

TRANSCRIPT

ROAD SAFETY COMMITTEE

Inquiry into serious injury

Melbourne — 10 September 2013

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Witnesses

Associate Professor B. Gabbe, head, Victorian State Trauma Registry, and

Associate Professor R. Judson, chair, steering committee, Victorian State Trauma Outcomes Registry and Monitoring Group.

The DEPUTY CHAIR — We will open the hearings now. We welcome you and thank you for attending. Unfortunately the chair of the committee, Mr Murray Thompson, is unable to attend due to ill health. He contacted me, as the deputy chair, and requested that I chair this committee and extend his apologies to you, which I do. He sincerely wanted to be here, but he is unable to be.

We welcome you to the public hearings of the joint-party Road Safety Committee inquiry into serious injury. The evidence given is protected by parliamentary privilege, but any comments made outside the hearing are not afforded such privilege. The transcript will become a matter of public record. If I may, I ask you to state your names and introduce yourself for the purposes of Hansard, whom we thank for their work. After that we invite you to speak to your submission. We again thank you for coming.

Assoc. Prof. GABBE — Thank you very much for the opportunity to speak at the inquiry. I am Associate Professor Belinda Gabbe. I am from the school of public health and preventive medicine at Monash University, and I am here in my role as the head of the Victorian State Trauma Registry.

Assoc. Prof. JUDSON — I am Associate Professor Rodney Judson. I am the director of trauma at the Royal Melbourne Hospital major trauma centre, and I am also chair of the VSTORM steering committee, hence my presence here this morning.

The DEPUTY CHAIR — Thank you. Should you wish to make comments to your submission in camera or off the record, we welcome you to do that; just indicate to us so for the purposes of Hansard we are able to make sure that we structure it properly.

Overheads shown.

Assoc. Prof. GABBE — All right. We have actually have not made a submission to the inquiry. We were asked to come and talk about VSTORM and what VSTORM does and its capacity to monitor serious road injury in the state. What I have done is prepared a presentation just describing what VSTORM is and talking about the registries we look after and the capacity of those registries to link with other datasets as well, which I understand is of interest to the inquiry. What I will really talk about is just the role of VSTORM, and then I will just clarify a bit of terminology about VSTORM and the Victorian State Trauma Registry. I will introduce the Victorian State Trauma Registry — what it is and what it does and what it collects — and provide some examples of how we are using that registry to monitor serious road injury and also the linkage capacity of the state trauma registry and a little bit about another registry we hold that might be of interest.

VSTORM itself is the Victorian State Trauma Outcome Registry and Monitoring Group. We are actually the group that holds the registries; we are really the custodians of the registries, not the registry itself. We were put in place as an independent entity for the analysis of data about the Victorian state trauma systems. In the late 90s — 1999 — there was a ministerial review of trauma and emergency services in this state. Out of that review came the ROTES report, which was the blueprint for the change in the trauma system and the change in the way we deliver trauma care in this state. As part of that ROTES report one of the recommendations was that a monitoring element be put in place for the Victorian state trauma system and that that monitoring be independent of the Department of Health. That went to public tender, and VSTORM was successful in being awarded the tender. We have been the custodians of the registry since its inception in 2001.

Our role is really to provide independent and objective analysis of the data that is contained in the registry that relates to the Victorian state trauma system. We are really guided by a steering committee of expert clinicians, trauma service providers, funding stakeholders and researchers. They are there to represent the different components of the state trauma system, and Associate Professor Rodney Judson is the chair of that committee. We have a reporting role directly to the Department of Health and the state trauma committee, which is the ministerial committee that oversees trauma care in this state. We are really part of the Department of Health monitoring of serious road injury, if that makes sense.

What do we do? We are very much focused on monitoring of the state trauma system through the analysis of the data in the state trauma registry and also associated datasets. We are here to look at how effective that state trauma system has actually been in reducing preventable death and permanent disability in the state. We also play a role in identifying any deficiencies — any issues that arise in the state trauma system — and our role there is to provide guidance and to provide the data to support changes to the trauma system. We provide data directly to trauma services to help them do their continuous quality improvement, and really what we have been

working towards is integrating available electronic databases so that we get maximum monitoring of the state trauma system.

Aside to that, we also use the state trauma registry to conduct research, and the research we are particularly interested in is around the delivery of trauma care, looking at the incidence of serious injury and of burden, so looking at longer term outcomes. We do quite a bit of work with international benchmarking and benchmarking with other jurisdictions as well. That is really what VSTORM has been tasked with since the state trauma system started.

