Digital And The Everyday: From Codes To Cloud
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Lecture – 13
Promises and Challenges of e-Health Part 03

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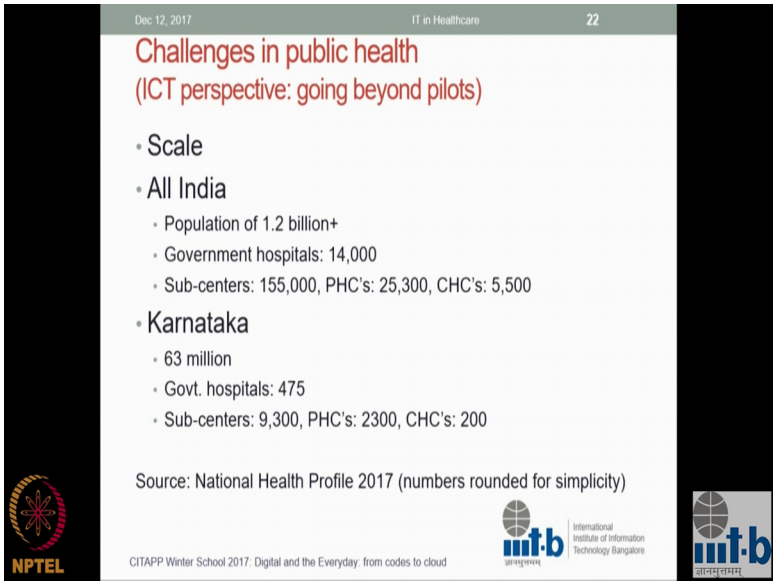

So one of the big problems is scale, I mean it is not a problem it is like the other problem right. So, that in the government scheme, we were talking about a population of what a 1.2, 1.3 billion, there are across India government hospitals are 14000 and if you collect everything from the sub centers to the PHC is so, then thousands of them. So, any solution you come up with has to work in the scale. We have looked at problems just in Karnataka to start and there you have you know if you just add the PHCs and CHCs and they are about 3000 odd hospitals involved.

So, any solution you do has to quickly scale up to that kind of size, they are very diverse users and the challenges these numbers while these numbers are large, in proportion to this it is very small again it is roughly a 100; 1000 to 1. So, there is a challenge of you are going to have a huge load on the hospitals and typically the node gets pushed higher into the more you know the better hospitals or the higher level hospitals and so on. So, these are there is one aspect that any technical solution will need to come up with, and if you really want something that is going to scale up you are really talking about a billion

population that has to be addressed across you know 10,000, 20,000, 30,000 entities and if you add the sub centers and many of these since they have to reach the persons in the field, you have to get the Asha workers AMS and others involved, that number just multiplies by tenfold or something.

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Student: So, but it took kind of flip to around that right of if you could published some of this data in anonymous base. So, the moving (Refer Time: 01:46) mean etcetera will shows some of these. So, like for example, you showed that table which said what is that infant mortality, those thing right fine, but you were published an infographic. The basic that (Refer Time: 02:08) you know out of out of these minutes states suitable right data on the data this is the work. So, whatever so, today right you will find enough competition between states on.

But all these data is public.

Student: (Refer Time: 02:21)

All the data is public.

Student: Is it in a way that is accessible to the public.

Yes once spread a.

Student: Not census data.

National health profile 2017 published every three years only, that has complete data by state that is where I got some of this data from. So, it is available maybe it is not present.

Student: Awareness is not there.

Analysis no they actually do their analysis.

Student: No awareness

Awareness is not there. So, yeah, but presumably the people involved and these are looking at those sites there is data available. So, the good news is part of all this collection of data has meant that they are able to publish them, they can tell you how many visits there were for cardiovascular diseases across all these states and that is to some extent they have the data.

So, you could potentially drill down, the government is trying to put some of this in the open data dot gov dot in. So, those are happening, but I think these. So, let me I am not trying to say ITs going to solve the problem, I am exposing a bunch of issues, and I am saying there is no solution I can think of that will address all these; it has to be by looking at it from all standpoint, IT alone is not the solution absolutely.

Student: (Refer Time: 03:18)

What are we saying is can IT magnify the effectiveness awesome, can it reduce pain for the patients, can it provide better help provide better care. IT is not the endpoint right it is a I have been talking to know what IT can do to, say that this is where we can go, but there are lots of obstacles and impediments that are coming in their way, that have been there along we have to see some of can be cracked.

