

Jane Mussared ([00:00](#)):

Okay. I think we can start welcome everybody. Welcome to Can big data help you age? Well my name is Jane Mussared. I'm the chief executive of COTA South Australia. The older people's movement in, in south Australia. I want to frame today's conversation. Our hypothesis is that big data will help us individually and importantly, collectively to age well, Nobel prize winning economist, Ronald Coase said torture the data and it will confess to anything. So will it confess to the secrets of aging? Well, I think we all have a rough idea of what big data is. It refers to extremely large data sets that whenever allies are capable of revealing patterns, trends, and associations, the collection of millions of individual records within a service or system within a service or system provides a very unique opportunity for us to pose questions of it that will help us spot and understand patterns that are not otherwise evident.

Jane Mussared ([01:12](#)):

Surely it makes sense then to pat, to harness the power of that data, to understand the wonderful fortune of our time, the gift of our aging and to ma, and to help us all age well while each of us lives lives uniquely and individually, there is a knowledge that accrues from lots of individuals with similar experiences that helps us to understand changes, trends, patterns that will shape policy systems and services of the future. There are two facts. I think that frame the conversation today, the first is that whether we like it or not, our lives generate lots of data that forms a digital record of our many experiences. And the second I think is that we all share an ambition to age well today's panel will focus on the upside of big data, using examples that are making very good use of all of the information that is already being collected by our governments.

Jane Mussared ([02:16](#)):

When we access health and aged care services, the panel will give you a chance to have a look inside three large scale health registries to various establish one emerging, including the registry of older, older south Australians that I'll talk to in a minute, each has very strict ethical confidentiality and privacy constraints in each is, are the very tight governance arrangements of some of our best academic and stakeholder minds. So let me start by telling you a bit about Rosa. Rosa is the affectionate name for the registry of older south Australia instead said it was established in 2017. It is a new population based multidisciplinary data platform. It connects the information from the cohort of people, older people who receive aged care, aged care services in Australia. We, their health records the first time in Australia. And indeed one of the funny, very few examples across the world with aging as the focus, it was founded in 2017 by the south Australian premieres research and industry fund and by members of the healthy aging research consortium here at San Marie under the directorship of, of professor Steve Wessling, it's designed by associate professor Maria and NASCIO who's in our audience today, who is a registry and population surveillance expert.

Jane Mussared ([03:43](#)):

The aim of Rosa is to monitor the health and wellbeing of people accessing aged care services in Australia, and in doing so learn more about the patterns of that aged care while their individual identity and information remains private they're collated data. Their big data will be used to help shape and improve services and interventions into the future. The first stage of the project, which is already reported has been an examination of their historical records of 2.9 million people who received across Australia who received 6 million different types of aged care between 1997 and 2014. We've just started a prospective phase, which began in April, which looks at the big data of 16,000 older south Australians who undergo an aged care assessment each year. These people are being asked and almost all like

giving consent to have their data from their aged care, their aged care assessment data linked with the data available about them in the health sector.

Jane Mussared ([04:57](#)):

I'm part of a steering committee for Rosa. And from my perspective, browser has four very, very important strings. The first is that it is able to link the data or with aged care assessments with health data. It's able to link data from those health from, from an aged care assessment to their information about ambulance use about medic Medicare benefit schedule about pharmaceutical benefits scheme about the Australia with the Australian death index with emergency department use. And so it allows us to check how well those sectors are aligned in supporting the needs of older, older south Australians. The second great strength of course, is the volume of data about available on indeed the completeness of the VA, the available data with 16,000 assessments each year. And very few opt-outs the evaluation of infrequent events, health assessments, surgically treated, fractures, cardiac events and rare conditions, liver or kidney disease, which can't normally be tracked through clinical studies because they're to take too long or too costly can, can be followed.

