Digital And The Everyday: From Codes To Cloud

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Lecture – 12
Promises and Challenges of e-Health Part 0I

Good morning, welcome back to the lectures here. I hope you enjoyed the series of lectures you had so far. So, far we looked at you know the IT digital and the overall impact from certain perspectives which kind of cut across domains we looked I guess we looked at things like privacy and how algorithms might work or might not work and identity and data itself.

So, now, we look at it from a different perspective we will take certain verticals or domains where IT is used or can be used and look at issues both from the standpoint of how IT can help, how IT can make a difference and also what we have to be careful about what are the possible, you know larger issues that need to be taken like when it is not purely a technology issue.

So, we will focus on healthcare in this session, like I mentioned briefly yesterday I also am part of the e-Health research center. So, we have a center here where we look at how look look at research programs in the area of how IT our ICT in general can help healthcare we have lots of issues in healthcare; healthcare is a huge complex area and we are trying to analyze that from different standpoints.

So, my talk will be more on kind of where IT is there in healthcare today give examples of that. So, huge topic a complex area; so, I am good only for a sample around, and will spend some part of the time on looking at who can benefit from IT and health care.

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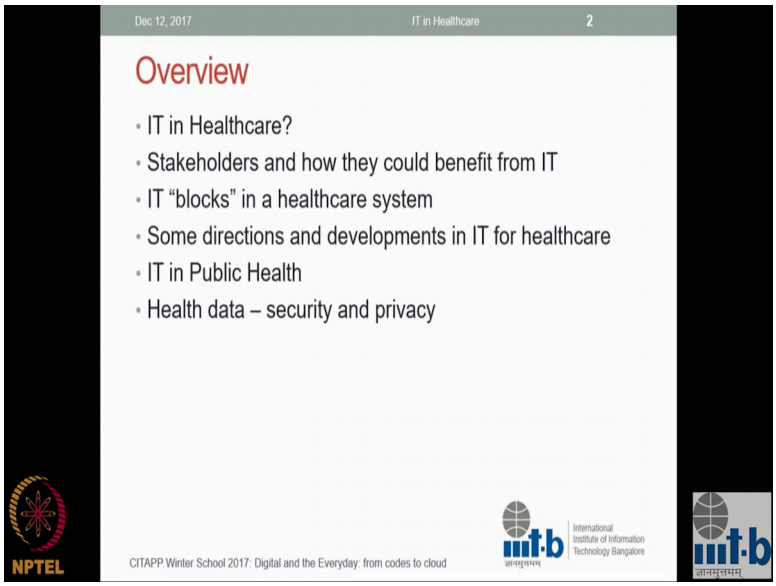

And look spend a bit of time either in the second half on public health specifically because that is a large area in need of a lot of help in some sense, and we look at how IT is being used there in what directions it could have. And one of the core issues that what I want to come around when you talk about IT and data and healthcare, the whole notion of privacy confidentiality security which you have looked; at a bit we look at it from the standpoint and the nuances that healthcare brings in, and possibly what are the solutions that could be out there.

So, that is the broad agenda please feel free to stop me and ask questions as we go, I have lot of slides when I run through them and you know focus on a few of them as you go. So, when we say healthcare and IT what are the who are the players and this is something we should think about who all can benefit, who all can use IT who all are using IT in the current context. So, if you think about healthcare what are the different types of (Refer Time: 02:50) the kinds of people who might be using it.

Student: (Refer Time: 02:54)

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Student: Insurance (Refer Time: 02:56) insurance (Refer Time: 02:57)

Insurance.

Student: Hospitals.

Hospitals.

Student: Patients.

Patients of course.

Student: Health workers.

Health workers.

Student: Government.

Government.

Student: The banks whether to keep use on (Refer Time: 03:08) not (Refer Time: 03:09)

Ok.

Student: You judge (Refer Time: 03:11)

Yeah that is possibly on the edge of it, but yeah that could also happen.

Student: Corporates.

Corporates (Refer Time: 03:20) companies working in the healthcare space it is actually a very complex ecosystem, and if you assume that the goal of healthcare is to improve health of patients or ideally avoid having patients at all, but let us say there are patients, we have a lot of players who come into play in working on improving the health conditions of patient or patients.

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And their patient probably directly deals with doctors, hospitals and the family, caregivers who are also important to this whole chain, but we definitely deal with labs, you deal with the insurance companies and as you go out there are probably, more indirect interactions that you have with people who are part of the system.

So, you have the administration of the hospital, you have pharma companies or doing research to come up with new drugs, device manufacturers increasingly we are seeing many health devices coming up of course, we always had the large CTMRI type data, but increasingly we are talking about variables that can help health related conditions and various research institutes.