So, partly the slide is trying to address that part of the reason it is not working is there are multiple solutions being done, again with all the best intentions each program has it is own solution, but mental health program has no access to the dip sorry the diabetes program as an example and they are correlated, that there is comorbidity between those they are done independently.

So, one of the challenges we face is that you know we are saying IT, but it has to be used by such a wide variety were starting with the ANM and Asha workers, all the way to the

top m ds who are doing this thing and they all have different, and they are all from different parts of this cultural diversity geographic diversity language diversity and skill diversity, and we still saying we have to have a system that works for all right.

And every one of them is critical to the whole thing working if the if you have a tablet based system that the ANM will use to make sure that things are being tracked, that better be usable by the ANM in within their context. While if a doctor in a consultant in a super specialty is doing it he is got two minutes to deal with the patient and cannot ask him to type elaborate notes the problems are there everywhere right.

So, that is sorry clearly one issue is every one of these stakeholders from the doctor to the you know the endpoint also do not see value in this yet, they see lot of it as just I am adding data to the hospital administration or to public monitoring order I am not seeing any benefit. So, that reduces their acceptance of the solution it is not moving well enough. So, sometimes you have fake data also that gets just to finish the process.

By and large these have not been done with usability in mind usability of the specific user I mean broadly maybe they look nice they do well, but I recently was talking to a person who is working on delivering health solutions in the field and says they had our company come and build a very nice they put their best UX engineers, and built a very fancy interface, but it was not usable by the people involved, but it looked very nice you know got awards for design, but it would not it was not getting you. So, they redid it completely and it looks clunky, but is very usable it. So, the IT approach would be to let us get a I pod type, I pad type design done well that may not be what is needed.

So, a lot of it is because the workflow is not probably I mean pretty much every system you will see you will have to log in your to do multiple pull downs enter data and so, that is not the way, the doctors and the practitioners think it has to adapt to their workflow much better. A big issues about data protection because we do not have a proper laws and regulations in place lot of doctors medical professionals are very vary about sharing data and they do it in two ways either they do not enter the data or they enter it in paper and keep it with them, and it is going to till some of these regulations fully fall in place this is going to be an open issue. And of course, we have all the usual problems, we can put all the IT systems then you build a room for the computer then you put a UPS for it and you know you do all those things, the money is going to things that are needed just to sustain

that; and at the end of the day you may not have any. So, we build all these complex systems in the end of it we find out that, while initially it was assumed that good 3G connectivity is, everywhere when you go into the field actually you find connectivity is not there and the entire system has to be redesigned.

So, depending on the amount of money available and either get redesigned or it will get canned. So, all these are happening program by program. Cost is a big issue there is still a lot of lack of awareness in the larger medical and government system of what it costs to run a large software to develop and run a large software system hardware is not a problem, we say I want to have a tablet in the hands of every ANM some budget will be found for that, but if you go and say I need ten lakhs more to get the software done you would not get that budget you already spent 5 lakhs 10 lakhs on this thing, what do we need more money.

So, there is a lot of lack of awareness on what it takes to build these systems. So, we had many systems developed that fitted to the cost that was available and they do not work, and definitely beyond the initial use the whole challenge of deploying it and maintaining, it things change windows gets upgraded something else changes and a lot of cost that needs to go into updating these things. Almost no program budgets for these things ok.

So, it is global awareness issue that when policies and budgets are being defined, the tale of cost is not usually and say we can manage it the 50,000 year AMC why should we need more than and you know a software engineer salary starts with money multiples of that. So, those are all problems.

So, these are problems you have you know which are I would I am looking at again against from the standpoint of technology, what are the things that are coming in the way of it getting to what it you can; obviously, some of these are to be solved from other directions, how is budgeting done how was that managed, how is infrastructure provided, what are the right tools that should be made available at these points, what are the policies about there around data protection and privacy; you cannot suddenly change the law and say no privacy means something else then your whole system has to be redone and that those are the challenges that are happening ok.