Jane Mussared ([06:15](#)):

And we can therefore use Rosa to understand the patterns of resource use. We can ask it questions about risk profiles for events, and we can ask about the associations between various sectors that can't be evaluated in the absence of the availability of that big data. The third thing that Rosa has done is that it's assembled a pretty, I think a very clever sophisticated team across disciplinary team of programmers, statisticians, epidemiologists, and data scientists. These are people who specialize in handling large amounts of data and a clever when it comes to creating ways to look at data, to design systems, to collect and evaluate the data and to use the best strategies for analyzing them. Finally from my perspective Rosa all also has very, very important clinical and and consumer, or, or older person's representation at each step of the way. And that makes a lot of sense to me.

Jane Mussared ([07:19](#)):

And it is a really important part of the governance of, of Rosa, because it means that it is, it is designed to ask the right questions of the data that's available. It also means that we're able to access the opinions, the views about both clinicians and older people about what are the most important questions to ask about if we could prioritize those questions, what would those questions be? It also allows us to interpret the findings appropriately and it has avenues, and it means that we've got avenues to implement the findings of it. It means that the people who are, who are very interested in what the outcomes of, of that data analysis are, are also the people who are part of the governance structure. So, so the, the the project is made at the governance of the project is made up of geriatricians aged care providers, but also consumer groups such as my own, their council on the aging and south Australia and the health consumers Alliance. So that's Rosa that's one example I want to now introduce you to our panel members. And start with that. I think Steven Graves is first Steven, he's an orthopedic surgeon and he's been the director of the Australian orthopedic association national joint replacement registry since it was established in 1999. I'm going to give each of our panel members that a bike bill reminder at six minutes because each you've got seven minutes to tell you a lot of stuff. So Steve, hopefully

Steve Graves ([08:55](#)):

I can get through things a little bit quicker than that. All I really want to do is just give you a quick overview of what the registry is and what it does and hopefully leave plenty of time for discussion that

at the end, when we've completed our presentations. But so as it's mentioned, the registry was established around 20 years ago, and it was actually an initiative of the Australian orthopedic association, which is the professional body that covers all orthopedic surgeons in Australia. And the reason it was established was that orthopedic surgeons didn't really know how many people were getting joint replacements in Australia. And what were the devices being used in that, and whether those devices all worked equally as well, and what were the techniques that should be used in different clinical situations? You know, do you use a different technique with a younger patient compared to an older patient?

Steve Graves ([09:54](#)):

And there is that so it was really to look at the practice of joint replacement surgery in the country, because there was really no information on that. We established the registry. I was asked to do that. And what we did was we rolled it out in all the hospitals in Australia. So every hospital doing joint replacement contributed data to us on every procedure that is actually undertaken. And we're able to actually check that we get all the information because the state governments also provided us the information on who's had a joint replacement. And so we're able to match the data that we received from the hospitals and from the state governments to identify everyone that's had a joint replacement and it, the way that it works, it's actually very simple in that. All we do is record that information.

Steve Graves ([10:42](#)):

And then if someone has a problem with their joint replacement, they usually require what's called a revision operation or a redo operation. And so they get registered again. And then we link that data so that we know when someone has had to have their first operation redone. And so that indicates that there was a problem and Toby asked what the problem was. And through just that very simple data collection, which was what we established initially that we were able to identify a lot of variation in practice and a lot of things that were very good and a lot of things that weren't so good. You may remember that there was a problem a number of years ago with metal on metal hips and that it was the Australian registry that actually identified that problem. It was the first organization globally that was able to identify that there was that problem, as well as metal on metal.

Steve Graves ([11:37](#)):

Hips is 150 different devices that we've identified that don't work particularly well. And they've been removed from the market in Australia, but it's changed the rules around how new devices get introduced, the evidence that's required. And so that's actually significantly the outcome identifying different patient groups and what is required for those different patient populations has also been very important in improving outcomes. And in fact, over the years, we've actually halved the number of people that are requiring having redo hip operations and that we've reduced the number of people having redo knee operations by about 30, 40%. So they're quite dramatic changes in if you want to put it in a thousands of people each year, because there's 110,000 people who have a hip or knee replacement each year in Australia. So, you know, bigger than an mcg full of people each year have hip and knee replacements in this country.