The Victorian State Trauma Registry is the major vehicle. It is the major source of data that we use for VSTORM's work. It is a population-based trauma registry, which means that we collect information about all eligible cases in the state. It is completely integrated into the Victorian state trauma system, and from the latest slide you can see how integrated the registry actually is and the pathways for reporting. We receive data from all trauma receiving hospitals in the state; there are 138 hospitals that provide data. The bulk of the data actually comes from the major trauma services, which are the Alfred, the Royal Melbourne and the Royal Children's hospitals. We use an opt-off consent process, so every eligible patient is entered into the registry, then we send them a letter and a brochure explaining that they have been included in the registry and then they have the opportunity to opt off if they wish to do so. They can do that by calling a 24-hour hotline. Our opt-off rate at the moment is around 0.5 per cent, so we get quite amazing compliance and coverage with the registry.

We have been collecting data since July 2001, and we have had complete coverage of all 138 hospitals since July 2005. For the year prior to that we were down one, and in the years prior to that we had two hospitals that were not contributing data, but everybody is on board now. We collect data from a number of sources. We get data from the pre-hospital settings, so essentially what we are looking at is roadside right through to hospital discharge, and then we also follow up patients as well, which I will explain in a moment. But we get data directly from the ambulance service for each of these cases. We get information from all their acute hospital admissions. For example, if a motor vehicle crash occurs in regional Victoria and the injured person is transported to Ballarat and then they are airlifted to the Alfred or the Royal Melbourne, we would get information from the referring hospital and the hospital that is actually providing the definitive care. On an annual basis we also get data on all trauma-related deaths from the National Coroners Information System as well, so that gives us all the information that we need about deaths that occur prior to arriving at a hospital.

We follow up all our patients after hospital discharge. We follow them up at 6 months, 12 months and 24 months after injury. We do that by telephone interview, and we collect information around functional outcome, quality of life, return to work and pain. We also get an indication of where they are living, so the level of services that they are requiring. That is a unique aspect of the registry. There is no other trauma registry in the world that does that.

It has been a really successful registry, and we have been able to use it for a number of different sources. If we talk about the measures of burden — and I understand this is part of the terms of reference for the inquiry — we can do quite a lot with the data that we have. From the mortality point of view we can look at the incidence over time, and we can do that for deaths that occur out of hospital and also deaths that occur in hospital. We can look at long-term mortality risk, because we also have a linkage with the Victorian deaths registry. We link routinely and repeatedly with the deaths registry, so we can determine how long patients live after discharge from hospital. We can look at years of life lost, which is a major component of disability-adjusted life years. We can really look at many measures of mortality burden.

With respect to non-fatal injury, we are in a fairly unique position because we collect functional outcome data. For adults it is something called the Extended Glasgow Outcome Scale and for children it is the King's Outcome Scale for Childhood Head Injury, which is really the Extended Glasgow Outcome Scale equivalent for children. While these tools were developed for head injury, they are well validated in non-head-injured populations.

For people who were working prior to injury we collect information about return to work and work disability, so whether they have returned to the same workplace and if they have returned to that same role. We collect information about pain and health-related quality of life, and we do that with a number of instruments, such as the SF-12 and the EQ-5D, which most people know of as the EuroQol. For children we use something called

the paediatric quality of life inventory, which is the PedsQL. Each of the EQ-5D and SF-12 can be used for economic analysis as well.

Next is self-reported disability. We also get global measures of self-reported disability, and we have been doing some work looking at converting our long-term outcome data to years lived with disability. I will show you some slides around that.

With respect to the other things that we can do, we can also look at cost data for serious road injury, because we have a linkage with the TAC claims data. Every six months or so we get all the TAC claims data from the TAC via the compensation research database, which is held by the Institute for Safety, Compensation and Recovery Research — it is a very long name, but that is the way it works these days — so we can look at what the costs of these patients have been in dollar terms, but we can also do it through disability-adjusted life years as well.

I guess what you probably need to understand are the types of patients who are included on the state trauma registry. Death is an immediate inclusion criterion, so all deaths will be included on the registry. If a patient is admitted to intensive care for more than 24 hours and they are mechanically ventilated for part of that admission, then they are automatically included irrespective of the injuries they have sustained. If they have a significant injury to two or more injury severity score body regions or an ISS greater than 12, then they are automatically included. The fourth major trauma criterion is urgent surgery for intracranial, intrathoracic or intra-abdominal injuries or fixation of pelvic or spinal fractures. We have a long list of surgeries that meet that criterion. In addition, we have some inclusion criteria around electrical injuries, drowning and asphyxia, but they are a relatively small component of the registry. We also attempt to get information on every case where their main reason for admission is injury and their length of stay is three days or more.