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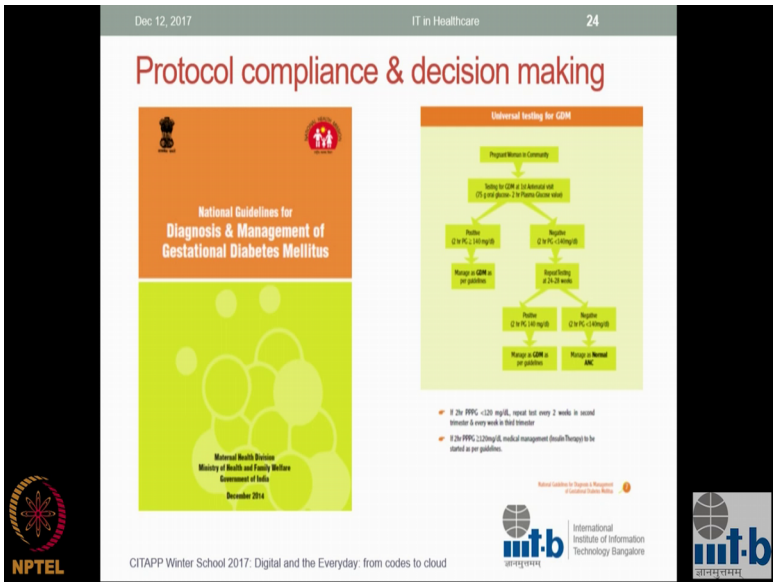

So, while I have been saying all this it is also a fact that public health programs are working, in their own way to different levels of success and it is fairly process i. So, you know it is now at the stage where you can expect that any patient say in another m c h scheme is tested for diabetes and it is there is a very clear protocol, under which they will be handled all the way through. And if they go to the right in at least in some states this is very well done right.

So, there are processes and one of the uses of IT would be just how to make these processes better more enabled, how do you help the field workers to execute this process better rather than following charts and paper and so on, is that fill in the data it should be telling them what the next steps are.

So, that is one of the uses that is being done. So, here you see a thing where you can take a program, identify exactly what aspects need to be technology enabled, and make it available to the right players so that they can do their job better. That is the flavor of what we are looking at really.

So, what is the policy view of all this? We talked about all these things we said it is difficult complex lot of standards, lot of interoperability issues, privacy issues and so on. Anyone familiar with the policy side of this or the government's approach to this any of you involved in that space a health in general. So, e-Health is now a big initiative of the

government right. So, the intent is to set up an e-Health authority in India a national e-Health authority.

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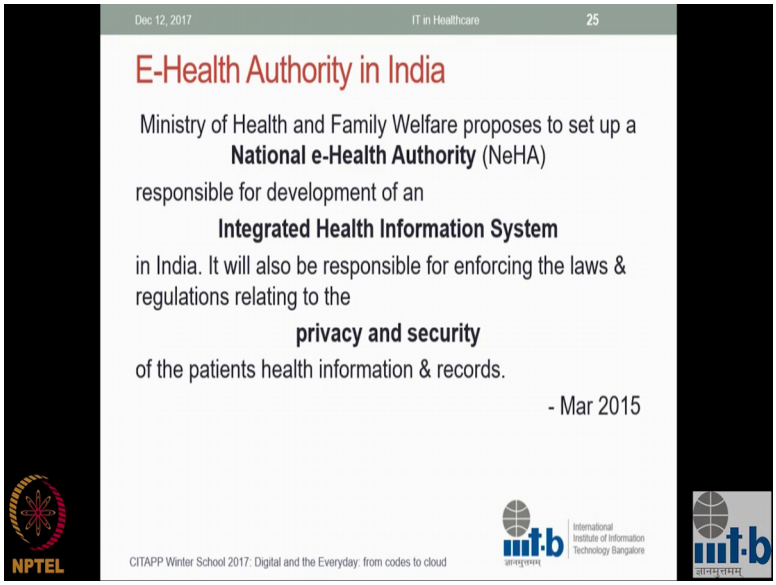

It is been in the works for a couple of years presumably it will get announced anytime right there has been enough video. So, the idea is that there is going to be with the government realizes that e-Health is something that needs a global view that needs lot of things under it. So, how do we have an integrated health information system, and also look at privacy and security issues that come into that, and also how will this get deployed and rolled out and all that. So, those of you in this space I mean I think they are still in I think the concept node consultation phase are going on they are probably done with that.

So, we should expect that some kind of roll out will happen in some time maybe in the next year, two it was expected two years back. So, one year back. So, I do not know when it is what the exact state something it is a complex thing, because you are going to handover lots of power to a different authority now which deals with a lot of the issues that health and IT and others deal with.