Steve Graves ([12:37](#)):

Great. And that there wasn't dependent assessment does to the value of that over just a, a ten-year period. And that was a, the benefit was around \$640 million to the Australian community and savings. So that means that more procedures can be done or that money can be spent elsewhere within the

health system. So it's been very, very dramatic, the benefit, but not only has it benefit joint replacement patients in Australia, it's also benefited them overseas because one of the things the Australian registry did was it linked all the registries to that exist globally. And there's about 50 national registries globally in joint replacement. And we actually all work very closely together. It's a very tight network, so we're able to compare techniques across countries, resolve to cost countries. And so we can help to optimize health care globally with respect to joint replacement.

Steve Graves ([13:33](#)):

So that was a very simple data set that we collected. And since then, we've actually grown. And there's a couple of areas that we're working in right now one is that the federal government has given us permission to link all of our data to their data sets. So it's the MBS data, which has all the hospital admissions and so on as well as all the pharmaceutical data, the PBS data. So that means that we get a much better idea of how healthy people are and whether their host deteriorates or gets better after joint replacement surgery, because we can look at what medications they're taking. I might mention that all of that information when it's provided to us is de-identified, we don't know who the patients are and that, so we're just looking at the massive data and that but the other thing that we're doing, and I think it's, it's a very good thing is that we've have developed an automated system, which begins to be rolled out in the country in about two weeks time, which contacts patients, if they wish to be contacted, to get their own thoughts about how their healthcare has gone with respect to the joint replacement.

Steve Graves ([14:45](#)):

So what we're doing is also getting information directly from the patients as to the success of the procedure. So we think that that will add override, you have new data that we can use to further enhance the outcomes of joint replacement surgery. Thank

Jane Mussared ([15:03](#)):

You. I'd now like to invite professor Stephen McDonald, who's the director of dialysis and senior staff nephrologist at the Royal Adelaide hospital, but he's important. He also the executive officer of the Australia and New Zealand dialysis and transplant registry.

Stephen McDonald ([15:21](#)):

Thank you, Jane. So the dialysis and transplant registry is based here, but as the name implies collects information about everybody who receives long-term dialysis for kidney failure in Australia or New Zealand, or has a kidney transplant. And that as a, as an entity has actually existed since 1977, but that was the point at which the separate dialysis and transplant registries were combined. And, and so that data in fact goes back to 1963, when those treatments began here in Australia. And in fact began here in south Australia where the first successful kidney transplant was performed. And one of the pleasures I have in my, my role across the courtyard is on the custodian of, of an old exercise book. We've actually recorded in long hand, the first dialysis treatments in south Australia, and then at the queen Elizabeth hospital. And it is actually a remarkable reading, but fast forward to the present, you say, well, this is not a common problem.

Stephen McDonald ([16:24](#)):

And it isn't it isn't. And why I'm here talking about big data is that kidney disease and dialysis and transplantation in particular have become major challenges for, for the health system and for the health of society and in particular, the older segment of society. So if you look around the country at the

moment, there are around about 25,000 people who are in so-called end stage kidney failure, and all of that, about half a little over half receive long-term dialysis, either most of those three times a week through hemo dialysis. And the other group are have functioning kidney transplants of the dialysis group. A half 50% are over 65 years in age. So as you work through the numbers, if you look at the 65 to 75 year old group, about one in every 340 people actually receive long-term dialysis. So again, that's a lot of people across the country.

Stephen McDonald ([17:20](#)):

It's not millions of millions where we do get the attention of the health system is that every year, somewhere between that costs, the direct costs to providing that treatment are somewhere between 1.2 and \$1.5 billion. Put that into context. The total public health expenditure public health hospital expenditure in the countries ran about \$46 billion. So we have a very big profile with the health service. And so from the health service perspective, and starter has a major role, and I have frequent conversations with in fact, every state and territory and nationally about understanding the numbers of people who receive treatment and what the types of treatment they receive are where those people live and where, where you expect those trends to go in the next five and 10 years time. And, and that, so that is a direct role of, of the data collection that we have that informs hopefully good health service planning.

