TRANSCRIPT

ROAD SAFETY COMMITTEE

Inquiry into serious injury

Melbourne — 10 September 2013

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Adjunct Professor D. Rosman, program manager, data linking branch, Department of Health, Western Australia.

The DEPUTY CHAIR — Thank you for joining us via telephone link.

Adjunct Prof. ROSMAN — That is okay.

The DEPUTY CHAIR — We will go through the motions on a couple of matters just to get things right, and then we will start. Firstly, I welcome you and thank you for your contribution to this important inquiry. As you understand, the evidence you give will be protected by parliamentary privilege, but any comments that you might make outside of the hearing will not be afforded such privilege. The transcript will become a matter of public record. I invite you to start with some introductory comments, and then we will follow with a few questions.

Adjunct Prof. ROSMAN — That is good. I will cover two areas. There is some history, which I hope you will allow me to describe just briefly. The first one I am going to talk about is the data linkage and its use in Western Australia and the history of that. The second is the use of linkage in road safety or road injury research. Is that according to your plan?

The DEPUTY CHAIR — Yes, thank you.

Adjunct Prof. ROSMAN — I guess it is fair to say that Western Australia has been at the forefront of building data linkage infrastructure for quite a while. The group that I have the privilege of being Program Manager for has been in existence since 1995. In 1995 we started making links between hospital records.

I am not sure, but you probably all know that a hospital record is created when somebody is discharged from hospital. It is called a hospital discharge summary. In Western Australia each one of those that is generated in any hospital, private or public, is provided to the central Department of Health collection, which is called the hospital morbidity data collection.

Those data go back to 1970, but in 1995 we started to join them together so that you could tell which discharge belonged to the same person and count the number of people admitted to hospital each year, not just the number of times somebody left a hospital. That is a very important thing for health to be able to do. We have been supported by the Department of Health in doing that for 18 years now.

Those hospital records are joined to each other, and they are joined to death records. That was done very early, and that is up to date; we do them every month. That is an infrastructure, if you like, or an information resource that the department supports.

Since 1995 many other data sources have been joined to those health records, and the health records themselves are much more detailed. They come from other sources as well now. I just wanted to describe that background of quite a mature linkage system that exists in Western Australia. It is well known and has a website that describes it, so I will not go any further with that, but I will answer any questions you may have about it later. The processes that we use are also well described in the literature, but I will also go into that later if you would like me to do so. That is the data linkage system in WA.

Part of my branch also undertakes demonstration analyses or pieces of research to demonstrate the use of linked data. One of the projects that we have been undertaking since 2007 is funded by the Road Trauma Trust Account in Western Australia to use and join linked data about road crashes primarily to provide information back to the Road Safety Council and researchers on outcome measures other than fatalities, so serious injury and different ways of measuring that. Again we have been doing that formally in the Department of Health since 2007, but it is an area that I have worked on in the past at the University of Western Australia.

Those two things we have worked on here for a while, but it has always been with the aim of using it for research. Just recently we have been trying to move towards a more timely collection and use of that information so that it can be used for what is called surveillance, which is much more useful to people in government. That is the status of where we are up to. I was going to stop there and maybe allow for questions, if that is okay.

The DEPUTY CHAIR — Yes, that is fine. Thank you.

Mr TILLEY — You mentioned that Western Australia has quite a mature system now. What are the necessary administrative and procedural requirements for a data linking unit or branch to operate efficiently and effectively?

Adjunct Prof. ROSMAN — What are the key elements?

Mr TILLEY — Yes.

Adjunct Prof. ROSMAN — There are several things. I will describe the people in my team because I think that will demonstrate what you need.

Mr TILLEY — Yes, that would be great.

Adjunct Prof. ROSMAN — We have a team of people who are very well trained and skilled in computing, so they are technical — we have our own computers and our own software and we have our own system developers in house. They are not from the Department of Health and not from the university; they are employed directly with us. That is an important element. From day one we have had our own technical capacity.

We have a system that is tunable. We licensed some software that provides what is called a linkage engine. I will not go too much into how linkage happens, but I can later. There is something called a linkage engine, which takes pieces of information, tries to work out if it is similar to another piece of information and joins them together. That system and that linkage engine are run by a team of linkage officers who have experience in operating the system. So we have the technical team and the linkage team.

Another important element that we set up after about 10 years of operation was a client services team. We started with a technical capacity and then we built the client services support later. The client services team includes someone who manages the help desk, answering client queries, and someone who does the project management side of it, so manages end to end, from an application through to the date of delivery. That is the client services team.

Another important part, though, is what I touched on a little bit with injury severity work. We have some analysts here working with the client services team. The data is complicated when you have many sources, and these analysts are working on particular projects to demonstrate how things can be done.

Does that answer your question? That talks about the people and the skills you need. There is a management team of three of us, but we have 23 people here now in the team. They are not all public servants, but 10 to 11 of them are.