So, looking at health from different standpoint it could be policy type issues, it could be drug discovery, it could be you know diagnostics and so on and medical colleges who are doing research and doing capacity building who all need some information about patients. All those works because we understand patients. So, we try to understand patients and try to work on data that we get from patients and that ultimately is what helps improve the overall system that at least what I would say the promise or the hope is.

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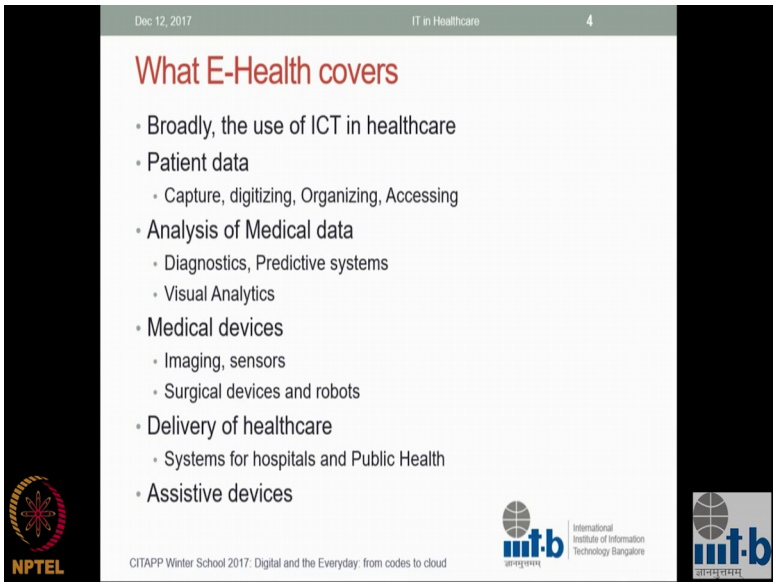

So, we look at e-Health which is one particular perspective of health and very broadly we look at healthcare that where any of the ICT technologies are used in the delivery of healthcare. So, there are many different aspects of this, one is just collecting patient data you have to collect data organize it, analyze it do various activities based on that. You analyze it both for diagnostic and predictive things for the patient itself and then larger analysis which could be more to look at public health, epidemics and those kind of things.

Devices are being manufactured and there is a lot of hardware software that goes into them to make them meaningful in the healthcare context. So, image the imaging devices the sensors that get created and how you convert all the data back to something that can be used. At the higher end we increasingly seeing devices that will help make surgery better, all the way up to robotic surgery or surgical robots itself.

And so, all these are part of this ITE ecosystem that we are talking about or that we will use as a e health broadly. And ultimately you need hospitals and other entities through which healthcare is delivered, for which you need to manage lots of information lots of data and so on. So, all this is part of what we what would be considered. So, you could pick any one of these and spend days on it.

So, we try to kind of do a broad brush work through these, and I should also mention assistive devices. Devices that could be for disabled or people with certain motor and

other kinds of conditions, which are helping them you know do better overall. And technology in the sense of information communication technology is used heavily across all these and that is where a lot of research in focuses happening. So, if you focus in on a patient what we are trying to collect is data about the patient, the medical records very briefly the history of the patient.

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to do meaningful analysis or meaningful healthcare, meaningful treatment of patients over time you need as much of the historical data as you can, otherwise you are doing very local symptomatic treatment. So, ideally we would have longitudinal data for a patient that is over their entire lifetime. We want to capture this all kinds of information about illnesses, diseases, immunization.

So, they might have done anything to do with the development history allergies medications and broadly maybe even social habits and even family and other environment. All this is part of the data that is needed to make a eventually a meaningful holistic decision about the patient. There is also demographic data having to do with their where they live age groups lots of other issues that come in. Now while this is at a broad level, there is a lot of data that needs to be collected by the way the data a lot of this data is being collected maybe on paper today. So, it is not as this new right it is just that we are saying if this moves into the digital space how does the complexity come in.

So, when you go meet a doctor, what is typically called an medical encounter you have information about who are the people participating what time what location those kind of things, but the list of symptoms complaints examine what was found any tests that were done the results that came out of the test and there and finally, what is the diagnosis and then a prescription or a treatment plan or something that all this is part of the record of a patient and typically today by and large this is done on piece of paper they either kept in the hospital or the clinic or when you leave they give you a prescription or a discharge summary or something where some summary of this is there.

Obviously it is very it is very obvious that that is not a sustainable or scalable system, because it depends a lot on those pieces of paper being around and that they all get integrated the right way, which if the registers are sitting in different buildings different hospitals and you can maybe lose some of the papers, you have then your history is never complete.

So, that is a basic challenge which comes in the way of large scale reliable healthcare and. So, one of the big focus of e health is to say how can we manage that better. And now we also have a lot of patient generate data we always had patient generated data you would go tell the doctor that yesterday morning I had fever yesterday night I had something and all these things, now we have devices that will help us gather this data at a much finer granularity and so, there is lot more data coming in patient generater which also has to be added, which is meaningful in many contexts right.

