



**The DELPHI Project
of the Centre for Studies
in Family Medicine**



**ELECTRONIC MEDICAL RECORDS (EMR)
IN PRIMARY CARE RESEARCH:
IMPROVING DATA QUALITY
PROCEEDINGS**

**February 9th, 2009
Toronto Marriott Downtown
Eaton Centre**

*Sponsored by Enhancing Quality of Primary Health Care Initiative,
Ministry of Health and Long Term of Ontario*

KEYNOTE SPEAKERS

Dr. Simon de Lusignan



Dr. de Lusignan is a general practitioner and academic GP with a research interest in informatics. His research focuses on how routinely collected data can be used for quality improvement and how IT is best used at the point of care. His quality improvement work has been in: cardiovascular disease, chronic kidney disease, diabetes, mental health and osteoporosis. Dr. de Lusignan has led the development of on-line information sources for primary care but latterly focussed more on the evaluation of how these and electronic patient record (EPR) systems might best be incorporated into clinical practice.

Dr. de Lusignan is trained as an educator and has developed new courses including the UK's first full time undergraduate informatics degree; he also has a long experience of supervising undergraduate and post graduate students. He is the Head of General Practice and Primary Care, a role which involves supervision of an academic team and a network of nearly 300 practices.

Dr. de Lusignan has been a partner in his practice for over twenty years and has been active in the local health community, including a period as PEC (Professional Executive Committee) chair of his local Primary Care Trust.

Dr. Karen Tu



Dr. Karen Tu is a Scientist at ICES, a Family Physician at Toronto Western Hospital and an Associate Professor in the Department of Family and Community Medicine, University of Toronto. She graduated with an MD from the University of Toronto in 1992 and an MSc in Health Policy, Planning and Financing in a joint degree from the London School of Hygiene and Tropical Medicine and the London School of Economics in 1998. She is experienced in data collection from primary care physician offices and data linkage to administrative databases, primary care electronic medical record data collection and analysis and has extensive experience in health services research centered around the identification and management of hypertension.

The DELPHI project has created a researchable database, to describe, assess, and improve the quality of primary health care delivery in Southwestern Ontario.



The Delphi Team: from left to right: Amardeep Thind, DELPHI Investigator; Nicole Robinson, Administrative Assistant; Heather Maddocks, Data Analyst; Vijaya Chevendra, Systems Manager; Moira Stewart, DELPHI Co-Principal Investigator, Director of the Centre for Studies in Family Medicine; Louisa Bestard Denomme, Research Program Coordinator; Amanda Terry, Post-Doctoral Fellow; Neil Marshall, DELPHI Investigator, Sonny Cejic (absent), DELPHI Investigator.

Executive Summary

The DELPHI Project of the Centre for Studies in Family Medicine held their 2nd conference entitled “Electronic Medical Records (EMR) in Primary Care Research: Improving Data Quality” on Monday February 9th 2009 in Toronto, Ontario. The conference was held to continue the discussion of EMR data research advancement for a Canadian audience of practitioners, researchers, and policymakers.

The specific goals of the conference were threefold. First, to learn about the challenges surrounding EMR data quality and consider ways we can improve it. Second, to discuss the realities of using EMR data for research; and finally, to discuss possible solutions and next steps along the road to further Canadian EMR implementation, EMRs in primary care research, and EMR-based policy and development.

Attendees were from across Canada and included policy makers responsible for implementing an EMR strategy, practitioners, Local Health Integration Network staff, and representatives of national research institutions including the College of Family Physicians of Canada, The Canadian Institute for Health Information, Canadian Institute for Health Research, The Institute for Clinical Evaluative Sciences, and the Public Health Agency of Canada. Also present were representatives from Ontario MD and Healthscreen.

Keynote lecturer Dr. Simon de Lusignan began the day with a presentation on improving data quality in primary care. He combined a Donabedian approach to looking at structure, process, and outcome with the Realistic Review evaluation method to suggest what changes in policy and computerization are actually implementable in the clinical context and therefore lead to the improvement of data quality. He discussed the accolades and shortcomings of several UK data quality initiatives and their links, while also reviewing the very definition of what data quality should come to mean. Dr. Karen Tu of the Institute for Clinical Evaluative Sciences discussed her lessons learned using EMR data for research along with several projects she is currently working on involving the validation of de-identification software for free text. The DELPHI project also spoke about their current projects and presented some of their new results with regards to symptoms analysis, data quality, and wait times.

In the afternoon, three small group discussions were held and several issues and recommendations were highlighted. The first group whose focus was on research was assigned the task of brainstorming the basic method and reporting requirements for research papers using EMR data and subsequently prioritizing each requirement. The second group focused on EMR data for clinical practice and discussed data element requirements to improve practice. The final group, centred on policy, discussed what their respective organizations could do to improve data quality in primary health care.

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"Improving Data Quality in Primary Care: Challenges of Structure, Process and Utility"

**Dr. Simon de Lusignan
UK**

Good morning everyone. Thank-you for that tremendous introduction and I hope that what follows doesn't disappoint you! From the delegates' names, you are obviously a distinguished audience.

Could I just ask the audience some questions just so I can have a feel if I will lose you or not? If I talk about clinical coding, can you put your hand up if that means something to you straight away, if I talk about clinical coding? Okay, so pretty much every body but not absolutely everybody is into clinical coding. Can I ask how many people are clinicians? Out of the clinicians how many people use the computer at the point of care? Okay, so pretty much all of them. Good. So I can probably canter through my introduction. Anyway I shall start.

My abstract follows a well articulated *mantra*: That if we introduce IT across the health care enterprise, sharing coded clinical data, we should be able to improve patient safety and health service efficiency. This goal perhaps has been a little more elusive in the implementation systems than people perhaps have previously thought.

There is also this opportunity to use routinely collected clinical data for research and there are already existing models to do this. I will also present a couple of mine, models that attempt to assess and raise the quality of data. Though these models are only descriptive, and not based trial data.

So what I have tried to put together and present today is a model in which we can appraise the latest lessons from computerization of UK primary care, which importantly raise data quality; and hopefully can be applied in another setting. The method I've used to do this is to combine a Donabedian approach to looking at structure, process, and outcome with the Realistic Review Evaluation method. I will try and suggest (and I will guess these will be my own personal suggestions) about what changes in policy and computerization actually are implementable in the clinical context and therefore lead to improve data quality.

The results that I am going to present to you are the structural changes that are capable of being integrated into clinical process and will improve data quality. The ones that are not adopted, I'm going to argue, are largely not so because you can't introduce them into the clinical setting.

However, the thing that trumps everything are large financial incentives. I will present a couple of examples –where when a scheme was started and no one would use it. However, put money behind it and it suddenly changes.

I will also try to stress the point about "*niche improvement*" in data quality, how important that is, and how pertinent it might be to the development of a network. By a niche, I mean things like detail social class data, or ethnicity data. If niche data are complete they can empower a research network to do very high quality work in that given area.

I am going to summarize with the idea that I've come along with a model that might help the DELPHI team appraise which UK

data quality initiatives they would like to adopt. So how I am going to do this, I am going to tell you a little more about me. I will skim through the introduction having seen the audience that you are. I am going to show you the two previous models that I proposed as ways to improve data quality. I might perhaps touch on their short comings. I am going to present this methodological framework I've talked about, my analysis of where I think there are links between the initiatives in the UK – how they entrap the clinical process and how they have changed the data quality discussion and conclude.

So a little bit about me. I am a GP in Guildford, which is about 30 miles southwest of London. It is halfway between London and Portsmouth, a road that ran from the Capital to England's major naval port. In the picture there is my practice which you'll get to see later on. We are about six and a half full time equivalent GPs and just under 12,000 registered patients. We have been computerized since 1988 when I started building my own computer system with two other GPs and some computer engineers. We have been with a brand of computer system called EMIS since 1994 and we use the data quite a lot in our practice. We are now involved in locality choices about care, something called practice based commissioning. We have just created along with six other practices a thing called an Integrating Care Organization, which is one of the latest government initiatives. I think, because ours was set up quickly I think we will turn out to be UK's first. So that is my practice life.

At St. George's the two interests I have are illustrated by these two pictures. The picture on the bottom left is something I call the ALFA tool kit which is an open source method that you can freely download. The

ALFA toolkit allows a user to integrate multiple video and other recording to see exactly how technology interferes or contributes to a better clinical consultation. On the right is a graph of how I think a diabetic prescribing was improving prior to our finance incentivized targets. The graphs that are growing and more use of Metformin and very short acting sulphonylureas; the medicines that are declining over time are the use of long and ultra long acting sulphonylureas. And this was all quality improvement prior to the finance incentivized quality targets. I will talk later about one of the drivers of clinical coding.