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So, how do we guide the adoption of e-Health systems, how do you what does it mean to aggregate these things, how to set up health information exchange because it is accepted that there will be silos of health data, you need to think about health up front and then again go back to what a security confidentiality privacy and so on. So, that is the goal, as a tin in parallel with this the government has put out some standards. So, the problem is in the medical industry so many standards. So, what is the standard, what is a universal standard is forever under debate.

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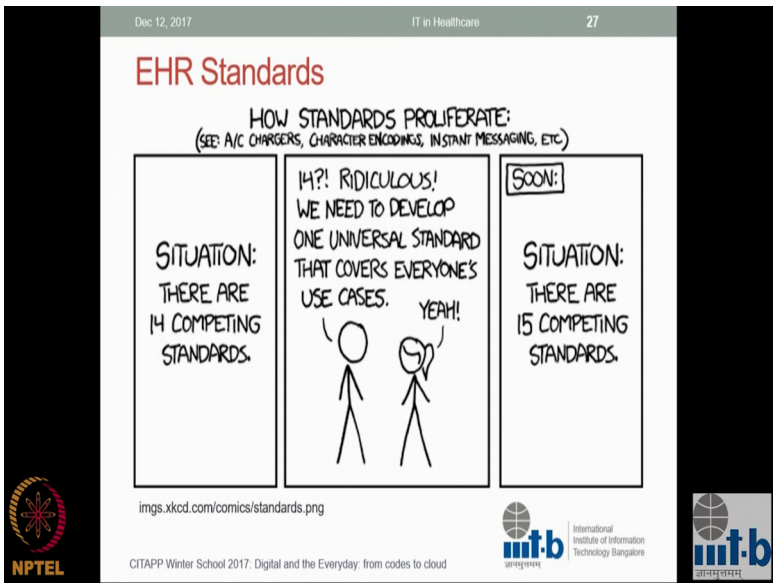

So, as this indicates you do not want to create yet another standard, just to say that we cannot use any of the existing standards right. The government has now published EHR EMR standards for India.

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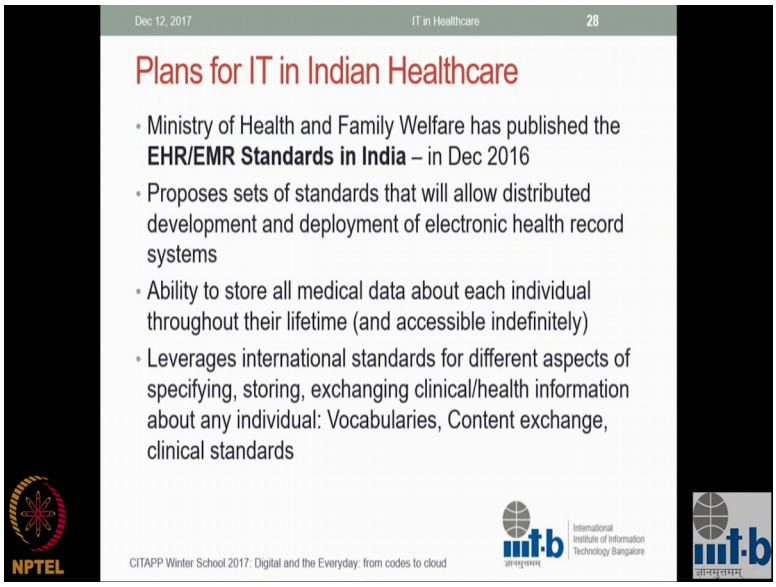

So, now, it is standardized, there is a formal standards that are brought out in December 2016, and at least we have a working starting point rather than worrying about what are the standard, the government said these shall be the standard for India after elaborate consulting process. They are broadly taken up prevalent international standards successful once, mostly around the ISO you know ISO basket of a standards, and specifically have recommended open EHR as the architectural framework.

So, advantageous I mean. So, from day one it is been assumed that this will be a distributed health information system, we are we can we do not want to say one central data we should be ready for a distributed system, and store all data about the patient and have access infinity persistent data. So, these are going to be come with these are standard. So, at some point they will be enforced then no were near there right now and they have not tried to create any new standard these are all standards that are working in different parts of the world, that are being leveraged to do this.