Ideally diagnosis should take into account all pieces of data that is there, because you do not know what the real clues are. Medicine by and large is data driven it is evidence based or of course, sometimes experience based, but experience comes from looking at lots of cases.

So, ultimately the practice of medicine involves dealing with lots of data. The setting of the medical encounters if you might call because doctors have a very limited time they can spend with you there is a maybe they have over time with practice, they figure out what is the right set of data to look at to treat a particular condition, and it may be not data that is explicit you could be rated as implicit here. Look on your face the way you walk all these can be close for the doctor to decide a diagnosis. But obviously, that works

better if the doctors more experience and works less with the doctors less skilled or less experienced. So, those challenges come in ok

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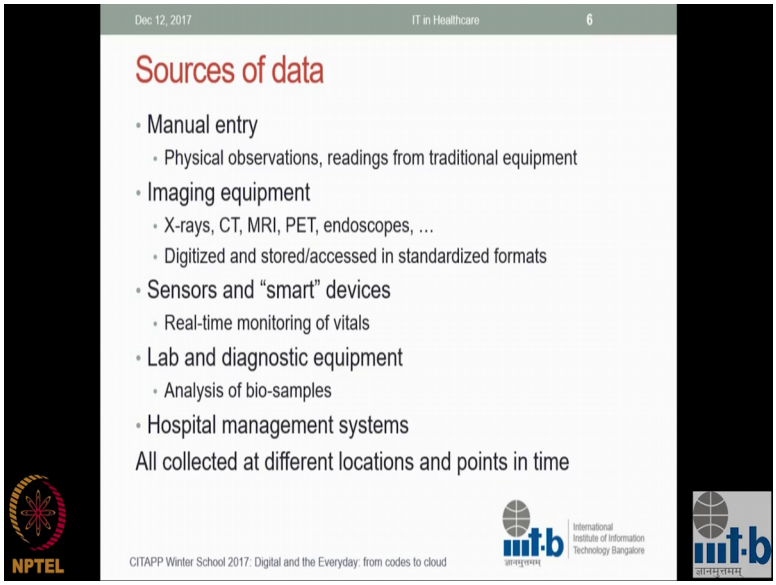

So, the data itself is coming from a variety of sources and from a technology standpoint we need to understand how the data is sourced. So, lot of it is manual entry, still even if the even if the clinics have sophisticated equipment, some of the things still has to be entered either by typing into a keyboard or writing in paper or somewhere. One of the biggest places where data has been used and collected is whole thing around imaging starting from x rays to MRI, CT, PET and so on where you are collecting large amounts of intricate data about the anatomic anatomical details of patients and then having a structured way to store it and access it.

So, that. So, this different heterogeneous kind of data that we need to deal with, sensors in the smart devices we talked about they are bringing in more data in real time and probably each sensor or each set of devices generating data in a different format and different sequence of time. Labs again are all about analyzing samples and coming up with some information about them you get a hemoglobin count or you get a creatinine level count or. So, these are numbers that come out of the, at the end of it and become part of the data base of each person and. So, the big challenge is that these are all collected by different players, at different locations, at different points in time, in

different formats. And you still have to make sense of all this and next time you go to the doctor ok.

So, it is clearly a challenge and we are probably quite a far away from making it really big (Refer Time: 11:39) and consistent.

So, the challenge with this is that, we have what we call continuity of care; you do not always go back to the same hospital or doctor every time over a course of a lifetime for sure you would go across many different kinds of entities that deliver health care and; obviously, in the current environment, they all do not have access to all the data that you generated that was generated about you because especially if it is paper based, and even if it is not paper based and if it is in some health record system with the hospital, these are typically silos given hospital or hospital chain might have a data base about you, but that is not necessarily easily accessible or shared with the different hospital.

So, if you as an individual have to move around and its; obviously, the history is in your longitudinal history it has to be consistent it has to be used throughout how do we bridges problem. The clearly there is a need to integrate all this different data, and the whole notion of what are called electronic health records or EHAr s is trying to address this problem and especially what we will call a shared EHR or.

Student: So, I have been talking about the scenarion India specifically (Refer Time: 12:52)

I will get to that I think the.

Student: I mean it is a problem is worldwide problem (Refer Time: 12:55)

Problem is worldwide.

I will talk.

Student: It is better than other.

It is not any better in other countries right I mean. So, India is clearly much behind both in the urban private health practice as well as in the public health for sure.

So, the in the private the larger corporate health practice they have started putting together EHR type systems that at least span their network, but they do not necessarily talk across networks.

Student: You will talk (Refer Time: 13:20) also they are not falling line through global scenario.