From my practice data goes to all sorts of places. If I go down the left hand column, we provide data to a number of databases. We are an RCGP spotter practice; we send data to the Royal College of General Practitioners Birmingham Research Unit whose webpage is in the bottom left corner. That is an interesting network because they collect data from different brands of computer system but they have really created a niche for themselves. They are a good example of a niche data collection network. The niches they have created are: (1) They are interested in the incidence of conditions in general practice, and (2) They are interested in surveillance of viral conditions. There are only between 70 and 80, and those practices for example are pretty much all skilled at doing nasal swabs - because when there is a flu epidemic is to take lots of nasal swabs and having only made people gag when I was a medical student, I think the people in those practices have all become much more skilled in this procedure. They have supported their role in this particular niche by collecting extra data: for example, if anyone codes measles in the practice they will get a form to complete: was the condition clinically

diagnosed, was it proven by blood test. That is an example of a niche role for a data collecting network, I think the RCGP network is probably famous for this role.

We also belong to a brand-specific network called QResearch which is run by Julia Hipsley-Cox in Nottingham who has done some really good work particularly on cardiovascular risk. The QRisk calculator has been developed using data from this network though people may be more familiar with the Framingham risk score. So we have data that goes off there.

We have our "QOF" as we call it; this is the Quality and Outcomes Framework. Now as a GP about 20% of my income comes from management of chronic diseases measured by computer data. I will show you my QOF data later. So if you don't believe me you can look it up yourself as it is publically available.

We have four various inspections appraisal and we have got emerging revalidation as professionals, audits that we have to show that we are active in. Now, if someone has an infection in the laboratory, it shows that they have salmonella, then it is automatic notification of that pathology result to public health. When I started as a GP we had to fill in a little form and I think we got paid, I can't remember what it was, it was some tiny amount for filling in these forms and we have prescribing and referral data and I have just pulled down some change in items prescribed year on year in our practice. So that is sort of the scenario that I come from.

So the introduction, having seen how you answered my questions I will skim past these but I think that these landmark reports were the key things that lead to health services looking towards electronic patient

records as being important tools for improving patient safety. The second of these two reports pointed towards the need for a health informatics infrastructure and these reports really set the scene for the idea that health services would be safer and would be more efficient if they were electronic; and obviously to do that you need coded or recorded data. I think this, and the audience is familiar so just flash past this, when we think about an electronic medical record it has various components, the administrative data, the patient details we must be able to identify people uniquely and then there are really three sorts of data within a clinical record. There is structured data and this is data that is associated with a particular area of the record. So for example, an x-ray report might be free text but it's in a structured place associated with that x-ray and so the structuring of the record isn't necessarily coded data and there is some confusion with the way "structuring" and "coded" is used. Coded data is data recorded either with a picking list or data entry form or when you go to prescribe, there is an underlying code behind it, and I think everyone is familiar with that concept. But, coding is quite a difficult thing to do. Then we have the free text or narrative that is entered into set fields within the electronic medical record. In most systems only the coded data can be processed and used and analyzed for patient care. The real problems with using free text for analysis: there is the medical context which is particularly difficult, you know patients come in and say to me *"well I have come in about my headache Doctor because my great Uncle Bill had a headache like this just before he died of liver cancer."* If you were to type in that search term "liver cancer" using the Word "Edit – Find" search for "liver cancer" you might find it contextualised as in my sentence above. Further, much in the

medical form of words that will use "not" and "negatives" or "excluded" that what's called "Disambiguation" is extraordinarily difficult. You also have the problem that multiple synonyms can be used for the same term. There are numerous ways we can describe a heart attack (acute coronary syndrome, myocardial infarction, MI, etc. etc., etc.). So coded data for the meanwhile is probably going to be the primary way that we will look at what is happening to patients and perhaps where we need to focus.

Using a computer in a consultation I don't think is that easy and I brought along a video clip of me using the computer.

Unfortunately I chopped this off, I wanted to show clinical coding, recording narrative, doing a prescription with a character user interface, an old fashioned interface, to show you how quick it was and doing some data into a data entry template. That is why I wanted to find a clip that did that and then I sort of cut it off wrong. Anyways, should we just go for it? I will just show you, it is not too long but I will at least show you. I was shocked when I saw this by how much the computer interferes.

video clip shown

I hope it gives you a flavour for those of you who don't use a computer all the time, that the computer really interferes quite a lot and it's actually quite a difficult thing to incorporate into the consultation. The system I was using there, EMIS LV is probably the most common used in the UK and we will return to its features and the features of different systems later in the presentation. So I have shown you sort of how quite awkward it is to use during the consultation and the other thing we need to recognize when we come to analyze our data is that coding is not a neutral action. I am

sure for those of you clinicians in the left hand column, in the blue column, I have suggested why there may be a reason for difference between what's the recorded diagnosis and what I have arrogantly said might be the true diagnosis. If I can run through the rows there and I have quite often seen a patient come in with a headache and you can see they are uncomfortable about the idea that it might have a psychological underpinning and you think well it's not going to help them come back to me if I insist on giving it a label that they are not happy with. We have issues like if we put in a problem title it automatically appears in the summary table when the patient comes in or if it's opened. If someone has had a termination of pregnancy which is the true diagnosis, many physicians will not record that as a problem title because they don't want it to appear within the summary line.

The next row is beliefs. I find it interesting in my practice that, as a group of similar doctors, we each have a different scale of when we give a diagnosis of asthma. I am not sure if this resonates with other doctors, but I have one colleague (who if I was to exaggerate) will have a patient come in wheezing half a dozen times before he will contemplate it and others who will have patients on Salbutamol steroids before and that may not be recorded in the disease code. I sort of have this image, as we are all linked up in the country, that someone in the department of health in Whitehorse sitting there saying "Gosh isn't the health service working better this year. We have diagnosed 3% more asthma than last year" when actually underneath that is the point of which different doctors may be coding at different levels.

Decision to prescribe, I get a flavour that the decision to prescribe sometimes drives the

problem title. My view as I look at colleagues is that on a Friday afternoon you are more likely to see a label for acute tonsillitis and penicillin prescribed then you were to find on a quiet Tuesday clinic.

The next line about patient complaint and this was a true story from our practice nurse that we had a formal complaint to the practice that how dare the nurse put into the computer record, so now it is in her summary, "marital disharmony". The lady concerned had come to the practice nurse for more than double her allotted appointment time. She let the nurse know how awful he was, how potentially violent he was, how awful it was, and the nurse dared to put this as the title and she complained later that this was a bad credit rating type complaint and that was interesting and part of the phenomenon of coding; not being neutral and not being an objective measure necessarily of what is going on.

Obviously, we have things around target payments that may or may not be distorting our clinical coding. These are all factors that I think, when we get data at the other end, we need to think carefully about, we need to sort of visualize that video of when coding is being done and the other pressures that might affect what is recorded.

My title includes data quality and there are all sorts of arguments about what we mean but I would like you to accept from me the definition that data quality means data fit for purpose. I prefer this definition, not because it was at a workshop that I organized that came up with it but, because you can't get every bit of data right in a record. You have to think "what is the record there to do in terms of patient care and if you are developing a national database and make sure the data is fit for that purpose" so the

RCG research unit has gone down the route of viral surveillance and has made, in my view, it's network as fit as it can be for that purpose.

Historic data is all focused on evermore mathematical concepts which I don't think are that helpful. Mike Pringle started off with completeness and accuracy, John Williams added currency which affects some things like smoking habit, and how current recording is important. Krish Thiru and Frank Sullivan added ideas that you have to calculate positive predictive value in sensitivity and then Philip Brown added this idea about this data quality probe and doing data quality in two dimensions. For example: How many Salbutamol scripts – prescribed for people without asthma? How many people with asthma are not on a beta blocker? Because, it is not feasible to apply these types of definition to all data, I think the focus for data quality should be about what we are trying to achieve in terms of clinical objectives.

My introduction summary: UK practice has been computerized since 1990; there have been quite a lot of drivers that I am going to return to that in my results section. In this presentation I am going to describe why and how data quality, in my view, has changed in response to these initiatives.

I hope this won't confuse but I am going to mention by way of background two previous models I created. The first model was what emerged from my doctoral thesis where I spent a long time reviewing the literature and what were the things that had to be tilted in favour of clinical coding. I really thought at the end of me finishing this thesis I really had come up with something useful. What I subsequently discovered as financially incentivized initiatives arrive, that in fact

money, (I have changed this from pounds to dollars for this audience) actually trumps everything and actually I maybe should have taken that into account. I also wrote a paper with Chris vanWeel about looking at the opportunities and challenges that need to be tackled but I found in retrospect, this model was very descriptive but not predictive so I thought I'd think again before I came here today. So what set me thinking were really two things:

(1) We want to try to evaluate in some way what has happened in the UK that may be relevant to this network and perhaps more widely.

(2) And second, someone called Holzemer created a variation on the Donnabedian model by stressing that in addition to looking at structures, process, and outcomes look at provider settings, (the client as it was described in the original work) - but perhaps for us more the patient.

The other book which I have really enjoyed, which I don't know if people are familiar with is Realistic Evaluation; I thought it was a tremendous book. This book stressed the idea that when you come to evaluation, the reductionist approach is sometimes quite difficult. And, what you should be looking at is how mechanisms applied in a particular context achieve an outcome. The plus sign between mechanism and context isn't simple addition but implies that you have got to come up with some plausible link between why a mechanism, applied in a particular context, produced this outcome. Also in the book is what they call the "*realist's mantra*", that you have got to think about what works for whom in what context. I thought this was actually quite a useful approach because then you can look at what hasn't worked within the UK context and maybe try and apply it to your own. So what I will present

as my results is a number of tables that look a bit like this.