So, there is a formal document that is available for the last year and I guess companies and others are looking at what it means. The current set of implementations especially in the public health, do not conform to this. So, it will have to change over time and these

are not easy issues there are no ready available solutions for these. So, solutions have to be built, these are standards and these are architecture specifications. So, somebody has to actually implement something that will work in our context for the costs, and the diversity and other things. So, that is going to be something that going on for some time. It is already causing you know doctors hospitals others to start adopting some of these things right.

So, for instance standardizing once sno med c t as the terminology is beginning to happen, looking at open EHR architecture is beginning to happen, I have no way to say how long that will take or what the output of that will be and has since there is a key part of it, the government also now just you will find this on the national health portal now.

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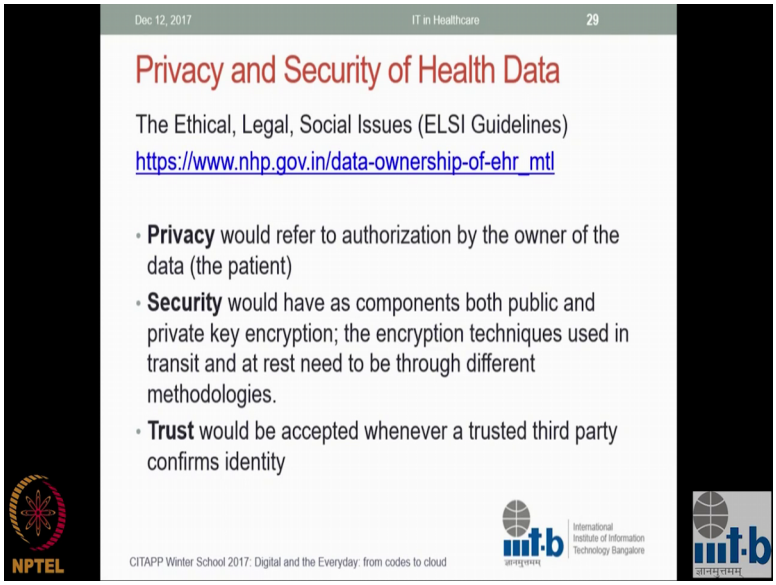

So, actually if you are interested you should go look at the national health portal they have a section on e-Health, they keep changing it a lot, but it is a lot of information's there at least on what the intended approaches. So, these are very early there I mean this is the way that standard or one year old; that means, it is probably people are just reading and digesting this some of these web pages change every two-three months. So, these are still very much your are time where some things are just happening. So, it is a good time to get into it, and try to do something contribute.

So, there very clearly define that, the owner of the data is the patient and patient has rights of privacy of it and yesterday you heard about privacy and with the current

direction in which the supreme court you know opinions are going this should get much strengthened a lot more. In India we do not have privacy of health data by enlarge, it is very easy for me to pretty much go directly ask somebody or go get anybody health data without too much effort.

So, that is going to get clamped down quite a bit hopefully. In security right one is privacy is I want to protect my data, I do not want my data to be public security is nobody should be able to hack a hospital and get the data and so on. So, standards are being proposed around these minimal standards. So, what level of encryption, where should encryption be done, all these are now part of the standards that are laid out.

Student: In recently somebody hack the Adhar data base and then stole data (Refer Time: 15:51)

They did not hack the Adhar data yeah they accessed it in a so.

Student: (Refer Time: 15:59)

Yeah. So, see those issues are there and that only heightens the need to be more careful about this week, I mean we have to take the approach I believe that these will be part of our ongoing solutions and it just had to figure out how to do it better you have to learn from those right. And in medical context there is some additional things essentially is the notion of trusts right.

So, who should access your data? So, if I have my personal health data under what conditions, and who should have access to that data, and to what level of granularity. So, I have my personal data it is secure, but I want different actors players at different points in time to get access to different data what could be some of those.

Student: Insurance company.

Insurance company, that to be very careful what data they get.

Student: (Refer Time: 16:48)

Yes yeah then it access to some part of your data correct.

Student: Families (Refer Time: 16:50) family.

Family yeah, but even they might be layers of.

Student: (Refer Time: 16:54)

Yeah they might be layers of protection.

Student: (Refer Time: 16:55)

That you are to put it not all data is accessible

Student: (Refer Time: 16:56)

By anybody. So, then trust itself could have many a hierarchy of.

Student: Maybe I can restrict it to my immediate family.

And even there is you might not want them to see something.