Yeah well global standards are emerging. So, they are also trying to fall in line, with that we will talk about that about standards in a little later. In the public health sector which I will focus on, but there is almost no data of this kind it is on paper I mean the data is there, but it is on papers and registers then each hospital maintain each sentiment.

Globally it is I do not think is anywhere near a solved problem, every country is struggling with this to different extents. Countries that have consolidated or universal health care like countries like u k s have developed more global systems, countries like US where it is distributed are also struggling with this right.

So, typically as long as you stay within a network you are the minute you go out data gets lost and there is also, a lot of questions about what data actually gets entered. So, while there are hospitals in India that use systems of some kind, it is difficult as we have seen a bit to enter all this data in a consistent way. So, the solution often is to not enter data, enter only the critical data that is needed to do some level of continuity. So, continuity of care as a concept is probably one of the most important things that will need to be addressed is being addressed, and it has different manifestations depending on whether we look at a urban type of setting or a rural setting in a public health type setting maybe we will.

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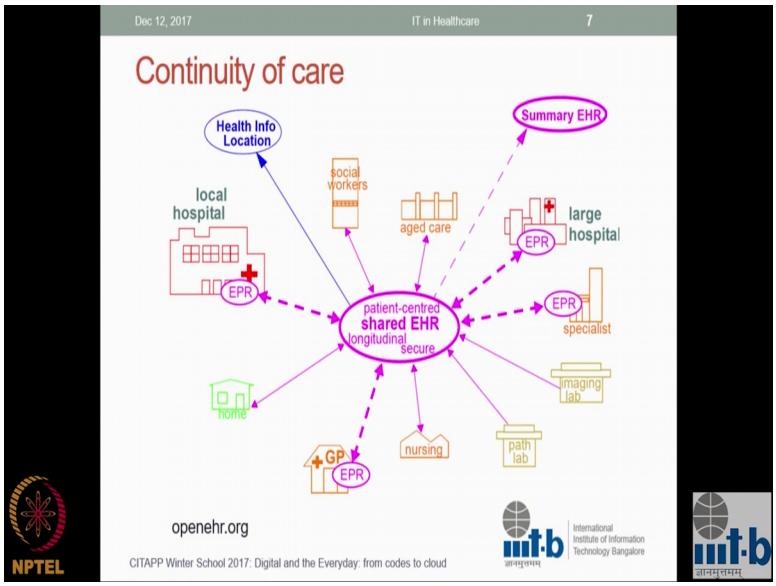

So, you can I mean you can probably relate to this in I will come back to this later maybe right.

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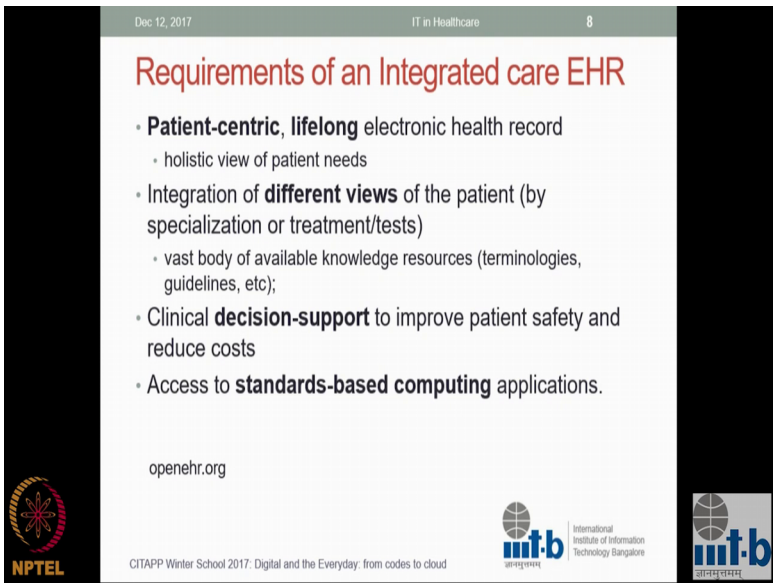

So, we can say that what we are really looking at is to have a patient centric data, base a patient centric data which is the lifelong health record. Everything from birth or preferably from conception to death, and may be data kept beyond death also because it could have ramifications for the family and other analysis later. And the challenge here is

the your so, many different aspects of healthcare that we have to deal with, there is. so, many different specializations that we need to deal with and.

Therefore we need to have a way that all these different views of data can be managed. If you have an eye issue and you go see an ophthalmologist they do not necessarily want to know that you fractured your leg last week may or may not and vice versa. Orthopedies problem you need to know your vision is bad, but not maybe the other way around right. So, these are very tricky it is very contextual and given the quantity of and a variety of data you do not want to dump these on the doctors because then they will have it is noise the too much data is noise right.