We will look at structures, inputs, mechanisms, how they interact with the clinical process and what I think their outcome has been in terms of improving data quality. We will then look at them in turn at the health service level, the system vendor level, regional locality level, and practice level. I hope that you will enjoy my opinionated but hopefully well thought out views.

So what did I conclude? Well I have said this already but, funding seems to trump all other data quality initiatives and one of the things you can say about primary care in the UK is we, as independent profit sharing partnerships, we don't often get to grips with anything that doesn't have a pound sign attached to it. I don't think it is because we are dreadful people but because all of us have too much to do in the day and if you attach the pound sign to one of the things it floats to the top. All of these things I describe here, when they have been implemented in primary care, primary care has exceeded targets expected or set for them. In the middle of the list or fourth down is "token incentives to link data" because one of the other things that may be more relevant to a network like this is that a number of the research networks have offered practices really quite small, but token incentives, a sort of almost Green Shield stamp model (if that sort of retro thought is one I can share with you?) I looked at in some detail at token incentives used to raise data quality in the Mediplus database, now the IMS database. To use their data they clearly needed to see linkage between diagnosis and prescription and they really didn't want to get into big payments and they had a literally like Green Shield

stamps type of arrangement where the better linked the data was the more points you got towards practice equipment. So it was a bit like one of these nebulous discount cards that you might use in a retailer and the amounts were really quite small, but those were effective. So it does appear that tokenism is important and just like prizes with completing questionnaires add to response rates it may be something to add into our armamentarium.

I am just going to pick at some more serious inputs that have happened in the UK and I'll then show you what they look like in real life. One of the things the national program has done is all of us in the UK "exist" as individuals on our clinical computer systems, we must authenticate as users when we log on. So I have a smart card I have to use. I then have to use a password and it is a right palaver. I could have brought a video of it but it's clumsy and really they should have gone and found something used in a bar. You know you see people in bars running up and down with something they touched on the till or radio frequency and then you pay for your drink. The problem for this is, in my practice, we don't see everyone in our same room. I might be doing my surgery, come down to sign some prescriptions, there is a problem with one, I want to go on a downstairs computer to complete it and the inevitability is our support staff and ourselves borrow other people's identities to issue scripts and do clinical work. So that's why, if you look at the code on the right in the implication column that's two minuses it's got there.

Next one down in line is the "national death demographic service" and this to me is one of the great unsung enormous successes of the NHS. It includes having a new NHS number and people having identities across

the whole system. It is a pain and I will show you how it pings up in your computer system that you have to correct it and cancel it but it means that we have a much more accurate denominator. Again I feel for your network, unless denominators are solved, for years we talked about "ghost patients" and denominator problems - this really has largely gotten rid of it. There are still some problems with, for example, young black men in various urban/city areas but it is so much better than it was before.

My next line which gets my lowest mark is our online clinic booking. Does "choose and book" mean anything to you? You haven't heard the abuse of choose and book? Choose and book is a great idea like many of the ideas that a patient can choose the clinic and the appointment for the doctor they would like to see. As a technologist I love the way in the middle of your consultation you connect to all these patient administration systems at all sorts of different hospitals but it takes ages. The fundamental flaw is the median age. My practice has an age/sex profile almost identical to the national average. Anyone like to guess what the median age of the patient I consult with? 50... not a bad guess but any other offers? 60? We went from 50 to 60, any other offers? Anyone go over 60? You're not far off actually it's 68. Because it's not surprising, as you know, there is a bulk of consulting of young families and then older people and because I have been in my practice the longest it is slightly biased. I tend to see older people than my colleagues. You get someone of 75 sitting there and you say "which appointment would you like" and they say "well, on Tuesday afternoons I think my daughter or my niece usually takes me shopping and they could take me... is there one a Tuesday afternoon?" You can imagine a sort of organized carrying

youngster in a policy unit saying "this is what we need to make outpatients bookings faster and better" and they would have pulled out their organizer and picked one. But for our patients over 70 where there are family and others to involve in the discourse around appointment booking – the situation is complex. That is why it gets three minuses in my rating scale over at the end there.

The next one which is very successful and if you haven't got it then argue for it - is lab test results online. There is a complaint from colleagues that it is a less social process – we all used to sit around at coffee time to share our results. Instead of having an information source to look things up we could talk to each other and say "John, what would you do about this blood sugar" so it is a less social process but you do have rapid access to records that we didn't have. I think it has really improved our capacity for work. I am just going to briefly show you what they look like and these are going to ping out at you and we are going to go along the top row and then the bottom row. Top left is me authenticating myself as an individual which I have to do with my smart card and in the clinical system. The next one is how this patient, and this is quite an old slide, but if you look at the top right hand corner you see age two weeks and this is why it is not known to the demographic service. You can still treat them and their NHS number will catch up with them and they are certainly being issued a lot earlier now. Down the bottom is the laboratory results and you run through pages like this to file them and down the bottom is this sort of *bête noir* of much of UK primary care choose and book, which you open, it doesn't have a coding system so its categories aren't classifiable even if you get data out of it. You get screens like this with individual appointments to pick. It is a very nice and

clever idea but it just doesn't fit into the work flow. Here is something structural done, its problem is it doesn't fit into our process so its outcome in terms of useable data has a lot of minuses; because everyone relies on workarounds. So there are some examples.

The UK and the United States of America are supporting the introduction of SNOWMED CT. They are going for an ever larger clinical coding system on the rationale that you can code anything that is in the GP or clinician's mind - but the problem is you actually have to find the code you are looking for, and this is a difficulty. The other problem is actually getting data out the other end. I have only experienced extracting data from what is called, CTv3 - Read Clinical Terms version 3. It has multiple hierarchies and whereas the old family tree type structure coding system (Read 2) was in some ways is a bit clunky and we know that, you know, pulmonary TB belongs in the A chapter as an infection and not in the H chapter as a respiratory disease – I know I have a vast, probably sad, but detailed knowledge of these coding quirks. Those sort of problems are supposed to be overcome by having multiple parents to different children. The problem is, if you search on one of those multiple parents – if I wanted to do a catch all for diabetes codes I could search under C10 and take the last 15 and I will by and large get a good diagnostic code within that. The range of codes that are linked to high order codes in these polyhierarchical systems in these means that you can only do low level specific searching which means we have to use many hundreds of queries when a small number would do. You get very high marks from me if you are using ICPC but ICPC will not do, and I hope you are all involved in ICPC 3 and have your

chair at the table for the development of ICPC 3. If you haven't then I strongly recommend it, but it won't have the granularity depending on where you want to go with your network for other things. ICPC is good for chest infection sort of idea but if you want to research types of pneumonia (e.g. Is it *Klebsiella pneumonia*, *Mycoplasma*, etc). In this context you need ICD for the more specific codes and you need some sort of procedure look up which people either get round by using one of the clinical modifications for ICD – ICDCM. There is an Australian clinical modification which incorporates the procedure codes like the operations that aren't normally in ICD, or you go through a procedure code book like the OPCS procedure code book. So I apologize if I have numbed you all with this information about coding systems, but I think it is dead important for your network. You get one plus if you are going for ICPC but getting a good version of ICD to go with it - and thinking about procedures coding system would strengthen things further.

The next line is a really controversial one; do you want to go for the same data for billing and care? That is perhaps a whole area to flag up for the panel discussion and it needs thinking through because if you're billing is based on the data used for routine care it has a distorting effect does that matter compare with double entry efforts – I think it is something to discuss.

The next scheme in the UK is the *Summary Care Record* and *My Health Space*. It is a bit like “*Choose and Book*,” these should have been marvellous ideas. The idea of the *Summary Care Record* (Is anyone familiar with the summary record? No?) The summary care record is the idea that there is a brief summary created predominately from the GP record that can be accessible by any

clinicians. For example, if I have diabetes and I had a heart attack two years ago and I went somewhere else in the UK and I had a further heart attack or collapsed unconscious, someone could straight away look up my summary care record, know these things about me and know that I was, say, allergic to penicillin. The problem has come with that and with *My Health Space* (the idea of *My Health Space* is that every patient who wanted it, could have a website that would let them look at their summary care record) and these are fundamentally good ideas the problem has been the method of implementation which perhaps we can pick up on later, but they have really been executed in a way that has poor organizational fit. They have become so limited in scope without the ability to drill down below, that clinicians have found them impossible to use and they have not been integrated with the actual system they use at the front end so I am afraid that gets a big minus score and I would avoid that one for the moment until those things are solved.