We do have some exclusion criteria. The types of cases that we exclude are very isolated eye injuries and isolated hip fractures — those types of things. This slide shows the main inclusion criteria. In all our reports it is the first four inclusion criteria that we consider as a major trauma patient. Rodney can probably talk more about this, but the reasons that the registry uses these inclusion criteria is that these came out of the ROTES report and these were considered to be the types of injuries that would need specialist major trauma service care. These are the injuries that raise the possibility that they need to be in a specialist service, and that is why we use these inclusion criteria.

This is a slide which looks at our reporting processes. VSTORM is fairly much in the middle of the state trauma system. We receive data from the trauma service providers, we report directly to the State Trauma Committee and the State Trauma Committee's role is to provide specialist advice to the Department of Health. We also have regular reporting and data verification processes between Adult Retrieval Victoria and Ambulance Victoria. We also provide reports through to the regional and metropolitan hospitals, and also directly to the Transport Accident Commission. We do a quite complex series of reports, but the main ones are a quarterly report and an annual report that go up to the State Trauma Committee. We also do special focus reports about emerging issues that are directed by the State Trauma Committee, and the data is always there for people to access through the data access policies as well.

Proceedings in camera follow.

Open hearing resumed.

Assoc. Prof. GABBE — One of the questions we were asked to discuss here is the capacity of the state trauma registry to link with other datasets, and the Victorian State Trauma Registry collects a number of items that could be used to link — and we do use them to do some of the linkages we already have in place, so we actually collect identifiable data. We know on the registry who our patients are. We know their names. We know where they live. We know their date of birth. We know their date of injury and their date of admission to hospital. For all of them we get a hospital UR number, so we can use that, if we need to, for linkage. We get the ambulance record number from the case number, and we also collect the TAC claims number for the major trauma service cases as well, so we have quite a collection, or a selection, of data items that could actually be used to link with other datasets.

We actually have established linkages. We link directly with the Victorian ambulance clinical information system. That is the electronic collection that the ambulance officers all use. We also have a link with Adult Retrieval Victoria. We use that as a data verification process so that we know when patients are being

transported by that specific service. As I mentioned previously, we received TAC claims status, so we do not send any data about patients to the TAC but we receive all of their claims data for the cases that are on the registry. We also have a routine linkage with the Victorian registry of deaths for the reasons we discussed earlier, which is that we need to know — for a start, we do not really want to contact patients who are deceased, and we try to do everything to make sure that that actually does not happen.

Mr ELSBURY — It proves a little bit hard too, doesn't it?

Assoc. Prof. GABBE — It does! The death registry is not fool proof.

Mr ELSBURY — Ouija boards are not overly good.

Assoc. Prof. GABBE — We cannot really ask them about their quality of life; we can make some assumptions, but I would prefer not to do that! Patients can leave a hospital alive, and by the time their data comes along to the registry and we send out the letters they may have actually passed away. What we do is use the deaths registry to try to filter out as many of those as possible. With deaths, they get a specific letter that goes to the family members. It is obviously quite different to the one that says, 'You are on the registry. This is what we do. If you would like to get off, that is fine, but otherwise we will contact you and see how you are going'. The deaths registry linkage is not fool proof. Some deaths take quite a long time to actually come onto the registry, so it is not the panacea that we sort of hoped it would be.

At the moment we are in discussion with the Department of Health about linkage with the health datasets — so the VAED and the VEMD — and we would also like to have some linkage with rehabilitation datasets, but that is slightly more complicated because they are not necessarily state-held datasets. The VAED and the VEMD — that looks like it will progress because we have had parliamentary approval for the VSTR to come into the Department of Health map, but we are just working through the memorandums of understanding and the ethical issues that are related to that. That is all quite new. We have had discussions with VicPol about linkage with data there and also with VicRoads about linking registry data with those two data sources.

There has not been a lot of progress there, obviously, for many of the reasons you all have heard repeatedly, probably, through this process, but we are hopeful that that may be a possibility in the future. If we could understand more about the crash, the vehicles' safety features and all of those types of aspects of the crash and we have all the very detailed clinical diagnosis and outcome data, we would get a much better understanding of what is going on and why we are seeing different patterns of trauma and what the impact of that actually is on the longer term burden.

