, now I'm just looking technically because obviously there are a lot of sociopolitical issues, but technically it's getting atomized data right, it's being able to deal scalably with content to those things which is a big deal and, you know, with clinical content, it's being able to deal properly with local variability, in other words the problem...you've sent me a CDA but it's not exactly one for which I thought you were going to send, change this field here.

The problem of variability has to be built into the infrastructure of the, you know, architecture. If it's kind of add on thought at the end it's not going to work. Change over time, if the approach doesn't deal with change over time, because everything is changing over time in medicine and clinical practice and protocols and so on.

And lastly, like Stan reiterated, content based query, if you can't do that, if you can't get the data in a fine-grained way based on the logical models of the content the effort probably isn't going to succeed beyond the average couple of years when everybody tries it out.

Now, it maybe probably too early to say that about FHIR, but I think FHIR has got some characteristics which are going to help on some of these points.

Steven Emrick, B.Sc – Head Terminology QA & User Service – National Library of Medicine

This is Steve from NLM and our response submitted one of the recommendations there was a NIST effort...on FHIR and CDA, but some equivalent to a universal patient identifier...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Steve we've lost you I believe.

M

There has to be some kind the law that a universal patient identifier has to be the conclusion in any such discussion.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I find it very interesting that whole stream of conversation got blanked out and I'm wondering if it's divine intervention.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

It's the NSA they won't let us talk about it.

Steven Emrick, B.Sc – Head Terminology QA & User Service – National Library of Medicine

Right, sorry. I didn't hear that, you know, there was a recommendation for a universal patient identifier and that would probably, you know, go a long way to solving these problems that aren't always technical.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, this is David, I think we've certainly heard that theme over and over again during today's presentations that the technology maybe the easiest part and that the JASON report had introduced some good ideas about...any barriers to overcome to take advantage of these technologies as they emerge. I think we're about out of time and we need to have a few minutes for public comment. So, Michelle, do want to check and see if there are any public comments and then we can conclude?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Arien did have a question, I don't know if it's quick or if we just want to go to public comment?

Arien Malec – Vice President Strategy & Product Marketing – RelayHealth Corporation

No let's just go ahead for public comment.

Public Comment

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Okay thank you, Arien. Operator can you please open the lines?

Caitlin Collins – Junior Project Manager – Altarum Institute

If you are listening via your computer speakers you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. If you are on the phone and would like to make a public comment, please press *1 at this time. We do have a comment.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

It looks like we do have...yeah, sorry Caitlin.

Caitlin Collins – Junior Project Manager – Altarum Institute

David Kendrick please proceed.

David Kendrick, MD, MPH – Chief Executive Officer – MyHealth Access Network

Hi all thanks very much for the fascinating discussion. I feel much better educated about what's going on with this topic and I also had read the JASON report with interest. I was just going to point out an observation that there are places in the healthcare universe today, in particular one that comes to mind is the Microsoft HealthVault Platform, that publishes its APIs publicly and, you know, I'm aware of, you know, some folks who recently created a CCD or CDA exchange into that platform in just the matter of an hour or two from a health information exchange and so I raise it because it doesn't seem like an impossibility if that's possible. And I think it also relates somewhat to sort of the lamentations about having six different patient portals handed to you. Wouldn't it be better to have a common patient portal where a patient requests centralization of all of their data into one place and I'll take any answers off line.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Thank you David. Any other public comments, Michelle?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

It doesn't look like it. We're just checking. No, it doesn't look like anyone else has a public comment.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Okay, well...

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Thank you very much David, sorry, go ahead.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, I was just going to say we're at the top of the hour and at the end of our session. I want to just really thank the panelist for, on short notice, producing such high-quality testimony both verbal and written, immensely helpful to the Task Force in assessing the JASON report and producing our response for ONC.

So, on behalf of the Task Force as well, thank you. And then to my colleagues on the Task Force it's a lot of time put into these things and carving out two hours of your afternoon is not easy I appreciate it. We've got one more session coming up next week. Stay strong and join us for that session. Micky any comments before we say goodbye?

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative

No, well, first David I just wanted to thank you for leading us through this, I've got the next one. When is the next one Michelle if we could just get that out?

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

It's August 5th at 10:00 Eastern.

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative
Okay.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology
From 10:00-1:00 Eastern.

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative
Right, great, no and I just want to thank everyone as well it was a very, very rich conversation. I think we all sit in on a lot of these kinds of calls this one I thought was particularly rich so I want to thank everyone including the presenters and special thanks to Grahame I don't know what part of Australia you're in but it's early morning whichever part of Australia you're in so I really appreciate your joining us.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation
Well and also Thomas your far away as well so thank you for the time zone shifts.

Thomas Beal – Chief Technology Officer – Ocean Informatics
You're welcome.

W
Thanks, all.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology
Thank you everyone.

Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative
Thanks everyone, bye.

Meeting Attendance				
Name	08/05/14	07/31/14	07/01/14	06/18/14
Andrew Wiesenthal			X	
Arien Malec		X	X	X
David McCallie, Jr.		X	X	X
Debbie Bucci		X	X	X
Deven McGraw		X	X	X
Gayle B. Harrell		X	X	X
Jon White		X	X	X
Josh Mandel		X	X	
Keith J. Figlioli			X	
Kory Mertz		X	X	X
Landen Bain				
Larry Garber		X	X	X
Larry Wolf			X	X
Micky Tripathi		X	X	X
Nancy J. Orvis		X		

Tracy Meyer				
Troy Seagondollar		X	X	
Wes Rishel		X	X	X
Total Attendees	0	13	15	12