The next line down is “*GP2GP*”, that is electronic transmission of records. When we went into this the major shock is that all this narrative appears in the clinical record as soon as you read it you think “who on earth wrote that” because you get so used to how your colleagues in the practice write things and the euphemisms they use and then I have paged up a few times and then I looked at the name and realized that it was GP2GP transfer. So there are problems with integration but by and large it is really a very good system and will greatly improve the quality of care, which is very good. We have a lot of NHS national guidance; we have a legal obligation of clinical governance that patients must be treated according to guidelines and in the areas where the evidence is strong, clinicians who I work

with are very interested in audit based education, seeing how their clinical practice performs compared with best practice.

My last line on here is "online performance data" and this was quite controversial when it was produced but I am not sure it has changed anything and I would just quickly, on the next slide, show you mine because every practice has data taken up into the NHS information centre and if you go to that website and you look up a name like mine (which is very easy to look up) you find my one practice in Guildford which has got the address about two thirds down the screen. You can see from my picture how close it is to the road, if you look at the map middle right which is why I have the traffic noise when you are hearing me consulting and it shows me how many points I am just above the map when comparing me to the national and PCT average. It was all thought to be very exciting that this has happened but I am not aware that this has changed anything. It is publically available and I have no problem with that but I am not sure that it has changed any of our practice.

I want to move on if I may to vendor level issues. I am going to show you some pictures of how vendors produce very different systems which have various effects on the consultation and how things are coded. I am going to show you how the picking list for the same search term (I am going to show how myocardial infarction are different). I am going to show you how some of the character user systems (my system is "Character user interface" or CHUI) may be more efficient in some areas and less efficient in others, how data entry forms vary and search functions vary. One of the things for a network is to think very carefully about if you want to work with one or more vendor (I put in my bottom line the

advantage of working with a single vendor) because this, I think, is a big issue for how a network like this develops. There are some very famous networks I have listed GPRD, Qresearch, THIN. There have been others but they are all one brand of computer system related to overcome some of the problems that I will flash by you on the next couple of slides. So these are the four major systems used in the UK. You can see that they are completely different. Top left is EMIS LV the commonest still used in the UK (the one we use in my practice), top right is EMIS PCS, completely different look and feel. The bottom row – the end practice systems and I-Soft synergy on the other side. You can imagine when you come to consult with these that they must have differences. Not only do they have differences in interface but for example, EMIS PCS although the same manufacturer uses a different drug dictionary with a different coding hierarchy so it is very difficult to compare like with like when you search off drugs. So this creates problems. This is just some data from some of the work we did with the Alpha toolkit to show the different impacts, what you have got in each graph is on the left one you have EMIS LV taking longer to record a problem than the other three systems to the right of it which are all graphical user interfaces. So someone comes in with a problem you want to code and because it is menu driven, it is slow to record a problem whereas these ones with multiple windows I've shown you, often people can click right on the thing that the person has come back in with so they are faster in that context. When it comes to prescribing, and I don't know if you remember me prescribing amoxicillin, the character user interface is consistently faster (or as fast) as the graphical user interface and this is because the common things we can prescribe. For example, when I

prescribe Amoxil – a common antibiotic - I type M for medication, type: “A-M-O-X,” Return, F4, Return, Return P, return, put my hand out and there is the prescription printed. Whereas you get to the mouse driven systems and it is much much more difficult and so these choices will affect what comes out of your network. This is myocardial infarction, this is the Tri-set browser from the NHS this is the (sorry perhaps I should go back), you can see myocardial infarction and the terms that come out. If I come down one you can see you get a different picking list, if you come down again you get a different picking list in the iSoft Synergy system and that is just to graph across different systems how the same search term myocardial infarction produces complete different sets of codes.

Data entry forms don't want to be left out. They are completely different between the different systems and how they calculate risk. One of them, the vision system, constantly calculates risk and they all do it slightly differently and these are all things to take into account before taking assumptions about routinely collected data.

At the locality level, there is the opportunity to think about specialist data that your network may become famous for and people who have particularly got involved in programs for collecting ethnicity data have managed to do high quality research because they have managed to get complete ethnicity data on diabetes and likewise for specialist cross-sectional data. Again I go back to this message that you cannot get amazing data quality for everything, you need to focus on what are the bits of clinical care and what do you want this network to be internationally famous for, and then you need to focus and really go for those certain areas.

It is very difficult to predict what will happen at the practice level but I am pretty sure it will all be positive but the transition is quite remarkable. My practice, when I counted them in the weeks before we computerized, we had members of staff who were very happy doing a job where they took 440 notes a day from the drawers, put them in boxes and put them on doctor's desks and then came and re-filed them. Many of them had never used a computer. We have effectively pushed computerization over about 3–5 years and changed our workforce. We didn't set out to be horrible, it just happened because people are happy doing one job and now we have a different job for them to do but all sorts of things happened within our practice that couldn't have happened before computerization.

Of the things to pick out, prescribing is the one item that saves us time in the clinical consultation. Most prescribing alerts over alert and cause discomfort. We now have this ghastly system that if you prescribe Methotrexate a big red no entry sign or exclamation mark goes "mmmmmmmbonk" up into the middle of the screen and one patient who I was trying to persuade to take this for rheumatoid arthritis says "oh doctor, if it is that dangerous I am not" and people often don't think about the consequential impact of things that they put in. You know they design them remote from the clinical interface and they just, I would say, are out to lunch on what it's like for us who work with it in our day to day jobs.

You never see so much paper as in a “Paperless” practice? That is our computer with the note to stop the nurses using the printer directly attached to the server. We still have written records, any guesses for what those big white sticking out things are?

Until GP2GP when patients moved practice – records were transferred using a large printout. Unfortunately hospital letters and some results are not transferred electronically, we have to scan in all our post. Although electronic documents are created in the hospital they have to come in and be scanned. We've put our post-in trays, we mark it for coding, we have marvellous people who do our clinical coding that's done off letters and reports. So we've still got a ways to go.

This is my sort of results summary score sheet and down the left hand column is what I, from my review rate highly right down to what I give 3 minus signs. Full demographic details and a good denominator is really important and lab tests on-line I put as essential. I think thinking about my vendor locality lots of plusses box is all about high quality data in the areas where you want to be a specialist network for investigation practice level as much as prescribing data as possible is important. If you can get to on the next line down, electronic transfer between general practice would be a great thing. Administrative data, I think, has all sorts of potential. One of the big advantages you have using ICPC is you have reason for encounter data which as far as I know I don't know of another English speaking network that uses ICPC and has reason for encounter data. Because in the UK systems the way appointments are done was never part of a standard system records of appointments and number of encounters around difference of illness is a complete gap in the literature. Because these problems are more put in that tedious bit about my authentication card moving systems, because that is such a pain, people, you know, we may not have what we have got ascribed to the right person so there could be a big opportunity in that area.

My next line down is about national clinical standard; ICPC - I have talked about already. I think the thoughts about whether you try to work with multiple vendors or a single vendor is an interesting question and one that deserves a debate. I think that we have only found that in particular niches computerized decision support is effective. If I was to go back 10-15 years, nearly all the informatics conferences you went to were full of professors saying "give me a domain ontology and a decision making process and I will design you a computerized decision support system that will make life better." I think they didn't take into account the complexity of primary medical care. That approach was tried in the UK with a system called "Prodigy." It is to prescribe support and there were two problems with it 1) it came at prescribing when it was too late down the decision tree, the problem was you could never find patients who precisely matched the cognitive schemata they created. So they created a brilliant one around atrofibrillation which has now become an evidence learning tool. It was marvellous but I always have patient atrofibrillation that have three other things or a drug or they wanted to talk about something else, not their atrofibrillation. So getting CDSS to fit into a GP consultation is extraordinarily difficult except in some niches like a Warfarin dosage for example. Information retrieval I think is much more effective and all of us will information retrieve from a drug dictionary.

Moving on a little more quickly, we have talked about many of these issues. I think I have told you already the things I think whose implementation has been the problem. So that the ideas behind the things I have given the 2 and 3 minuses from – there is nothing wrong with the ideas they were just developed remote from the context

in which they had to be used and maybe you think they will be able to work in yours. I think you have got the potential to be a world leading research network and I think the way to do it actually is to reflect and compare the potential of research from your network comparable to other databases. ICPC should give data about encounter and that is something that I think is very much under recorded and you've got billing data about attendances which people tell me is very good. So there might be a whole raft of things about how around particular problems the number of times people present this network could deliver that simply can't be delivered from the networks we have in the UK.

My third line about this is considering surveillance or even trials around implementation in IT and other trials because you have got the potential here to be as ambitious as you would like to be. I think having decided where you want to go is about judicious investment in things that will be effective and are valuable in your own clinical context and I am not going to be arrogant enough to suggest what those might be but I would take the Royal College of GP's Burn Research Unit as an example about how relatively low investment and the right partnerships (they partner with the Public Health Laboratory Service) I think has produced a first rate little network.

I have said this many times but don't try to assume there is some way you can make all the data good – you just can't. Data linkage is really important and presuming cause of death in Canada is equally not secret. I mean it is one of the things we're allowed and we have no problem it is an important end point for many studies. Other data is really important including surrogate markers you can link to other data. For example, you can

do your zip code link to deprivation indexes – that sort of thing. As you work and develop the network, it is really important to have a strong relationship with vendors. As I look down the list here, and maybe apologies if you're here and if I missed you but I didn't see the vendors as part of this group and a strong relationship with the vendors, I think, is really, really important. Particularly when one needs to link with codes like ICD and have your work be able to be easily internationally linked.