The only other registry I did want to bring up is the Victorian Orthopaedic Trauma Outcomes Registry, which is a registry for which we have been custodians for almost as long as the VSTR. The Victorian Orthopaedic Trauma Outcomes Registry has the acronym of VOTOR. It is a sentinel site registry. Four hospitals actually contribute, and they have been selected for particular reasons — the Alfred and the Royal Melbourne because they are our adult major trauma centres and Geelong and Northern because they are very busy regional and metropolitan trauma services respectively. This registry is a little bit more inclusive than the state trauma registry, which is focused on major trauma. Here, if you are admitted to hospital with an orthopaedic injury and you stay for more than 24 hours, then you are automatically included. The only exclusions we would have are pathological fractures. It is a very inclusive registry. We have been integrating it completely into the state trauma registry, but it is funded through a slightly different source; it is funded by the TAC.

It has been collecting data since 2003, and it captures about 5000 cases a year. We follow up all of those patients again at 6 and at 12 months after injury, and we have now started doing 24-month follow-ups also. It has a multidisciplinary steering committee, and that has some very extensive clinical engagement from the orthopaedic community. As for the state trauma registry, we also link with the TAC and the deaths registry. In fact the two registries now share the same ethics approval. They share the same database, and we pooled a lot of the resources for the long-term follow-up interviews. I just raise it because it is another particularly fantastic source of data about road trauma and serious road injury.

Mr PERERA — What is the difference — the people who have the limbs and stuff like that?

Assoc. Prof. GABBE — Exactly — a lot of single-limb fractures.

Mr PERERA — No internal — —

Assoc. Prof. GABBE — If they have any orthopaedic injury, they will automatically go on, so there is overlap between the — —

Mr PERERA — To both registries. Okay.

Assoc. Prof. GABBE — Yes. There is overlap between the two registries, but the difference is that VOTOR will also collect all of the single-limb injuries and the injuries that are not severe enough to classify a patient as a major trauma patient.

Mr PERERA — But still the other registry — the VSTR — will have an entry as well?

Assoc. Prof. GABBE — Yes.

Mr PERERA — Both duplicate it.

Assoc. Prof. GABBE — No. They are fully integrated, so we will know. There is an indicator variable that tells us if they are VSTR or VOTOR or both.

Mr PERERA — Right.

Assoc. Prof. GABBE — I thought I would just finish with some of the key messages that I hope came across today. The VSTR captures all deaths — so, pre-hospital and in-hospital — and all hospitalised major trauma patients in the state. Our definition of major trauma was defined by the ROTES report, and we have been working with that since we started. The dataset is pretty extensive, and the focus is on population incidence and quality of the trauma care provided. We try to feed into injury prevention initiatives, and we are also very interested in looking at the burden of fatal and of non-fatal injury, which we are ideally placed to do. These registries, the VSTR and VOTOR, are the only trauma registries worldwide to capture any post-discharge outcomes and longer term burden of non-fatal injury. Other registries will link with their various death registries, and you can look at long-term mortality, but we are the only registries in the world that actually capture any information about long-term quality of life on a routine basis. We do about 1100 telephone interviews a month, which gives you a bit of an indication of the sort of scale of the operation.

The registry is fully integrated into the state trauma system, and we have that routine reporting to the Department of Health and the state trauma committee. It is a substantial data resource for research, policy and planning. We have established linkages and the capacity to link with other databases if that was deemed to be appropriate. I think that is it. Thank you very much.

The DEPUTY CHAIR — Thank you very much for a very comprehensive submission. May we proceed with questions?

Assoc. Prof. GABBE — Absolutely.

Mr ELSBURY — Obviously it has all been about data collection, so I will spread it out a little bit more. Do you believe that integrating medical insurance claims data and police crash data would ultimately be the most effective way to report and monitor road safety?

Assoc. Prof. GABBE — Do I think it would be the most effective way? I think it is the most efficient way. Both datasets exist. If you were designing it from scratch about exactly what you wanted to collect and how you wanted all the datasets to collect things, then you would have the most effective system, but we are not really in that situation. I think combining the linkage of those datasets would make it the most efficient way to better understand what is going on.

Mr ELSBURY — Would there be any difficulties with the methodologies between the datasets?

Assoc. Prof. GABBE — There are, but the datasets are well established enough now that everyone knows the pros and cons of them. The data dictionaries and definitions are also so well defined that you can usually find common ground. There will always be caveats in any observational data that you are analysing, but they

are so well known and well defined now that we should be able to better understand what is going on if they were all linked.

Mr PERERA — Thank you very much for your very detailed submission. You mentioned that you are collecting from only 138 hospitals. What about the other ones? Are there more than 138 hospitals?