Student: You have a family also suppose somebody (Refer Time: 17:07) come to know about the son of daughter suffering from HIV they were not allow to (Refer Time: 17:12)

Exactly. So, there is different levels of confidentiality in some sense that are needed, and some of these are protected by acts the act for the mental health and that covers HIV all have very rigorous restriction, how the data can be shared access. So, that has to be built into the backend in whatever way, but at the same time we want to trust doctors and medical institutes because you need them to access data when you may not have be in a position to give consent.

One approach to privacy is consent based opening of data I will consent who and what access they can at for what period of time, but what you do in emergency situation? That is the unique requirement in the healthcare sector, and it could be from any part of the world let us let us not restricted to India it could be in any part of India, get into an accident and a doctor there has to access my data, how do they do that? They cannot ask me or try to on my family. So, that. So, the government is going to put in place a trust framework for this or proposes a trust framework.

Student: At any breach of this should be act with law.

Yeah. So, that is also the laws around this would control all that is what the policy part now comes it. So, based on these a whole bunch of the u I am hoping that the see the consumer protected data protection act, would cover some of these things and I am sure it well.

Student: Equation that is cover the e-Health that the (Refer Time: 18:31) more a where a data from gets stored public or private (Refer Time: 18:35)

No it does not, but those are regulations that will come in expectations is we will say any cloud that is hosted locally hosted in India, private public. I mean a government is already empaneled cloud providers in India that you can put in any kind of data.

Student: (Refer Time: 18:57)

No as your EHR they are only providing the hosting service you know.

Student: (Refer Time: 19:02) does not (Refer Time: 19:03) boundary.

Right now I think it has to be India hosted in India of course, they will be subject to the usual confidentiality and privacy issues. So, we are assuming those guys are not going to you know violate the, but yeah it adds to the complexity. So, hospitals are having the hard time deciding they should have inpremises as they are upgrading a system.

Student: (Refer Time: 19:22)

So, they have inpremises systems or cloud basis systems and if cloud based which cloud base. So, those are these are all very current happenings right they are changing fast.

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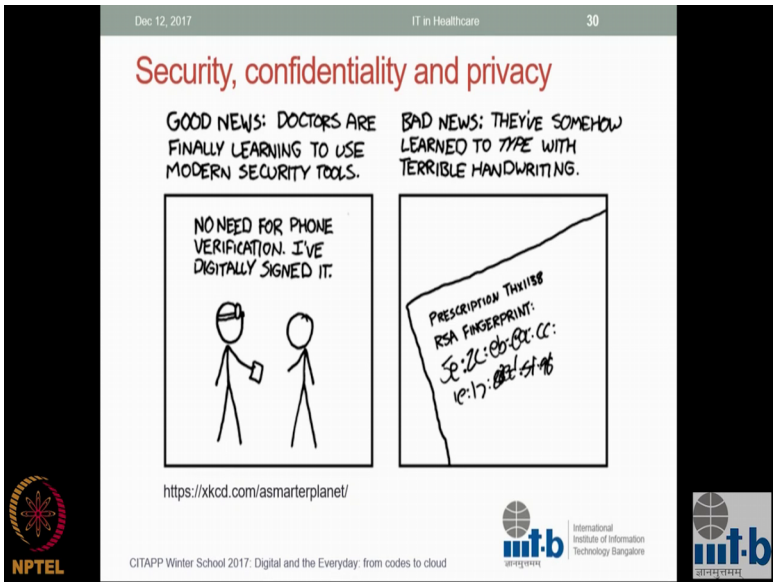

So, security brings up whole kinds of issues. So, security brings up whole kinds of issues, we have to get the whole chain working with security, and different people have different ideas of what security means and there. So, that is a huge awareness issue that has to come in security privacy and so on. So, it just does not mean writing something or I have seen the term digital signature, used for somebody just signing using electronic means like putting the jpeg there ok.

So, we need something more than that and that brings us to the others these are all needed for trading the patients better, the other side of it is we want access to data for research the whole thing has will move only when there is more research done, and we get better solutions, better devices better systems and so on and. So, we have to now talk structure server what does data mean what kind of data do you make available which is this whole notion of anonymized data.

So, the general belief is you have to make anonymize data available; you take data you strip out certain identifiers and other things that will not the which you cannot locate the individual, and then you make the data available in whether in public or in a controlled form. So, that research can happen, the research can be of all kinds of things right health care runs on data.