Mr TILLEY — Terrific. That is what I was going to ask next, about the manpower and size of the team.

Adjunct Prof. ROSMAN — We started with one person in 1995, and when I joined as manager in 2000 we had three. So you do not have to start with 23. It is where you get to after 18 years.

Mr TILLEY — Sounds great. I want to draw on your experience or knowledge. You may or may not be aware that in New Zealand they have an integrated database, and that is something which other jurisdictions are also actively exploring. Do you have any views of the approach taken in New Zealand with respect to its accident data, specifically the benefits as well as any limitations of its approach — that is, of course, if you are aware of the New Zealand model?

Adjunct Prof. ROSMAN — I am not aware of the details, but I will answer that in two ways. The first is to describe a model that we use, whether it is for road safety or cancer research or genetic disease or childhood maltreatment, whatever the topic is. We have done 800 pieces of research — we have not done them, but we have supplied information to more than 800 research projects since 1995. So the system has the capacity and the model we use has the ability to provide information that is specifically tailored to the research question. So it is not a linked database at all; it is a database of links. The piece we manage is the index, if you like, to all the information that remains with the data source.

We do not draw in all the crash data, or did not up until recently. I am telling you what it is not so that I can tell you what it is. It is not a repository, which is another word that is used, or an integrated database or a linked resource. It is not those things. It is not just for road safety, it is for many things; I think that is the reason. We

realise that that is not the most efficient way to do really complex work, and we have set up not a linked database but what is called a custodian administered research extract server. It is a parking lot for raw data.

Mr TILLEY — Can I just get you to go over that again slowly?

Adjunct Prof. ROSMAN — It is a parking lot for raw data. Its name is CARES — custodian administered research extract server. That is not a linked database either, but it is a place where data can be held. The people who manage that work with the custodian, who manages the raw data. This data comes from many different sources. We have about 30 MOUs with different agencies. This facility is our answer to the linked database. We do not have the mandate to set up a linked database; the consumers and community representatives that we have on our committees do not want a linked database in Western Australia. We have a different way of doing it.

Mr TILLEY — Thank you for that. I am sure you are about to get some questions about privacy.

Adjunct Prof. ROSMAN — Go for it.

Mr ELSBURY — What, in your view, are the privacy considerations and concerns that arise with linking data? How have these been overcome in WA, and are you aware of how they have done it in other jurisdictions?

Adjunct Prof. ROSMAN — Yes, I am. Can I describe another protocol? In Western Australia we invented something called the separation principle. If you think of a road crash report, for instance, somebody puts in their name and address, their date of birth and then also adds in information about the crash location, the crash time, how it happened and if someone was injured. If you think of all that information as one crash record and then cut it in half, the half that has the name, address and date of birth is separated from the other, which is the crash site and crash details. The part that has the name, address and date of birth is all you need to make a link happen to another record, which is the hospital record that also has the name, address and date of birth. This works better with pictures. I am sorry, I am trying to wave my hands in the air.

Mr ELSBURY — Yes, we can see that!

Adjunct Prof. ROSMAN — The separation principle means you separate the data, the linkage variables and analysis variables, and you separate the people who see the data into the team that does the linkage, sees the linkage variables, and the team that sees the analysis variables only. That is how you protect privacy but still maximise the utility of the information and get research to happen. You will find that process is mimicked or is used in South Australia, New South Wales, Victoria and elsewhere, and at Australian Institute of Health and Welfare these days as well.

Mr ELSBURY — What do you see as the potential benefits of an integrated dataset as compared to a linked dataset?

Adjunct Prof. ROSMAN — Can you tell me what the difference is?

Mr ELSBURY — You have one dataset that is the be-all and end-all, which is the integrated dataset, and a linked dataset, which is multiple datasets put together.

Adjunct Prof. ROSMAN — To me they are the same thing, I am sorry. The term 'integrated' to me means the merged data that has got the linkage keys in it from many different data sources. That is what I call an integrated dataset. I think they are the same thing, so I am not quite sure what the difference would be.

Mr ELSBURY — An integrated dataset is where it is all put into one dataset, so every department puts all their information into one dataset, whereas with the linked, each dataset is separate but has identifiers to allow it to talk to one another. They are able to collect similar data and correspond it with other records. In one place you have a single repository, and in another one you have multiple departments holding their own data and then being able to share that data between them.

Adjunct Prof. ROSMAN — Okay. I would refer to the second of those as linkable; they are not 'linked', past tense. Sorry to be pedantic. 'Linkable' means you have the opportunity, if the permissions are in place, to join it up. I guess if you want to get my private, personal opinion, there are advantages in a linked or integrated repository, whatever the word is, data source because it could be standardised and available. You do not have to

take any steps to join it together, it is just there. But to get to the point of what it would contain will require a lot of negotiation and a lot of approvals and access permissions et cetera.