Assoc. Prof. GABBE — No, they are all the hospitals in the state that have been deemed to be part of the state trauma system and approved to receive trauma patients. Some of those, for example, are bush nursing hospitals where they do not have an emergency department but they may be the closest hospital to wherever the trauma has occurred. They might see one patient every three years or something along those lines. About 85 per cent of the patients are definitively managed at the major trauma services, so the bulk of the data comes from there.

Mr PERERA — So you cannot capture 100 per cent?

Assoc. Prof. GABBE — We can capture 100 per cent except for the patients that opt out, so it would probably be about 99.5 per cent. We have data collectors working in all of the regions who go to each of the hospitals and capture that information, but there would be no hospitals taking trauma patients that were not included in that registry.

Mr PERERA — You mentioned people opting out of the registry. What difference does that make? When someone opts out of the registry, do you completely lose them and there is no analysis?

Assoc. Prof. GABBE — We do. Because of the way the state trauma registry runs, we actually have ethics approval from every health service. There are about 138 hospital ethics approvals that are required for the registry to run. That means 138 annual reports and various other things. It is quite an administrative load, but it is part of the process of being able to capture the identifiable data and being able to follow up on the patients and the like. With an opt-in process what we would have to do is go to each individual patient, explain the study and ask them to sign a consent form to take part in the study. Registries that have used that process around the world have found that only about one-third of patients actually opt in to the registries.

Registries are here for a public health and a clinical purpose. We need to be able to get as high a level of coverage as possible to be able to achieve the aims. What we are looking for is population level data, so 99.5 per cent is very good. But once the patient says they have opted out and they want their data removed from the registry, we are obligated to remove them from the registry, so we can link to no information about them. We are fortunate it is a very small percentage.

Mr PERERA — For the people on the registry, what privacy issues, if any, have arisen with the outcome registries compiled by the Victorian state trauma outcomes registry or VSTORM? How were these dealt with?

Assoc. Prof. GABBE — Privacy is obviously highly important. We collect patient-level data. We have very strict protocols in place for the follow-up of patients. Patients can opt to stay on the registry but decline the telephone interviews, and that happens; that is part of what we do. The database is kept in a red zone; it is ISO accredited. We keep the state trauma registry with the equivalent privacy and security that you have for your banking details. Occasionally we get a patient whose data has been received and they want to know why and they have not been happy about it. We have only had one complaint in more than 10 years from a patient, and the review was by the ethics committee. We put in some additional steps and that has all been fine.

For the follow-up of patients, when we first applied for the registry we wanted to follow up patients by telephone interview, and ethics committees were not inclined to approve it, because they felt that patients would not want to be contacted by the registry. We have found that it is the complete opposite. When patients leave the hospital often we are the only contact that they have; we are their only follow-up. A lot of the interviewing is not just about collecting the data; it is about dealing with patient issues. If they are having troubles or they do not really know where to go or what to do, the interviewing staff are trained to direct them to the relevant resources they need, whether that is back to the patient advocacy person at the hospital or to a helpline or whatever it may be.

Our follow-up rates are very high. We are looking at about 85 per cent to 95 per cent follow-up, so the patients are very much voting with their voices to say that they are very happy with the follow-up. We get letters from

them that say that. Privacy is their biggest concern; it is about keeping the data as locked down as we possibly can. We have data access policies. People can apply to access data from the registry, and all of those requests have to be ethically approved. If it is for research purposes, they have to go through an ethics committee and receive approval for their project. It then comes to us as the data custodians, and Rodney is the chair of the committee, and we need to make a decision about whether it is in the interests of the registry and what the registry has been put in place to do — to approve those requests. We have had situations where people have had their project approved by ethics but knocked back by us because we felt that the project and the analysis were not appropriate.

We have the capacity to approve aggregate data, which is really just summary data, and we do approve that quite easily, but a patient can never, ever be identified by anything that is released by the registry.

Mr TILLEY — Firstly, I would like to apologise to you both for being a little bit late. I can assure you I was on the road well before most people were out of bed this morning. However, I probably missed a significant part of your evidence this morning. As you can probably appreciate there are a number of prepared questions. I picked up something you said in relation to the possibility of linking data held by VSTORM with the data held by police and other road safety agencies such as VicRoads and the TAC. In black and white terms, can you give some examples or impediments that you may be aware of, such as privacy? We often hear it used as an excuse rather than what it is intended for. Could you speak frankly on those matters or matters set out under the Health Records Act and any other legislation that you may be aware of that creates these difficulties?