So, one of the big challenges is how to organize this data. So, that it can be used appropriately at every point of interaction and that is a difficult sorry. And part of that will be since the thing is so, heterogeneous and how the data comes about, how do we agree on how it should be stored, what does it mean to store blood pressure or temperature. We say temperature do you store it in centigrade a Fahrenheit and when you say blood pressure do you store it a certain way on. So, right down to that level of detail that has to be standards and agreements and how data will be stored. So, that sharing can happen so, that ultimately we get better care.

So, and if you have standards based storing of data, you can start thinking about applications that can work which are somewhat independent of the exact database or health record system that you are working right. Now there is a lot of vertical integration, in a sense that you can get fancy systems you can get elaborate systems that can manage all this data, but then you can only run applications that are done on that preferably by the same company and so on. So, it kind of narrows the spread of these things. So, there is an organization or a initiative called open HER, which is trying to address this it is an international entity that is putting together a set of standards for health records.

So,. So, it is open EHR the specifications are open, it is done by a community across specialists all over the world, and it is trying to put together architecture specification architecture, information model, security model and other things that will help make EHR workable and shareable and interoperable.

Student: It does not make to (Refer Time: 17:32) standard storage methods like relation method way similarly.

That the intention of these kinds of standards is to abstract away from those. So, it does not matter whether it is relational or non-relation. So, long as we can provide a certain view for different users, that becomes more of an implementation issue as interspace (Refer Time: 17:52)

Student: if those methods are erostical type of data, it is for US approach, but here they are wont follows the separately another so; that means, there is deviation terms of standards.

No the standards though these systems I will get they are very detailed in terms of standards. So, with, but the, at the lowest level whether you use a relational database or not is a decision that will define that will be defined by your size your need for performance and so on. So, if I have a small clinic, and I have an open EHR based system does not matter what database are on there.

So, long as I can let it interact with other systems. So, the architecture is defined with sharing in mind. So, you can have different instances of EHR at all these different place, but they all conform to the opening EHR specification and therefore, they can collaborate that is the promise that is the goal that we are driving towards. So, this is one big an open EHR is probably at this point the most significant one, but there are many such initiators the many proprietary initiatives that have happened over time and. So, on and this is relevant again in our context of public health I tried back to that.

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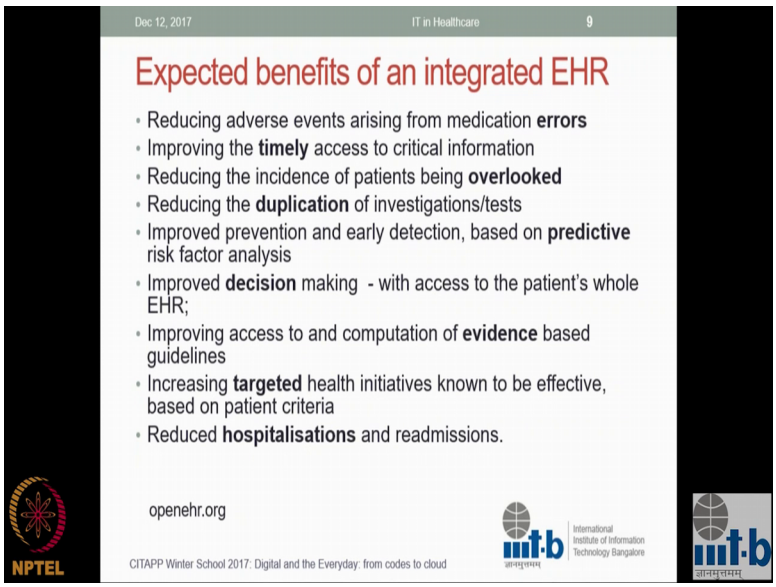

So, there are a lot of I mean. So, what the summary is that if you have an integrated EHR or you would rather say that you need an integrated EHR to be able to improve various things about healthcare, how do you reduce errors, how do you get access to information as and when needed, how do you get how do you make sure patients do not fall through the cracks slip through the cracks, how do you make sure that we do not keep doing the same test right. Now you might go to a doctor they might do a test, but that is kept within the hospital and you move to another hospital for a second opinion they might ask you to do the test again depending on the kind of test.

So, that is clearly a waste how can we start looking at analyses better. So, that we can start making better predictions about risk based on risk factors and things which is. So, rather avoid the disease then handle the disease it. So, it should go into managing the whole scenario. Decision making using complete data is probably one of the most important aspects, and later when we talk about m l and related things. This is becoming a big issue is, that just the sheer quantity of data and the variety of data that a doctor needs to process in a very limited amount of time is becoming more and more of a challenge. And so, we need systems based on access to a lot of data, that can help the doctor make decision in the decision making.