So, you need research data, but. So, anonymization and public access to some kind of data is required we do not have here on it the question is, is it really on anonymous and

you know some of the things you have heard in the last couple of days about aggregation and all that should tell you it is difficult anonymize data. So, specifically in the medical area we have this whole notion of what is called re identification, can I take the data and re identify the person, even though the person making the data available claimed it was anonymous and there are many many you know facets of that.

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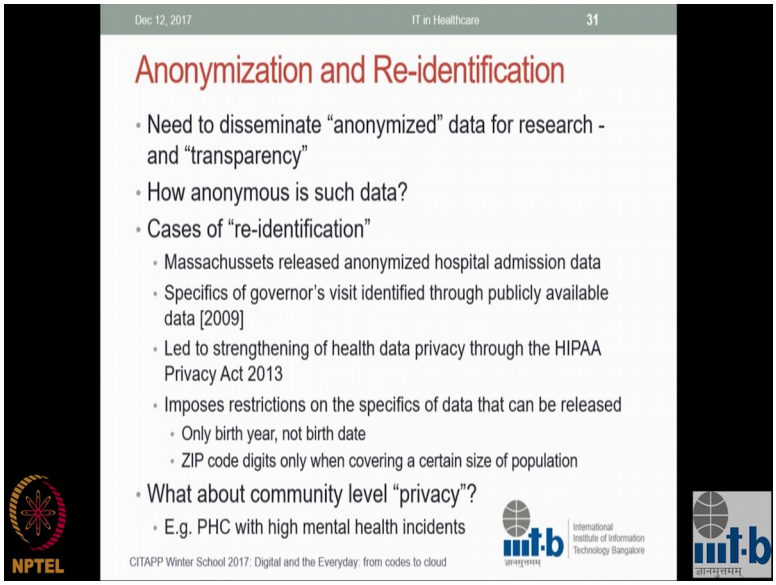

So, one classic case which is you know it is caught that incident caused a lot of regulatory changes is this massachussets had a law that they were trying to pass in 2009 saying that hospital visit data would be made public by insurance companies after anonymizing it.

So, they take away your name, your address, various other things they left a few fields. Then that is a tremendous protest and, but they just passed the governor signed it into law so; obviously, this cause also one computer scientist at howard I believe grad student, wanted to show that this data is not anonymous. So, he or she basically took the data that was made public, connected to certain other public data that was available and was actually able to narrow down the governors data and send it back to him.

Student: (Refer Time: 22:04)

Ok.

Student: (Refer Time: 22:09)

It was very ironic right and that was the point of the exercise is to show the so, that is a huge problem that led to a complete rethink of what privacy means in health data and led to the hipaa act and other things in 2013 I believe. So, one of the strongest data protection act that we have is American Hipaa privacy act, which is health insurance privacy and something act which basically says that how data can be shared, how data whether in whether between valid entities or when it is made research. So, as an example very simple examples would be that, you no longer put the birth date in the published data you maybe put the year of birth. Before they said birth date is they are going to be lots of people in the same birthday why do you need to worry about it, and this person you. In fact, use the birthday to narrow it down.

Basically all you have to take is this data some public data like birth and death records water records, I things you can triangulate and get pretty much any information these days that is becoming much easier with more such data being available and social media and other things. So, it is going to be easier and easier to triangulate and pick individuals out.

So, that is big issue. So, if I m not mistaken even the India privacy act just says you cannot go below a pin number pin code right and we are counting on the fact that in a pin code there are lots of people right, but what if there is some particular condition where in a pin code there is only a few hundred people, and then the data becomes less anonymous. So, one of the things in the US Hipaa thing is that, the zip code that is you only should have three digits if there is less than 20,000 people that zip code or something. So, you start aggregating or showing less granular data when it is needed.

So, these are similar things are being I think you know will evolve in India also. So, which is one level of re identification, the other especially public health data is can we start now identifying communities, what if there is a spike in mental health disease in one particular community and that gets public. The mental health problems are very worried about that about that kind of because that could stigmatize the entire community, and we do not know what that granularity will be right.

So, it is not very obvious going back to an earlier question saying, how much of this data should we put up even if it is anonymized the fact that one particular PHC saw a spike in a particular thing can be important information from a privacy standpoint, and we have

to get back to what is the meaning of privacy and at what level is individual versus community and so on ok.

So, law will conclude this. So, at least now we have clarity on what data ownership has and this is part and act part in the guidelines.