Assoc. Prof. GABBE — There are a few roadblocks. One is the legislation that controls the datasets. There are also privacy and the various sorts of privacy legislation that are in place. There are also the ethical principles. We are bound by the national statement from the NHMRC because ours is a project for a registry that is approved by ethics committees. There are also the custodians of the registries themselves and their willingness to actually share data. We have been in that situation, too. When you have a significant amount of data you want to be sure that it is going to be used well. Often that is just about relationship building, really — getting processes in place where everyone is comfortable with what the actual linked data is being used for so that everybody approves it. That has to be maintained because I think otherwise, even if you could get through the legislative, the privacy and the ethical aspects, ultimately the people who have the final say about whether the data are linked or not or whether the data can be used for those purposes are the data custodians. They are ultimately the people who will make that choice.

Mr TILLEY — In frank language, I suggest, are there some little suggestions of empires, with the personalities and such? Do you have anything you can offer the committee?

Assoc. Prof. GABBE — No, we have not experienced it with the linkages. I mean, we obviously have some successful linkages in place, and some of them have just been purely administrative roadblocks, like memorandums of understanding or collaboration agreements that have to go through Monash lawyers and other lawyers and the whole bit. But that is just a process, that just takes time, and if you are at that stage you already have an in-principle agreement that you are going to do this. We have had no issues dealing with the TAC; the TAC have been fantastic to deal with. The ambulance services have been great to deal with, and Adult Retrieval Victoria have been great to deal with. When we have spoken to VicPol they have been very supportive; they can see that we are sitting on data that would be very useful for their purposes. We are happy about that; as registry custodians the last thing you want is to be sitting on a data resource that is not used and is not useful. We would like to see the potential of the datasets to be maximised. With VicRoads there have been some preliminary discussions, but at the last meeting the VicRoads representative did not arrive, so I do not get a feel for if there are any particular issues.

Mr TILLEY — Sorry, you said they did not arrive?

Assoc. Prof. GABBE — They did not actually turn up to the meeting. I cannot remember exactly why. I do not know if they were voting with their feet and that is the way they were going about it or whether there are any particular issues, but certainly I have not experienced that. Perhaps within the various arms of government they have been getting a bit of push-back, but we have not particularly had it. I know that is probably painting a slightly rosier picture than you may have heard, but the way the registry is set up with the engagement of major stakeholders from the state trauma system means that those relationships have been in place for a decade or

more, so we are in a much better situation, I think, to negotiate those linkages than groups that perhaps do not interact very often.

Mr TILLEY — In that sense, do you have any recommendations for any changes to legislation? Any thoughts? During this process have you had any thoughts about what might be able to make a change or contribute to facilitating these — —

Assoc. Prof. GABBE — Yes. There are a few things that we need from the point of view of the registry. For example, the national statement does not actually have a capacity for an opt-off consent process, so we have to argue for a complete waiver of consent and then build in something else. Our national statement on ethics needs to change. Privacy legislation is challenging — there is no doubt about that — but it is in the interpretation of the privacy legislation. When this registry was first being put together there was one older ethics committee which refused to approve it on the basis of privacy. We actually had the privacy commissioner go and present to that ethics committee to say that in no way did we breach the privacy legislation, and the committee still refused.

Mr TILLEY — In one sense, would you think that there needs to be better education of those charged with the responsibility of handling the matters of privacy?

Assoc. Prof. GABBE — Absolutely. I believe that is the case, and I think a better understanding is needed of the databases and the security that is around the databases. We could not possibly get our registry through 138 ethics approvals without convincing them that we know what we are doing and it is all okay. We certainly would not have been able to get any of those linkages approved that we have to date if we did not have a track record to show that we knew what we were doing and everything — that we were following all due process.

The DEPUTY CHAIR — Thank you. Evidence both in submissions to the inquiry and in the literature suggests there is strong support for the use of an International Classification of Diseases-based injury severity score to define ‘serious injury’ in Victoria. The committee also understands that other states, such as Western Australia, are actively engaged in adopting the ICISS. Do you agree that this system would be best practice for defining ‘serious injury’ in Victoria? If not, why not?

Assoc. Prof. GABBE — The ICD-based ICISS is a particularly good use of ICD data to look at the prediction of mortality. It is only for mortality, so if you were looking at burden of non-fatal injury, it is not your measure of choice. It is a very good predictor of mortality. It requires ICD coding to be in place, and that is only in limited environments, so many vital registers actually use ICD coding of deaths. That is one. But otherwise you would never have ICD-10 coding or ICD coding unless the patient is hospitalised. ICISS only comes into play for hospitalised patients. It is probably not relevant outside of hospitalised cases. It is a good use of a routinely collected resource. ICD is collected by all the hospitals — that data is already there — and it has been shown to be a very good predictor of mortality. We have used it in the trauma registry for a paper that we published a number of years ago, comparing it to the AIS-based versions of injury classifications. It did not perform as well, but it was not terrible. It was actually quite good; it just was not as good as the AIS-based measures.