Student: In decision making to what (Refer Time: 20:20) subjective matters in terms of (Refer Time: 20:22) such things. It is totally awares of these subjective.

No.

Student: Up to some extent (Refer Time: 20:26)

So, it is. So, medicine by bialy is evidence based and experience based. So, it is a combination of objective and subjective analysis today right the, what doctors practice. So, what algorithms will do is, as you would have heard in the things to whatever extent they are programmed, they intend to be objective, but they are as good as the data or the programs that have been fed into them.

Student: (Refer Time: 20:49)

So, they are not subjective in the sense we would normally think, but they can be probabilistic. So, a lot of it is about how to make the treatment of the patient better, how

to make the diagnosis better. The other part is especially in public health we run large programs you spending a lot of money on public health.

So, how do we know what of the effectiveness of these programs, how can this data help identify manage track the effectiveness it is program, and at an overall level both from a patient health standpoint and cost standpoint how do you prevent readmissions, how do you prevent you know reduce the amount of hospitalized, which is the big issue if the treatment is not done or the follow through is not done right readmissions happen.

So, all this would presumably improve if you have a good EHR and so, we can say that at a very high level we have a set of collaborating.

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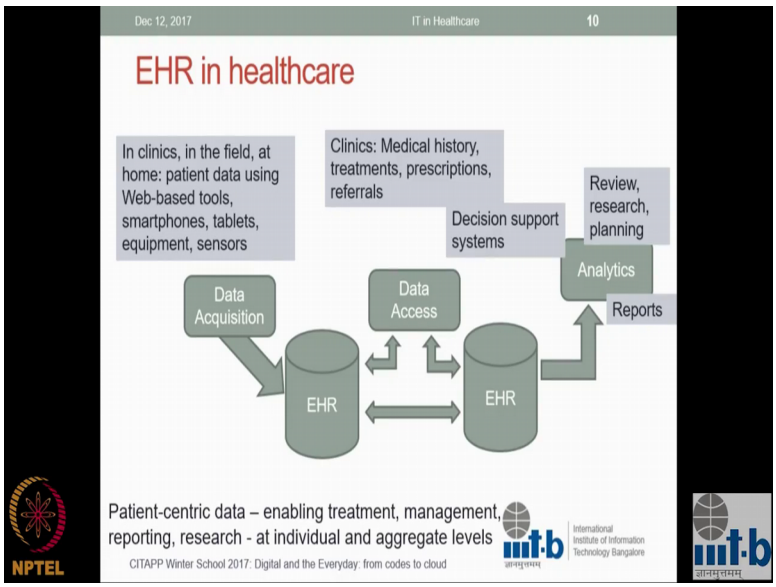

EHR s data is accessed and added to any one of them, various entities access this data either for clinical purposes or search purpose or other program type purposes, and over time we have more interesting analytics that can be applied to this which you would include just basic data analysis to machine learning and other things so, that you can get better systems, better report. So, this is the direction that a lot of a health care focuses research and health care, and the core point would be that this is patient centric data we are getting all the data in an organized form over patients.

Because most of the time in treatment your interest in data for one patient, it only occasionally that you look at things across patients it is slightly different from normal

data bases that you might deal with. So, but of course, with research and other things that cross patient information becomes very important, so, both are both need to be managed and that is why individual view of data as well as aggregate view of data.

So, these are challenges in any database data modeling issue they are not straightforward and since we are talking about distributed data, we are talking about data that is distributed across multiple instances of EHR s possibly, imagine you go to completely different hospitals, they will maintain their own data, but somewhere you would also hope that these all get aggregated in the cloud somewhere.

So, it is abstracted away from the endpoints of the usage, and that makes the whole that at least has the promise of patient mobility; that you can move from place to place and have access to your data and therefore, we get continuity of care, we even across geographies.

This problem is very important very serious from many different standpoints, any of us could at any time be in any part of the world and need access to medical data, and you would need access to your health records ideally. You might be in a situation where you are not able to you might be unconscious right you might and they still need access to the data. So, challenges are pretty large and when you get to public health, which is much more distributed in some sense these issues become much more challenging and have a look at.

So, while this is a sort of the high level concept, one there long way from being able to implement it consistently across. We have lots of issues to work with because once you start making data available public patient health data available, privacy and security become like the top issues health data is of high as you would have heard yesterday the personal information, sensitive personal information that the we have classifications in our in IT act, put health records as one of the most important things right. So, there is a huge issue around privacy security confidentiality.