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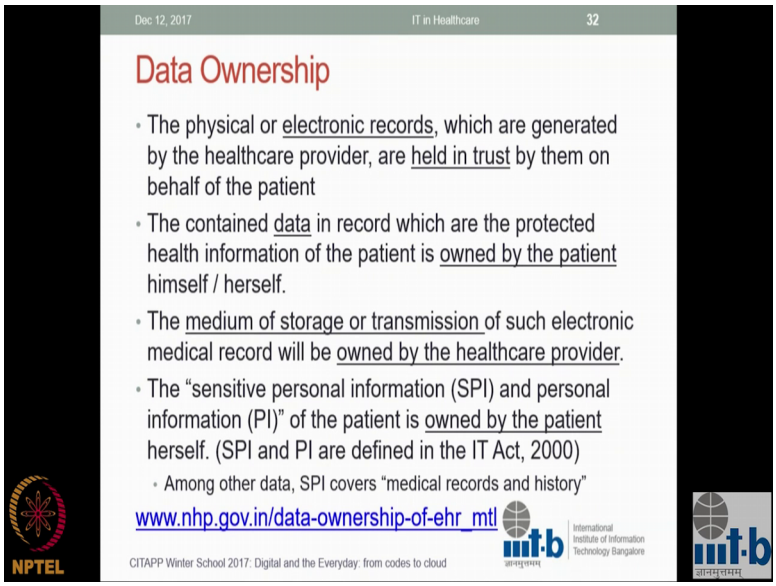

So, clearly the data is owned by you your personal data is yours, right now that is not the way to practice in India, try to get a your personal data out of a hospital it is very difficult right. So, it says it is yours, but held in trust by the doctors or the hospitals on your behalf, and is owned by the patient and the healthcare provider only owns the records and the physical and other medium that is used to do, it not the data itself.

And anyway we have the IT act which says that personal information sensitive personal information it comes under a lot of obligations and health records is one of those, medical records and history is already covered by the SPI. So, that sense the regulatory framework is there needs to be understood detailed out and exercised ok.

So, medical records are not meant to be published already under the IT act we do not even need any additional act; obviously, the new act that come in the consumer protection act will probably talk about data protection act will talk, at some point once neha is there some acts around specific healthcare might come in and these will tighten

this. So, the framework is evolving it is coming there, but lot of open issues lot of detailed to be work out I should say.

Student: Sir like with always IT enable you know the services, we always have like this local health worker at the local level. So, how do you think all this segment can contribute or like make use of the services (Refer Time: 26:22)

How can they do their part of the service better right?

Student: As a service provider plus how they can also contribute to you know IT enable like, is it like data collection can be denied.

Data collection they can probably provide more insights into what is happening they can talk about the effectiveness of the system.

Student: (Refer Time: 26:47)

Right. So, I think part of the assumption in many of these things is a larger population especially these health workers and others, will be more and more comfortable the technologies like smartphones yet they using phones anyway right. So, that brings in a better understanding of maybe how these should be structured, and hopefully they can give feedback on the design itself.

Student: (Refer Time: 27:06)

And then of course, the data collection and, but may be (Refer Time: 27:09) how can they contribute from a.

Student: (Refer Time: 27:001) I am in (Refer Time: 27:12)

I mean they already have feedback systems and things set in some form.

Student: Yeah. So, like because you know in many cases it is only the local health workers, which are available as of you know first point of contact and reach to the hospital is very you know takes a long time so, but. So, how they can be like you know working in this paradigm of you know complete you know IT enable and services how.

Ok.

Student: Their role can be you know like you know get more efficient (Refer Time: 27:42)

So, there are yeah so on. So, there are pilots out say going on right now where to give very specific application app that a health worker would have, which would allow them to manage what they are doing, but they can plan their day better, they can track what they doing better, they do not have to come back and then send s m s and write reports and so on right. So, how to make the how to integrate this within the work that they are doing and that is happening in some places, but again early stage.

Student: Ok

Yeah I mean either when we say IT system, I think it includes everybody involved right up to the field workers the health workers otherwise this will break down.

Student: (Refer Time: 28:19)

I mean otherwise you only have the data collection part to some extent, but not the healthcare delivery part of it. So, it has to be integrate into the whole delivery and that is the intention.

Student: Ok.

I do not know how many are there yet, but so.

Thank you.