The only other point I would make about that is that ICISS is based on a probability of survival linked to a diagnosis, and as clinical practice improves, that probability will change over time. Whatever your probability is, or your SRRs or SSRs, or whatever the terminology they used 10 years ago, it would not be relevant 10 years later. If you are looking at change over time, you have to be a little bit cautious about that.

The DEPUTY CHAIR — Thank you for that.

Mr ELSBURY — I am just trying to digest what you said there. There is a question here that has been predetermined, so I will go with it. By comparison to the MAIS and ICISS definitions, what are the benefits and advantages of the major trauma definition currently used by the VSTR?

Assoc. Prof. GABBE — The major trauma definition used by the VSTR is about finding the appropriate hospital for the appropriate patient, if you know what I mean. Basically you are looking for the types of patients who are going to need a specialist service — a major trauma service. The MAIS, the maximum AIS severity, is really about a single severity code. It is all about anatomical injury. What we find is that we get a lot of major trauma patients whose injuries may not be particularly severe but because they were sick prior to injury — they

had comorbidities prior to injury and then on top of it a relatively moderate head injury and something else — they actually do need the care of a major trauma service because they become complex patients to deal with. Our major trauma definition is not specifically for monitoring. It was not put in place for that; it was put in place to capture the types of patients that we expect to be transferred to major trauma services for care. So the purposes behind them are actually quite different.

Mr ELSBURY — This would be very important, considering we have the ageing population who will have more complex medical needs into the future.

Assoc. Prof. GABBE — Yes. Ours is really about clinical care and matching the patient to the appropriate trauma service. That is the way we were put together. The maximum AIS has the same issues that ICISS does. It is mortality based, so that severity score is based on a threat-to-life scale. The AIS is continually updated, for the reasons we have just talked about — that as clinical care improves, your odds of surviving an injury now compared to 10, 15 or 20 years ago are much better. Again you have the same monitoring issue. What we have done recently is change over to the latest version of the AIS, which has required us to back-map everything previous to the new one. There is a level of error involved in that, and it is not unsubstantial. It is a good sort of process to go through because you realise that the previous versions do not necessarily match very well with the later versions, and finding a decent map is very difficult.

The other problem is that the AIS was built for specific people with specific training to capture that information, it is not routinely collected by the hospitals and it is quite expensive to collect. The maps that exist from ICD to the AIS are not very good.

Mr ELSBURY — If Victoria was to use the trauma system definition of ‘major trauma’ as a proxy for serious injury, would that be considered best practice for the purposes of tracking trauma outcomes, developing countermeasures and understanding road trauma and the road trauma situation in Victoria?

Assoc. Prof. GABBE — From our point of view? That is a really difficult question to answer. Our major trauma definition has multiple elements to it, so you could take any one of them. Essentially an ISS greater than 12 is an alternative to an MAIS 3+, but we would be using ISS 12 instead. The deaths — obviously that is clear. You could take that component off and look at in-hospital and out-of-hospital deaths. You could take just the ISS component of our definition, and often when we are writing papers to compare with the international literature we take just that component and look at our patients who meet that definition. The urgent surgery and the ICU criteria and really more about clinical care and matching a patient to the right hospital. From a monitoring point of view I think they are probably going to be less useful. They are very useful inclusion criteria for us, but from the point of view of monitoring the number of cases over time it is probably not going to be as useful. Many of the patients who meet those criteria already meet the death or the ISS greater than 12 one anyway. But with death and ISS greater than 12, we are confident we have got all those cases and we have got them right back to July 2001.

Mr TILLEY — Going on from an earlier response about mapping this, what are the benefits, if any, of adopting multiple measures for trauma and serious injury — for example, having the resource of admitted to hospital, ICISS and a burden of injury measure such as DALYs to monitor road trauma? Speaking at a government level, would using multiple measure improve decision making and policy development?

Assoc. Prof. GABBE — Yes. You use different measures for different reasons and to illustrate different points, and it would really depend on where you are going. Obviously the DALYs, the QALYs and the economic valuations are clear. Hospitalisation is a tough one. It is almost like a quick and dirty cut-off: you are either admitted to hospital or you are not. The reasons you are admitted to hospital change over time.