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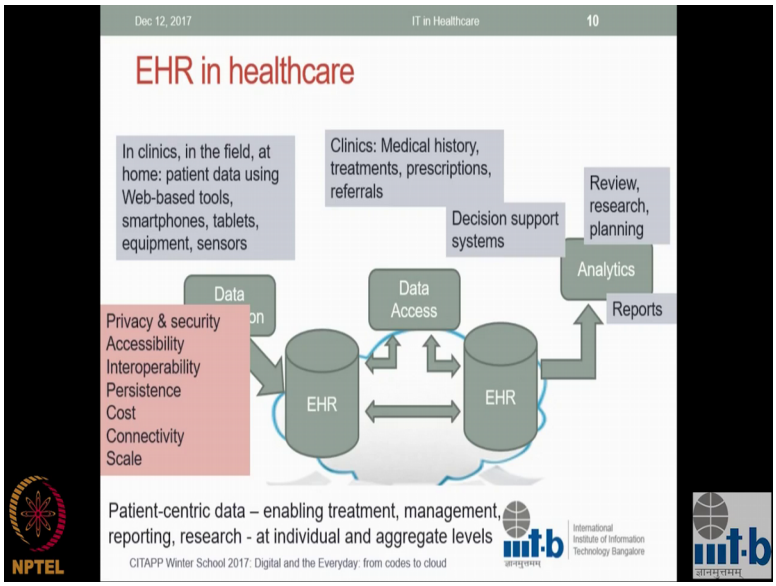

And, but the same time you want access like I said the scenarios that you have to handle a very complex, you have to go to pharmacist and get a medicine you have to show some kind of prescription and let us assume everything is electronic. The pharmacist has to have access to the prescription part, but not any doctor notes because that might indicate something about your condition. I said you might go to a particular doctor and you want part of your data to be available, lot of people if you if you look at health data you have all kinds of health data and mental health is one of the issues.

So, in general mental health data is protected or needs to be protected much more because there is lots of social stigma and other things associated with that. A patient might go to a doctor and may not want his or her mental health data to be exposed, that adds lots of complexities.

And like interoperability is a bare core requirement because we are going to go to a diverse set of entities who deal with a health data, and all this data better not be lost because we are saying this data has to last throughout your lifetime. So, persistence is a huge issue, and cost and connectivity and scale and other things that we can discuss how do you make this work for 1.2 billion people.

If you think other is a difficult problem that is nothing comforting, because there we are the store a small amount of well structured data and protected right biometrics and some demography.

Now, we are talking about potentially gigabytes of data per person, every MRI is could be a gigabyte of data, potentially even terabytes for a chronically ill patient and still have all the controls that you would like around it, going back to not just privacy, but also how do you access it, how do you do it and low connectivity areas and so on.

So, challenges are huge and you know I think there are initial work towards many of these things, it will probably take a few years to fully develop, but while those are being developed all these other issues are also being addressed or have to be addressed. And these are more from a technical level you can also look at the same thing from a policy and other levels especially, when you talk about security.

Make sense any questions there is already some amount of health information system around, pretty much every hospital has a system with at least they will do your billing right, they will make sure that you pay for everything they do or that you will not get services unless you pay for something right.

So, the typically the administration side of it because that is more like maybe any other enterprise has evolved quite well.

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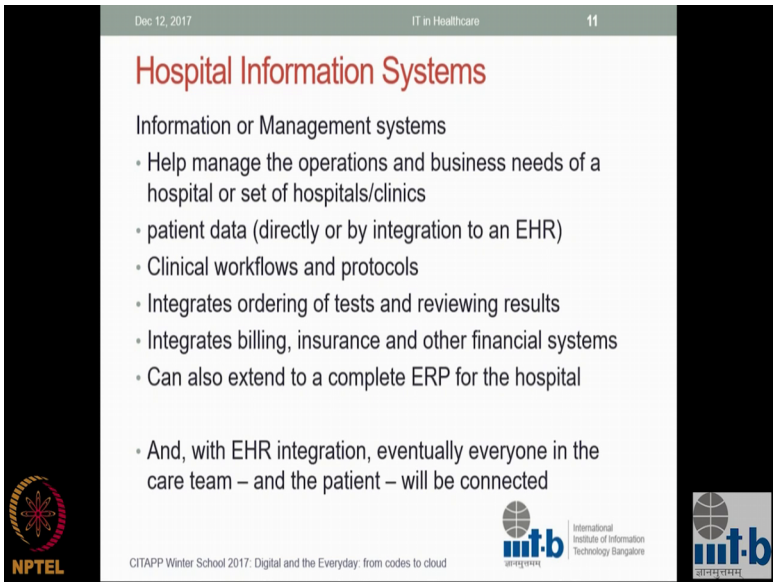

So, we have this hospital information systems, my hospital management systems which manage I would say the treat the non clinical part of health data quite well, and the focus has been on broadly making sure that the hospital runs as an it as an enterprise; revenue

billing, inventory, HR those kind of things. So, they are not very different from other enterprise systems and. So, there have been many many and by now many hospitals definitely many of the private hospitals are and the public hospitals I should say have this in place.