My conclusions and you can please feel free to attack my method but anyway... I feel you've got to drive this thing by what outcomes you want from the use of the records. My fixed requirements are an illusory concept which refers to what my summary care record (E-Health) space and choose and book have all gotten wrong. They are good ideas but they have been developed by means of what is called "waterfall principles" where you define user requirement and people go do a waterfall of steps remote from the user compared with agile development which is where you constantly work iteratively with users. So when I was building my own computer system and when many of the systems that were built in the UK which were clinician level built, they were built often with GP directors within those organizations so there was an enforced agile method of working.

In terms of quality, I am sorry in advance, I didn't really find anything but I am always bang on about denominators because if you don't have a good denominator you are, in my view, stuffed so you need to really work on that if it not sorted already. Focus on areas which raise quality in the network which is to establish excellence and have a strategy for improved linkage.

The last line I have said and I will say a thank you very much for listening. My final point is for you guys you don't have a monopoly on snow and this is my kids. The picture on the right is looking out of my bedroom window towards Guildford cathedral from the back of the house. The one in the middle is the kids riding on their aged toboggan which is nearly 50 years old! And, that is us on the downs – on a hill called “The mount” where the downs reach Guildford. It is less than 300 feet above sea level so it looks high up but it's not that high.

The end! Thank you very much for listening.

“Using Data from Electronic Medical Records: Theory versus Practice”

Dr. Karen Tu
Toronto, Ontario, Canada

Thank you Moira for organizing this day and for inviting me here to talk to you today. I have a confession to make, when you first called me and asked me to talk at this conference my first instinct was to say no, I'm not ready yet. Even though I've been working in this area for two and half years, I have yet to fully complete a project that is ready for publication. But in talking to you and on further thought, I thought well there are a lot of things I have learned in the last two and half years, trying to use this EMR data. So that is what I'm going to talk to you about today, about the lessons I have learned using EMR data.

So when I first started out my intention was to measure quality indicators in primary care cardiovascular disease prevention. And this was a project out of the Canadian Cardiovascular Outcomes Research Team, (CCORT team grant). It is a five year grant, and I thought oh yes this will be really easy. I was quite naive, I thought we'll get electronic record data, and we won't need to do chart abstraction; we'll get the results and we'll be done in one or two years and we can move onto other things. Well, we are now into year three and we are not quite done yet, hopefully we'll be finished by year five so we will have accomplished our goals but it has taken a lot longer than I would have expected.

So we started with a pilot project, 18 family physicians on Practice Solutions electronic medical record, and of those 18 physicians, we had approximately 19,000 active adult patients. We took a 5% random sample and

did a chart abstraction on this 5% sample to look at identifying patients with particular disease conditions. The reason why you need to do this is when you are measuring quality indicators you first need to identify your cohort.

So theoretically, EMR data should be good for research: there is a uniformity of the chart layout, which is true, but with different EMR software, the layout is different and also there is great variability and inconsistency amongst physicians in the way they populate the EMR so even within Practice Solutions' EMR some physicians code a particular disease condition under the problem list, some put it in the history of past health, and then some don't code or enter it at all.

With EMR data you don't need to deal with hand writing, and that's true but you also have to deal with typographical errors and acronyms and to a reader figuring out if they have made a typo is not a big deal but if you are using an automated electronic search tool and they've made a typographical error i.e. one letter difference, you're not going to find that particular word if the computer is looking for it. And then all physicians use different acronyms and this is just an example of an acronym. A reader can probably figure out that M d MI67; F d 60s MI, NIDDM means Mother died of myocardial infarction at age 67, Father died at aged 60 of an MI and the patient has diabetes but to a computer program to be able to figure out what this means takes a little bit of work.

With the EMR data you can electronically extract it and then you can transfer it over electronically which should be very efficient. We did this and we built an extraction program for Practice Solutions

but it is not as straight forward as you think as there are many different versions of Practice Solutions and these EMR programs are constantly updating their versions, maybe once or twice a year, and physicians don't necessarily upgrade their version of software just because the company has done it. We had an extraction program that worked for version 4.5 but then when we went into a practice and the practice was using version 4.2, our extraction program didn't work so those are issues you need to keep in mind. The other thing is security. When we transfer this data electronically we have to keep it secure. This is highly important, its individualized data that needs to be protected, so you have to encrypt it and then where we keep it also has to go through a process that is not connected to the outside world. We had to hire a computer security company to come in and try to hack the system and this just doesn't happen once they have to do it on an ongoing basis so there is significant cost to that.

With the EMR data, you can look at the entire practice, and that is true. I did a chart abstraction study where I went into primary care physician offices and took a random sample of patient charts and about in 2 days the abstractors were through about 30 charts whereas electronically you can take the whole practice and that's a good benefit. But patients die or move, and physicians die or move and that's something we need to keep in mind. We went and got data a year ago and went back the next year and pulled out data and we found a lot of our patients are missing and we thought "oh no our program isn't working properly" but on looking we found that patients moved or died. Then there was another instance where we went back to a practice and a physician had moved so that group of patients did not come over with the extraction. These are

things to keep in mind and account for because it does have implications for following-up a cohort of patients. Once they leave the practice you don't have their information anymore.

With the EMR data, you can do uniform central data collection and that has been a benefit with us. When I pulled in the data we had abstractors come to ICES where I do my research and they were able to abstract right in house at ICES and if they had a problem or question or they had a comment they could give me a call, they could ask me and we could clarify things and we could always go back and check if we weren't sure and make sure they were doing it correctly whereas doing abstracting in the field you rely on the abstractor's own judgment and there is no opportunity to go back and look or change anything.

With EMR data there should be time and cost efficiencies and I think we haven't quite realized that yet, there is a lot of upfront cost and technical expertise cost that we didn't originally anticipate. But I hope as we go forward, as we develop our extraction mechanisms and analysis mechanisms and as we increase the number of patients that come into ICES that we will realize this benefit.

Another issue that you have to deal with relating to EMR data is the anonymization of the data. Thankfully I work at ICES which has the privacy legislation as a prescribed entity so we are allowed to take this individualized patient health data under privacy legislation but we do have to anonymize it before we link it with the health administration databases that we have at ICES.

I breakdown the EMR data into that which is structured fixed entry format and that includes things like identifying information: the name, address, phone number and those are distinct variables, which is fine, we don't need to take those particular variables. We take the postal code and the health card number and the date of birth and we separate it out from the rest of the data and it is kept safe so you can't necessarily link it and identify the patient. We also take the health card number and we scramble it and then it can be linked to the administration data which is the physician billing data and the hospitalization data that we have at ICES. The numeric data - lab tests, and blood pressures, that's easy to analyze it's just numbers, there's no names in there, also prescriptions even though it is text words there's a finite list of prescriptions that we're looking at.

But the other data is the unstructured free text format which is a little more complicated to deal with in terms of anonymization and de-identification. I break that up into "unlikely to contain identifying information" so things like the Cumulative Patient Profile (CPP) and the progress notes which are generated each time the patient comes in to see the physician. And then there's the other data that is "likely to contain identifying information" and that's a little bit harder to deal with. These are paper documents that come into the office and they have to get scanned into the EMR. There are two ways to have documents scanned into the EMR: one as a PDF document which is like a picture and this is great for the clinician, they can read the whole document it's not a problem but it's not searchable and you can't edit or change anything from it. The other way is through an OCR process which stands for Optical Character Recognition

and what that does is it changes the text into a searchable format and also you can edit it so you can go in and change the name, or the hospital or location of the patient.

Thankfully in the EMR that I've been using they tend to encourage physicians to OCR their paper documents but OCR isn't a perfect process either it can introduce errors. For example when we were looking for patients with a myocardial infarction or an MI, it got changed in the OCR process to MI) bracket so when we were looking for that MI, it was pulling up these MI) bracket as denoting MI.

Currently I'm working on a validation of de-identification software for free text. There are commercially available products in Canada that can de-identify structured data but there wasn't anything for free text. We have taken an open source American free-text de-identification program and we are modifying it for a Canadian Ontario context specifically, now we are just testing that it is working appropriately.

We are also looking at analyzing the best way of identifying specific disease conditions within the EMR. I'm going to flip slides, this is a snapshot of the 1000 or so patients we abstracted on. The dark blue lines are indicating when we found the particular disease conditions in the progress notes or the consultation letters or diagnostic tests. And the light blue line is where it was coded in the cumulative patient profile or the CPP. As you can see diabetes wasn't too bad, it was 80% in the CPP, but it goes down from there, MI was only captured 70% of the time. Stroke, hypertension, heart failure was captured much less of the time, so it doesn't look like you can really rely on the CPP for identifying a lot of these disease conditions.