To give you a good example, a number of years ago we looked at foot fractures and foot fracture admissions — obviously this was related to the orthopaedic registry — and we saw a massive increase in admissions to hospital for foot fractures. It is not really because there are more of them occurring in the general population; it is simply because surgeons got new methods for managing those patients and were more likely to admit them so they could operate on them, whereas previously that clinical approach was not available. The threshold for when a patient is hospitalised or not hospitalised will change over time, depending on clinical practice. I think that is fair to say.

Mr TILLEY — I can understand that. Many years ago if you had a foot fracture from a motorcycle crash they would say, 'Go away'.

Assoc. Prof. GABBE — Yes, whereas now evidently they will admit you and put some metal in it. I had another example where hospitalisation has changed over time, but I cannot recall what it was. The foot fracture one is a good example; it is changing clinical practice.

I am part of the International Collaborative Effort on Injury Statistics. A group was looking at thresholds for hospitalisation around the world, so they were pooling emergency department and hospital data from around the world into a big study to look at whether there were particular diagnoses that were always admitted to hospital. They found huge regional variation around the world. For example, something like a flail chest, where you have got multiple rib fractures and a fairly sick patient, will not always be admitted to hospital in another country, whereas the only one that was nearly always admitted was a hip fracture. There was not consistency in it.

Mr TILLEY — Once again, I saw that firsthand when I was working in Thailand. Some car crashes there are incredible.

Who would determine and how would it be determined which measure would suit what patient? Is it subjective, or is it going to be a more precise science?

Assoc. Prof. GABBE — It depends on the circumstance. For example, if police are at the roadside and they are trying to make a decision about whether a person is severely injured or not severely injured, they just do not have the level of information available to them, so something quick — like whether the person was transported to hospital; irrespective of whether they were admitted or not, they were taken away in an ambulance — may be as good as you can get at that immediate time point. Ambulance officers do not have all diagnostic information available to them, so what they might use for their purposes is going to be quite different.

We are in a situation where our patients have been admitted to hospital, they have been in there, we are getting their data up to three to six months later, we know everything that has happened to them in hospital and what all their diagnoses are and we know what happens to them in the long term. If you are looking at day-to-day updating of road tolls and hospitalisations and all of that sort of stuff, our data will not be able to help with that, because it is too late in the piece. It will be detailed and correct, but it is much further down the track. But if you are looking at police or ambulance officers, they will need much more immediate definitions that they can use routinely, and things like AIS, ICISS, admission to IC — none of those things are relevant in that circumstance.

Mr TILLEY — At that lower level?

Assoc. Prof. GABBE — At that lower level. They simply will not be relevant. Even if you are asking the police officer to judge what they think is serious or not serious, we did a study in the UK where we interviewed police officers and first responders about their views of severity, and there are those who only consider whether they are likely to die or not, and then there are other people who think, 'This person is probably going to have a limp for the rest of their life. I'll consider that serious'. Their internal processing of what they consider to be severe is highly variable. You have really got to match the definition to the circumstances in which it is being used, and if you do not do that, then that is where it will get very messy very quickly.

The DEPUTY CHAIR — Thank you, Belinda and Rodney. Are there any comments that you may wish to advance before we conclude this session?

Assoc. Prof. JUDSON — The outcome data is going to prove the greatest strength to all that we have done. By having more mature data we will be able to cross link and answer a number of these questions that you have been asking about how best to define them and what we can get out of each of the ways we have defined them. There will be huge educational benefits in terms of whether it was money well spent to send these people to an expensive major centre. We will be able to answer in quite clear and well-defined economic terms the moneys that were saved in terms of the better outcome for that person. We are very well structured here in Victoria to be able to answer questions. I think the rest of the world is way behind us.

Assoc. Prof. GABBE — I agree with that.

Mr PERERA — When the ambos arrive at the accident site do they have a code to say that the patient should be taken to a trauma centre rather than to hospital? How do they refer them?

Assoc. Prof. GABBE — They have an algorithm that they work through, which is pre-hospital triage guidelines, which are freely available on the Department of Health website. If they meet any of these criteria, they are highly suspicious that they are a major trauma patient and they should go there, so they have an algorithm that they work through.

The DEPUTY CHAIR — On behalf of the committee I thank you both for your very comprehensive contribution. You will receive a copy of the transcript in about a fortnight. You are welcome to correct potential factual matters or typographical errors. As you will appreciate, the substance of it cannot be changed. We thank you again for your very important contribution.

Witnesses withdrew.