In some cases they integrate to the EHR or they might have a kind of EHR wrapped into them, but that is out call a very basic HER, at least it would have high level information about the symptoms and the and the diagnose is more than the symptoms so, that you can bill correctly right or do other things correctly.

And, but the goal is now how do I integrate h h I s h m I s with an EHR so, that actually everything gets connected. So, you know hospital the workflows are automated maybe through a digital system, the patient data is still on paper. So, you will find nurses typing into the thing and then carrying a register to the next let us; so, you have two system. So, eventually these have to get integrated, and then we can say that the whole health care team that is working on you is integrated including you and that is still Holy Grail at this point/

So, if you; so, will just stop looking specifically at health care, we have to health record we have to say that we want different issues that come up are how do we store them?

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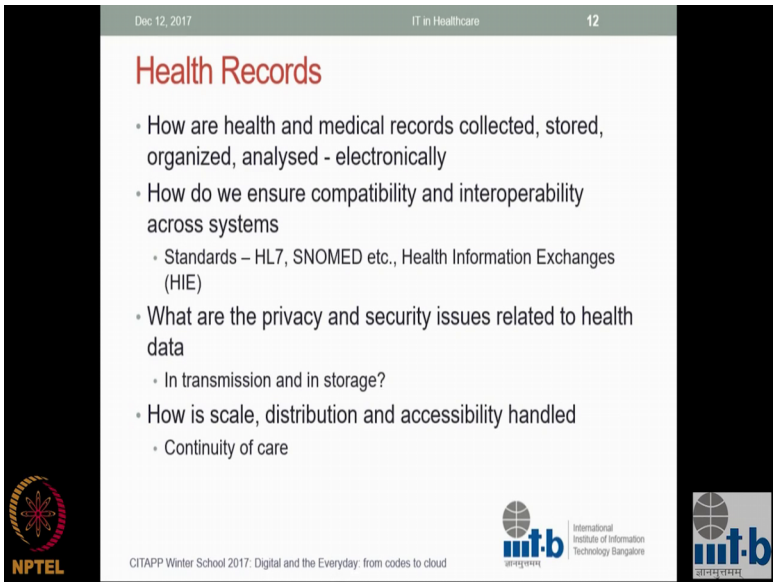

What is the repository what is the methodology, what is the standards will use what is the format will use, to store it in one place how do we ensure interoperability across different health systems and there are lots of standards in the healthcare, because healthcare is serious data and there is lots of health care.

So, there are standards relating to how you will classify a particular illness or condition. So, SNOBMED etc is one of the world standards for that. So, it will be able to specify you have a standard way of specifying every possible illness or condition that is there. But because it is trying to do all (Refer Time: 29:29) is also very complicated; you have standards relating to how data should be shared specifically about what are the formats of the messages, what is the encryption what is security and so on and this is where things like HL7, FHIR and so, on; coming these are well documented well a practice standard, they have been around for many years.

And any system that in India we do not have such strong regulations in place, but for instance in the US, if you are going to use such a system it has to comply to all these h l 7 hippo and other things that well talk about

The other challenges well we can do all this for one system, how do we ensure operate interoperability across systems. So, in health is typically a state subject. So, the state manages a lot of the even public health, it is no necessity to share it across state boundaries, even the u s because of insurance and other things similar things happen. So, how do you still exchange information across whatever boundaries that are there for commercial or geographical reasons.

So, this health information exchange is another whole set up. So, it is a huge number of standards that have to be looked at to umactually put such systems together, but then we want to share data. So, what is the privacy and security issues that will come in; you have data addressed data in the database, which is open to attacks which is open to hacking and your data in transit which is moving intentionally from one place to the other because you want data to be accessed at different sites, and then you know you the back to the question of scale distribution and so on.

So, you know just to go back. So, data in healthcare is not new managing of data is not new. So, the whole evolution of digitized imaging starting with X rays, CT MRI pet and

so on is all about collecting essentially X rays of your body at different levels of resolution and being able to analyze it visually at least.

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So, you have MRI machines from which you can depending on a kind of analysis you do you get, a very detailed information about the structure anatomical structure as well as b0ehavior of different parts of the body.

So, this is been I applied very successfully to you know understanding individual anatomy, in whether it is you know heart conditions, cancer, bone and other orthopedic issues and. So, on and it allows you know doctors to get a very realistic view of what is inside the body before they do any surgery or anything and this would become now common place in medical practice.

So, this is more along well and in this case there are standards like packs and dicom which define how data will be stored and shared. So, there is a working system and it is possible today to have data stored in one hospital and access from anywhere. So, long as they can like work out the protocol support who should access and why and the data will actually be by and large usable by the other doctor.