Another project we are working on is the developing and testing text mining tools to identify disease conditions. I think this has been discussed earlier but basically you can't just look at the words MI, you have to look at the phrases around it and see if it says "rule out MI, no MI, mother has MI", so it's not that straightforward as just looking for the occurrence of the disease condition.

The last thing we're doing is a validation of administrative data algorithms for various disease conditions. There are some disease conditions that are well recognized that we can pick up from administrative data, namely, diabetes. But with MI we have typically been confined to hospitalization data for identifying people who have had an acute MI. But the problem is not all patients with an MI go to the hospital. Some have their MI out of the country or province, or some have silent MIs and these will not show up in the hospitalization database so I'm hoping that the primary care physician data would be better to pick up that information.

So I think all of this work has had to do with my philosophical approach to EMR data, which has been a retrospective approach. I'm not asking physicians to code, I think this introduces error and more work for the physician and I think that they wouldn't necessarily be willing to participate if they had to do extra steps. I'm asking the physicians to continue on doing what you do and provide us with the data and then it is my job to figure out where things are and how things are entered to identify the patients with particular disease conditions.

Despite all these obstacles I do think that the EMRs do represent a rich resource of previously unavailable data and I'm very excited about the potential for EMR data for

primary care research in Ontario and in Canada. But there are significant infrastructure and technical costs and technical expertise costs that you need to consider if you are wanting to start out, and the other thing is to give yourself lots of time, its likely going to take twice as long as you think.

**“Using EMRs for Research –
The DELPHI Project”**

**Dr. Moira Stewart, Dr. Amanda Terry,
Vijaya Chevendra, & Dr. Amardeep
Thind
London, Ontario, Canada**

Dr. Moira Stewart:

This is an opportunity for the DELPHI team to tell you a little bit about the DELPHI project. We're not going to take a long time but we would like everyone to know what we've been doing in the last year before we start our panel discussion so you know what kinds of questions we might be able to answer and how we may contribute to the discussion.

"Using EMRs for Research: The DELPHI Project." We're based at the Centre for Studies in Family Medicine. I'm going to start the remarks but we have four people who are going to give us short presentations: myself, Amanda Terry, Vijaya Chevendra, and Amardeep Thind. The DELPHI project has a number of co-investigators. You can see that we have a number of investigators at the Centre for Studies location at The University of Western Ontario in London and we also have co-investigators at the Institute for Clinical Evaluative Sciences who you see listed. The DELPHI data are linked at ICES in the private confidential manner that ICES can protect. Here are the partnerships that the DELPHI project has developed. We have connections with funders who you see at the top, and Andrew Oakes is here representing the current funder, the Ministry. You see the participating primary care providers and moving clockwise, you see The Department of Epidemiology and Biostatistics at

Western, our Department of Family Medicine (we're connected through Sonny Cejic's committee "The Records and Quality Care Committee"). In terms of knowledge transfer - we have lots of meetings with the Ministry and our software company Healthscreen.

Here is what DELPHI is, it is 10 practice sites, which means 10 group practices, 25 family physicians, and 25 allied health professionals connected with those family physicians, approximately 31, 000 patients and for a two year period there are 284, 000 encounters. We started in October 2005 and we were implementing the Healthscreen EMR at that time for about half of those 10 practices. The other half were already on Healthscreen and well experienced with it. So there was a period where the physicians were actually simply taking the time to implement. So our data really starts in March 2006 and we are showing you today mostly 2 years of data. These providers were at various proficiency levels. There is the map of Southwestern Ontario with Lake Erie at the bottom and you can see a cluster around London, east in Brantford, north to Kincardine, and west near Windsor, where there are actually 4 practices.

Our task over the past three years has been to create indicators of primary care stressing these topics that you see listed: quality of chronic disease care, comprehensiveness of care, interdisciplinary care, volume, and diagnosis. The talks that follow me will focus on quality of diabetes care and also the referral variable which then became a wait times variable. What I'm going to present is the volume and diagnosis part of our work, and here we used the International Classification of Primary Care (ICPC) which Simon alluded to in his presentation. We think we are one of the first in Canada to use

ICPC-2-R in an EMR system and Healthscreen helped us by incorporating this ICPC classification system into their EMR software. ICPC is an internationally accepted classification system that is specifically suited to a fairly broad level of coding that is a typical kind of classification that family physicians need and Simon has talked about the fact that if you need more specific coding in Ontario we would turn to the OHIP coding which is based on ICD-9.

There are two foci of the ICPC-2-R the reason for encounter and the diagnosis. We are really committed to this part of the project because it provides richer data than the one code per visit which is what the health administrative data, the OHIP data, is based on which gives a pretty skewed vision of what is really happening in these complex visits in family medicine. We have asked our physicians to code more than one problem, as many problems as there are in the encounter. We have room for up to five, but they can code as many as they want and our upper limit has been fifteen problems for one encounter. Let me show you what we have asked our doctors to do. On the left you see the reason for encounter; this is the patient's perspective of why they came in to see their family physician today; they could be a variety of different kinds of issues. It could be a symptom: *"I'm coming in for my cough, or I'm coming in because I'm vomiting."* It could be the patient saying *"Well I'm coming for my flu shot or vaccination, I'm coming for my medication renewal"*, so that's a coding in ICPC called an intervention or process coding. Or the patient could know their diagnosis and say *"I'm coming in for my diabetes follow-up"* or *"I'm coming for my second visit because the Doctor told me last time I have pneumonia."* So the patient could say a diagnosis when they say their reason for encounter. In our

system, the staff, the family physician, or the nurse, or someone in the office is coding the reason for encounter based on what the patient told them, but it is the professional's view of what the patient told them. Then at the end of the visit, the diagnosis is the family physician providing this particular picture, but again it could still be a symptom, (the cough could still be a cough at the end of the visit). It could be a number of interventions and it could be a diagnosis but it is at the level of the physician's mindset or assessment at the end of the visit.

I'm going to present you some results but it is really important that I tell you something before I present them. Our family physicians received incentives to do this extra classification work. We randomly selected patients and they became blue patients, and as the family physicians in the audience know, the blue patients were the ones they were to code. They were randomly selected in increasing number over the period of the first 6-8 months or the first year. And the family physicians didn't feel the incentives were enough to do more than about 30% of their practice. Now that's lots of their visits. Remember, many of these family physicians are doing ICPC coding for 50% of their visits but that is actually between 15 and 30 % of their patients. So I need you to understand that this is a random sample, we have not succeeded having all the family physicians coding all of their patients all of the time doing ICPC coding. So that is an important message.

So here are some of our results. I want to tell you first about the reasons for encounter; the RFE is the patient's vision of why they are at the office. This is what Simon told us is actually quite rare in the international literature so this is a real contribution the DELPHI database is making. So you notice

that the top ten conditions are listed here, the RFE code is on the left, and the first one is medication and it is A which means it is general; so it is not a specific chapter or type of condition. The next on the list is the patient saying they are in for a health exam or health evaluation. Next is hypertension and you see down the list the first symptom that is actually mentioned is cough, and then back symptom. Depressive disorder is considered a diagnosis within ICPC. There are a couple of other things I want to tell you not shown on this list, and that is that on average, there were 1.6 reasons for encounter per visit. So the coding classification was being done more than once per visit.

I'm interested in symptoms, so the next slide shows just the symptom RFEs. So cough and back symptom are in the top ten symptoms. Before I leave this slide, I want to point out that the percentages on the right hand side are over the denominator of the encounter, so this is a workload reflection. This is your family physician workload in every encounter this is the percentage of those kinds of problems. Not shown in this slide these symptoms resulted in episodes that contained multiple visits only 30% of the time. So mostly, these symptoms are of one-visit duration. The second thing I want to say is of the top 4 or 5 of these symptoms, 50% of the time the symptom occurred alone; it was a visit just for the cough. However, with the other 50%, the visits had co-occurring symptoms. I'm very interested in looking at co-occurring symptoms and thinking about what they might mean and what they might lead to. The final thing I want to mention (that is not shown but is relevant here) is that compared to international studies this North American group of patients has a lot more musculoskeletal problems. They are very

high on the list and there are a lot of them. So we seem to have some sort of musculoskeletal expression going on in your practices. Also with those symptoms (the musculoskeletal) they tend to co-occur with each other and I think that this is very interesting.

Now I turn to the top ten diagnoses, again as you see on the right hand side, this is a workload kind of measure expressed over the number of encounters. So we see the chronic diseases high on the list, health maintenance/preventive medicine, depression/anxiety much higher on the list than the patient would have expressed. This is what Simon mentioned about stigma and labelling. In addition, we see obesity which is the physician's assessment; the patient never mentioned it at all. Several things not shown here that I want to mention to you are that on average there were 1.7 diagnoses per visit classified by these participating doctors. The top few chronic diseases had co-morbidities present 94% of the time. And that in terms of episodes where these were the beginning issues, more than 90% of those episodes had more than one visit. So these are the large visiting population.

So that is what I wanted to present to you as an update with what we found with regards to the ICPC coding and I'm now going to turn it over to Amanda Terry who is going to talk about the data quality work we've done.