I think it is fair to say that it is an ideal to have such a linked system available, because that is probably where Western Australia would like to go eventually for road safety. For particular topics you can do that. I would call what you are describing as an integrated data repository another name that we have been starting to use called the data pool. It is a pool of data that is specific to a particular topic. For road safety there might be one, and we would envisage others on other topics. Does that answer your question?

Mr ELSBURY — Yes. Thank you very much for that. Last but not least, evidence in both submissions to this inquiry and in research literature suggest there is a strong basis for the use of the International Classification of Diseases-based Injury Severity Score, ICISS, to define 'serious injury' in Victoria. Do you agree? What is the approach being taken in West Australia?

Adjunct Prof. ROSMAN — That is also not a straightforward answer, I am afraid. We are still working on refining that ICISS. There are some problems, we think, with the way it was originally done in New Zealand. Using linked data you have the opportunity to make sure that a sequence of hospital records — there will be codes in each hospital record. Remember that I said that every time someone is discharged from hospital they generate a record? If they come back into hospital and go out again and come back in, and it is all around the same crash, you need to collate that information.

An analyst is spending a fair bit of time getting that right. Linked death records are then required to calculate the survival risk ratios that go into the ICISS. There are a lot of things that have to be rigorously tested. The ICISS is not something you can generate immediately somebody leaves hospital. It takes time because you need the coded hospital record. The specialty people make that ICD coding out of what the doctor writes on the record; that takes time. Then an analyst needs to apply certain formula to generate the severity scores. Currently there is some work being done in New Zealand on the ICISS — and others have also published on it — and we are working on some refinements to that right now.

Mr ELSBURY — Can you tell us who those people who have published are and where we might be able to find those reports?

Adjunct Prof. ROSMAN — There is some work by the national injury surveillance unit, which is part of the Australian Institute of Health and Welfare. I do not have the references here, but the guy who is working on the topic certainly has copies of them. There is some Australian work and there is some combined Australian and New Zealand work. There is also an International Transport Forum report that recommends the ICISS because it has characteristics that make it robust and easily understood.

Mr ELSBURY — Thank you.

Adjunct Prof. ROSMAN — The second part to that question is that it is not necessarily the best answer to a severity score. There are some medical clinical severity scores which you have probably heard about too that are well known and have been used for a long time — the abbreviated injury scale and the injury ISS. Those are generated in trauma centres and trauma registries. We are looking at those as well and comparing them to the ICISS.

Mr ELSBURY — Thank you very much.

Mr PERERA — Hello, Professor Rosman. Evidence both in submissions to this inquiry and in research literature suggests there is a strong basis for the use of the international classification of disease-based injury severity score, which you mentioned, to define 'serious injury' in Victoria. Obviously you agree with that?

Adjunct Prof. ROSMAN — We are still looking at the different measures to come up with a recommendation for Western Australia. So far it looks to be very consistent, the ICISS, but preliminary work was done a couple of years ago and we are using more recent data to explore it further.

Mr PERERA — If Victoria was to adapt three separate measures to track road crash trauma — that is, the current resource-based measure such as an admission to hospital, a threat-to-life measure such as the ICISS and then an outcomes measure such as a disability-adjusted life year or a quality-adjusted life year — do you think

that would provide government and road safety agencies with the best picture of what is happening on our roads?

Adjunct Prof. ROSMAN — That is a difficult question. I am not an expert in DALYs and QALYs — the disability-adjusted life years. I know they are used. Again we would need to do some work with linked data that has enough follow-up time for these to be measured. It is very difficult at the point that a crash occurs to know what the outcome would be without following the data for some time. Does that answer the question?

Mr PERERA — Yes, thank you. The next question is: are you aware of any research or publications in the road safety area where linked data has enabled policy-makers or researchers to evaluate countermeasures — for example, in assessing the effectiveness of airbags or improved infrastructure?

Adjunct Prof. ROSMAN — Sorry, I have been out of the road safety research community for more than 10 years now. I was involved in a lot of work done in the 1990s using linked data at the Road Accident Research Centre at the University of Western Australia, but that is now nearly 20 years old. We did look at bicycle helmets and other evaluations at that time. I guess my general answer is that it is much better to use linked data for these kinds of evaluations than any one raw data source, I would propose.

The DEPUTY CHAIR — Are there any other questions? If not, Diana, thank you on behalf of the committee for your important contribution.

Adjunct Prof. ROSMAN — Thank you very much.

The DEPUTY CHAIR — You will receive a transcript of your contribution. You are welcome to make corrections to any factual or typographical matters. Should you wish to send any additional information, that would be welcome as well. We thank you very much for your time.

Adjunct Prof. ROSMAN — Thank you very much. Good afternoon.

Witness withdrew.