Dr. Amanda Terry:

I'm just going to spend a few minutes speaking to you about data quality as it related to the DELPHI project. This is a bit of a work in progress and in fact there are people in the audience I've spoken with over the years while working on this project. Now I'm talking broadly about data quality

in the DELPHI database and you're going to hear a little bit later about data quality related to the individual analyses but this is sort of the big picture.

It is a good thing this is a work in progress because this is based on the historical, mathematical approach that Dr. de Lusignan was talking about this morning. So we look forward to learning more over the next little while and improving this approach. I think it may be helpful to see how we have done this to date as it relates to DELPHI and in fact it is actually based on work that comes to us from the UK.

So for comparability we're looking at concordance or level of agreement between the database population and other populations. I'm going to give some examples of these things as we go through the presentation so that will be on the next slide. For completeness we're calculating sensitivity values for several test conditions using different elements within the EMR compared to each other. So for example, we're using ICPC codes (as Dr. Stewart presented) against a gold standard definition of this specific test condition. So just to clarify a bit, we're using sensitivity values in the sense of a screening test here. This tells us the proportion of people who have a test condition (according to the gold standard definition) that are identified with an ICPC code. In addition for completeness, we're looking at the level of recording for different clinical measurements within the record. Using this same approach I just described for sensitivity, we're calculating positive predictive values to assess correctness. So this tells us the proportion of patients identified within ICPC who have the test condition. As well, we're looking at any unlikely combinations of age and sex conditions to identify any errors.

So more specifically then, our approach to assessing data quality in the DELPHI database involves comparing the profile of the database with that of the Canadian census population. That's just looking at the age distribution and the proportion of men and women and so on. As well we're comparing the profile of the ICPC patients, this is what Dr. Stewart was presenting data on earlier, and we're comparing those patients with the non-ICPC patients so just seeing what the differences are between those two populations. As well, we're comparing the prevalence of disease within the DELPHI database population with published prevalence figures. So this is really just looking at concordance in the populations. For completeness, we're calculating sensitivity values for the conditions of hypothyroidism, hypertension, asthma, and chronic obstructive pulmonary disease. This is the product of a long conversation. As with many things EMR, everything takes longer and is more challenging than you think it might be in the beginning. So we're also examining the proportion of patients within certain age groups where blood pressure, height and weight are recorded. We're assessing correctness as I mentioned by calculating positive predictive values and this is for the same conditions I just mentioned. In addition we're looking for errors within the record by searching for these age and sex specific conditions, so things like child immunizations in adults and men who have ICPC codes related to women.

Now I'm not presenting any results today but I can tell you just sort of broadly the tests for correctness are quite good. Completeness is a little bit of a different picture. So I hope to share some more information in the future about this but we just wanted to give you a bit of a sense of the program we have in

place for data quality assessment in the DELPHI project. I'm going to turn things over to Vijaya Chevendra to talk about some actual results.

Vijaya Chevendra:

When Dr. Stewart showed you the slide on the top ten diagnoses, probably none of you were surprised that Diabetes Mellitus was on the list. This is a project that I worked on with Dr. Stewart Harris who is not here today. He is not only a co-investigator on the DELPHI research side but he is also a clinician with a large population of diabetes patients. We wanted to see if we could use the EMR to inform improved care on a day to day basis in a clinical setting.

In 2005, Dr. Harris conducted a nationwide study, DICE, that showed that only about 12% of people with diabetes are on insulin so we know that it's under-utilized in primary care practices. We wanted to see if within our database, we could identify patients who were potential candidates for insulin therapy.

Of course the first step is to identify the people with diabetes and that turned out not to be so simple in an EMR. We limited the analysis to the subset of population that had ICPC coding and this was about 3,000 people out of the 30,000 in the database. And within those people's records, I was looking for codes of T89 and T90, which are for diabetes, and found 272 people. Then when we looked at the medications list, we saw the standard medications for some people like Metformin but we also found things like prescriptions for diabetic socks. We included those people as well in our definition for diabetes. When we went to the problem list, certainly some people had "diabetes mellitus" on their problem list but

there were also entries like diabetic retinopathy, DKA, etc., and we included those 265 people. When we looked at the lab area of the EMR for people that had two or more A1C tests done, we thought those people were probably diabetic. As you can see, there is an overlap but it is certainly not 100% so this provides further work for Dr. Terry's correctness and completeness concepts that she discussed earlier.

So what's the population that we ought to use for our study? Well, the answer depends on the study and the definition has to be redone each time one does a different kind of analysis. We're working with ICES right now on a case ascertainment project to come up with an algorithm that will hopefully simplify this health condition definition step in the future.

For the purposes of this current question of 'who is eligible for insulin therapy', we did not use any of these definitions I described. We used yet another one: we looked for people with a billing code for diabetes. We did this to define our population similar to the DICE study, to address the comparability concepts that Dr. Terry described. This pie chart from the DICE nationwide study of about 2,000 people with diabetes shows that half of them do not have A1C control. And when we used a similar definition to identify our patients we found very similar results, a little more than half the people have A1C values not at target.

Now we're going back to our initial question of who are the diabetic patients who could potentially benefit from insulin therapy. First, we went back to the DELPHI database and identified all the people currently taking two or more oral hypoglycaemics and we found 877 such people. Then, we identified the people that were already on insulin so

they could be excluded. A third group to be identified were the people who were currently not at A1C target, the people in need of a change in their treatment regimen. We used a high cut off of 8% or greater of A1C and we identified 400 people. And then finally, we wanted the individuals that were on two or more oral hypoglycaemics, but still were not at target for A1C, and who are currently not on insulin. So we ended up with 133 people.

The DELPHI database is an anonymized one so we don't know who these 133 people are, which is not clinically useful. We then went to the primary care physicians that are within our project and showed them how to extract data from their own EMRs to be able to identify their own sub-population. They learned not only to identify this group, but also a range of sub-populations to whom they could target specific interventions.

Now, I'm going to call Dr. Amardeep Thind to tell you about our wait times work.

Dr. Amardeep Thind:

Just to set the stage as to what we are doing in terms of wait times. If you take a look at a patient's journey through the healthcare system you can break down the waits into basically three elements. The first one is the time that the patient spends in getting to the family doctors' office which we label Wait One. Should that patient require a consultation with a specialist, Wait Two denotes the time that that patient is waiting to see that particular specialist. Wait Three is what we would call the Downstream or specialist wait which is - should that patient require a specialized investigation like CT scan or MRI or a procedure, which is what we would call Wait Three. Now a lot of the focus of policy and research on Canada in

on Wait Three or the downstream waits, and what we feel EMRs suggest and what DELPHI is able to help us with is to look at Waits Two which have not been looked at in great detail within the Canadian context.

I'm going to share some preliminary results in trying to mine the data to obtain some results for this Wait Two in our dataset. And the way we were able to do it, was to leverage a unique component of the Healthscreen EMR in which two time stamps were used. Now if a physician makes a referral using the referral screen on his or her Healthscreen EMR at the lower bottom of the screen you will see a time stamp automatically being generated or entered into the EMR for the data and time of referral. Once this referral is sent to the specialist, the specialist agrees to see the patient, he or she sends back the date of that specialist appointment to the family physicians office that is then entered into that appt date box on the top right hand side of the EMR. Just by using these two time stamps, in other words, just doing a subtraction of the specialist date from the date the referral was sent we are able to get an assessment of waiting times for these patients.

Before we ran the numbers we thought it was prudent to do a data quality check to see how good, bad or ugly our numbers were. And if you just think for a minute there are basically three possibilities that we can get at by using a subtraction of this. You can get a positive number in which the specialist date is in the future compared to the date the family physician made the referral; just basically a legitimate referral time. This gives you a distribution of the positive referral rates among practices. We decided to go to the other side of the tracks and if you take a look at the number of time stamps

that were negative which basically meant that there was a data entry error that the specialist visit date was entered as occurring before the family physician referred them this is what you get.

Having done that, cleaned up the data somewhat, the next two slides give you a sense of what the wait times are. This is data for about 16,000 referrals made by the doctors in our practices over a two and a half year period. On the y axis is the median wait time and that is arranged in decreasing order by specialty. So in a sense, this chart gives you a kind of a good news, bad news type of scenario. The bad news is if you are referring a patient to see a gastroenterologist or an orthopaedic specialist in our neck of the woods your patient is going to wait a median of about three months just to get to see that specialist. On the other hand, if you are making a referral for a kid, the paediatric wait times comparatively are pretty decent. The median wait is around about 3 weeks.

Now, as you are aware this sort of presents a very 30,000 foot view, there are many nuances and many ripples under the current. And we delved a little bit more and this next sort of complicated chart gives you a sense of variation in these waits along two axes: by practice and by specialty. So each little chart is basically a specialty in which the waits are arranged by practice. So if you take a look at the chart which says Allergists in the top right hand corner numbers 1 through 10 are the practices. So the variation in waits for allergists in our sample ranges from just shy of about 100 for practices 2 and 3 to practice 5 which from this chart doesn't seem to be making any referrals or has a zero wait time. On the other hand if you look at the chart just below it which is Gastroenterology it gives you a sense of the variation in the Gastro wait

times. They range from a high of nearly 150 days in practices 6 and 9 to about 50 days for practice 7 and 10. That generates further research questions to delve into, into what exactly is going on, what is this variation due to? Is that due to a supply factor in the sense that some practices are blessed with an abundance of specialists who are willing to take their patients? Is that due to the referral pattern of the family physician? Is that due to other linkages? So looking at data in this fashion gives us a sense of what else we need to look at and this is amongst a number of projects under way trying to ascertain or develop a model for wait times which will be helpful for us in the future.

Last but not the least, for those who are interested in more information, please feel absolutely free to contact Louisa whose email is up on the slide. We will be happy to share with you more information and answer questions about things that come up along the way.

Small Group Discussions

There were three small groups in the afternoon discussion session: EMR data for research, for policy, and to improve clinical practice. Participant's comments are summarized below.

Group #1 ~ EMR Data for Research

Q1. List the basic method and reporting requirements for research/papers using EMR data.

A:

- Where did the data come from within the EMR (i.e. structure vs. free text)
- Case ascertainment -subsample validation (i.e. sensitivity and specificity or linkage with another data source)
- Definition of patient population
- Demographics of practices
- Purpose for which data was collected
- Ethics consent of project and which ethics review board assessed it
- Identify physician population who collected data
- Identify what stage of EMR implementation data is from
- Measure(s) of contradictory coding
- Data elements used in study related to billing
- Validation must reflect research question
- Who is missing from data (physicians and patients) (i.e. aboriginal patients often missing from administrative data sets)

- Variability of outcomes between physician and practices
- Describe use of technology and wider context
- Define gold standard of care
- Generalizability of findings based on use of EMR in populations
- Networks of standardized populations – know what you are comparing to
- Publish data cleaning methods
- Units used
- Translation of data from EMR or multiple EMRs

Q2. From your list, vote to prioritize/rank each requirement.

A: A democratic ballot vote was taken with each participant ranking their top three requirements. The top five as a result of the vote were:

1. Case ascertainment or subsample validation
2. Definition of patient population
3. Purpose for which data was collected
4. Where did the data come from (structured vs. free text)
5. Demographics of practices

Group #2 ~ EMR Data to Improve Clinical Practice

In this second group, the questions to be discussed were as follows:

Q1. What specifically do you want to improve in your clinical practice?

Which EMR data do you need before you begin?

Q2. What will you change in your clinical practice?

Which EMR data do you need to determine if you are effective?

A: The group discussed the above questions as well as the Plan, Do, Study, Act (PDSA) cycle of problem evaluation and came up with a list of issues to improve "practice" in its broadest sense. The list went beyond the purely clinical and included:

- Chronic disease management
- Monitoring residents and their assessment of acute illness
- Decision support tools in the patient encounter
- Better preventive care
- EPI/Population health (feedback to team, region, patients, doctors)
- Boost IT computer skills – Novice to expert
- Requirements to vendors
- Patient Compliance
- Patient education/expectations/satisfaction
- Understanding wait times/access of disadvantaged groups
- Improving electronic communication with hospitals, patients, other doctors, etc.

It was noted that not all of the above are available in the EMR. Discussion evolved further and went beyond the current EMR. Highlights from this discussion included:

- Role of a Personal Health Record that the patient controls (implications of Google health record) – Patients having their information and how this may change practice
- Evidence based IT – ie. EMR has to reflect what should be in patient record

- Usability is important. If bells and whistles interfere with work flow it is not worth it.
- How do we redefine what IT and EMRs would really change? Move away from EMR as substitute patient record. Need to look at using new functionality of it.
- Too much emphasis on getting information into the EMR and not enough thought on what the information that might come out of it is.
- More emphasis needed on Health of patients – outcomes, patient access, and patient satisfaction.

Group #3 ~ EMR Data for Policy

In the last group, the participants were asked to discuss the following:

Q1. What can your organization do to improve primary health care data quality?

A: Five key summary words were arrived at: Stakeholders, Connectivity, Flexibility, Resources, and Patient Centeredness.

Stakeholders:

- Understand who is asking what and for what purposes
- Who are your stakeholders? Collecting data for patient? Practitioner? Ministry? Researchers? Quality you want will depend on who is asking

Connectivity:

- To improve data quality, you need to improve connectivity and standardization of the data
- Standardization needs to be not only between systems, hospitals, and practices but also of the people entering the data (trainees, allied health professionals, physicians)

- Need standardized approach for labs, giving the same information to enter

Flexibility:

- Need to allow for changes that happen quickly (technology)
- Software system needs to be nimble and prepared for change
- Terminology has changed – ie. Juvenile and Adult Diabetes, Type I and Type II – How do you get at this and archive your data, pull up terms and understand what everything is saying
- Archiving of data for easy accessibility

Resources

- Need for dedicated time and resources – money, human resources, on the ground trainers
- If investing time to learn the EMR, need to have a reciprocity of information going back to the physician that lets them know it will be worth the time, money and effort (demonstrating utility to providers and people entering the data)

Patient Centeredness

- Improving primary health care data quality has to have patient centeredness rather than software centeredness – go back to what difference is this making to the patient
- Include patient as a stakeholder for software redesign and improving the data quality

Q2. What are the barriers and facilitators to such improvements?

A:

- Practicality / usefulness of information
- Resources / Money
- Time / Patient volume

- Small steps: mindset of 'perfection'
 - Can't move until things are perfect
- Connectivity
- Change management
- Openness / security
 - Do we want to share what we are doing?
- Push / pull of data entry
- Stop regulating EMR
 - Specifying into a corner
 - Need to know what outcome would be
- New development (e.g. Healthvault)
- Can have enough policy
 - Don't want to stifle creativity
- Flexible policy is needed
- Intelligent policy
- Need policy that specifies what we want to achieve
- Divergent expectation
 - Government and providers for EMR use
- Need to direct areas of research in EMR
- Research questions
 - patterns of care
 - impact on clinicians

Closing Remarks ~ Dr. Moira Stewart

It is my great pleasure to thank everybody and compliment everyone for all of the great ideas that have come from the conference. We are thrilled to have had the participation from Quebec, Newfoundland, Halifax, and all parts of Ontario. It is really important to us as we organize future conferences or events on this topic, hopefully in collaboration with all of you again, that you tell us what went well, what you would like to be repeated and what you think went not so well and how we should improve it next time so there is a feedback form to complete. That feedback form can be left at the registration table as you leave if you wish or you can mail it to us.

On your behalf I want to really warmly thank our international guest Dr. Simon de Lusignan who I think was a tremendous, tremendous asset to this day. He contributed to the research group in a really constructive way and with lots of content we didn't know about. We learned a tremendous amount, and your keynote address this morning was a really good kickoff to giving us lots of good ideas. I want to thank Dr. Karen Tu who gave a really impressive talk and many people have been buzzing about your good work, so thank you very much Karen. And thanks to the DELPHI team for sharing our results with the audience. I want to particularly thank the organizing committee. I'll name two in particular, Louisa Bestard Denomme and Sandi Richard, thanks for all your good work. For everyone else, thank you for coming and I wish you a safe journey home.

For more information, please contact:
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Appendix

Electronic Medical Records (EMR) in Primary Care Research: Improving Data Quality Toronto Marriott Downtown Eaton Centre – February 9, 2009

8:30am	Registration & Continental Breakfast <ul style="list-style-type: none"> ▪ Lobby – Trinity Ballroom
9:00am	Welcome – Trinity Ballroom <ul style="list-style-type: none"> ▪ Moira Stewart
9:10am	Improving Data Quality in Primary Care: Challenges of Structure, Process, and Utility <ul style="list-style-type: none"> ▪ Simon de Lusignan
10:10am	Using Data from Electronic Medical Records: Theory versus Practice <ul style="list-style-type: none"> ▪ Karen Tu
10:30am	Nutrition Break <ul style="list-style-type: none"> ▪ Lobby Trinity Ballroom
10:50am	Deliver Primary Healthcare Information (DELPHI) Project in Ontario - Experiences and Results <ul style="list-style-type: none"> ▪ The DELPHI Team
11:15am	Panel Discussion <ul style="list-style-type: none"> ▪ Participants: Simon de Lusignan, Karen Tu, DELPHI Team
12:00pm	Lunch Buffet <ul style="list-style-type: none"> ▪ Trinity Ballroom – Buffet in lobby
1:00pm	Small Group Discussions – Perspectives <ul style="list-style-type: none"> ▪ EMR Data for Research ▪ EMR Data to Improve Clinical Practice ▪ EMR Data for Policy Decisions
2:30pm	Nutrition Break <ul style="list-style-type: none"> ▪ Lobby Trinity Ballroom
2:50pm	Report Back From Discussions <ul style="list-style-type: none"> ▪ Trinity Ballroom
3:30pm	Additional Questions/Comments <ul style="list-style-type: none"> ▪ Trinity Ballroom
3:45pm	Summary of the Day <ul style="list-style-type: none"> ▪ Moira Stewart