Stephen McDonald ([18:21](#)):

What that data collection looks like is that weekly data, not from individual patients, but from the hospitals and the, the renal units that care for those patients. When patients begin dialysis will have a kidney transplant, they are given a consent form and they can opt out. But as you've heard from Jane only a small number actually up there, and we collect data about people's treatment on a yearly basis on an ongoing basis. And so that the data accrues that way, what that does end up providing is a rich data set that allows us to provide information. That's not just useful for health services, but for individuals. And one of the important things that's facilitated is providing accurate advice to patients about what to expect, because if you're an older person and you're confronted by end stage kidney disease, you've got some challenging choices to make.

Stephen McDonald ([19:16](#)):

And the reason those choices are challenging is that if you're confronted with that diagnosis, the expectation or the question is about dialysis, and the question then is, will what's going to happen to me and because of the existence of accurate registry and good data, as we can give you very exact advice about not just what the average expectation of survival and relate to quality of life is, but what the range is and what predicts, how you will go. And similarly to what Steve said about the orthopedic registry, that information really becomes important in, in integrating into decision-making. So if you're, for example, somewhere between 75 and 84 years of age, and you just look across the board in Europe about start dialysis the median survival. So th the average, if you'd like is about three and a half years, okay. And that's not too bad, it's, it's, it's not as good as the general population.

Stephen McDonald ([20:16](#)):

Importantly, though, that's the average and 25% of people live less than 15 months, whereas 25% of people live over six years. So the there's an enormous spread. And similarly there's an enormous spread in people's quality of life and understanding what predicts, how you are going to go. You can see is therefore very important to understand and help inform people about the decisions that they need to

make. And one of the things that that's driven is a trend in recent years to think very carefully about whether embarking on, on dialysis treatment in older people is for that individual a positive or a negative thing. And we have been able to track this through linking our data set with the the national death index and some other data sets. So we can look at if you like the people that we don't know about who don't receive treatment, but are hospitalized or die of kidney disease.

Stephen McDonald ([21:17](#)):

And we can say that in that age group, about half of people embark on dialysis at halftime. So that's one example. There are a number of other examples where we've, we've done data linkage to to particular questions. We've demonstrated, for example, that people have kidney transplants have substantially higher rates of cancer in particular, some types of cancer, but not others, and that role through, directly to screening. So for example, if you have a kidney transplant, we know you have a higher rate of bowel cancer, but not a breast cancer. And so you have screened for one, but not the other, the other area that we've become involved with in some of the joint replacement registry is using these big data sets as a means to run randomized controlled trials of new treatments that are not going to be done by drug companies, because they're not cost effective or effectively.

Stephen McDonald ([22:07](#)):

They're not interested as an example of that. We are running a trial, looking at the settings of the sodium level in dialysis fluid, which is simply a change of a setting on a machine. It's an important question to us as doctors, because it probably we think makes a difference. Nobody knows it's not something that's going to make anybody any money, but it's something that we are able to, to run at very little cost. And I think that's one of the things you will see much more of in the future out of big data sets and registries in particular is not just using them as platforms to want to accumulate data in an ongoing fashion, but to actively if like blur the boundaries, which have existed in the past between a large silo of an, of an observational data set, and the other world of setting up a small study to attack a particular question.

Jane Mussared ([22:56](#)):

Finally, can I introduce you to Dr. [inaudible] Who Is A Computer Scientist And Senior Research Associate In The School Of Computer Science At The University Of Alberta? Thank you very much.

Stephen McDonald ([23:10](#)):

So I actually work at the Australia Institute for machine learning, which is now a research Institute that's been established, but recently it's going to be situated at the old age site, and it's also Institute at university of Adelaide. And what we do is we try to work on effectively using this data, this big data that we speaking about to create new algorithms, to find new patterns, to actually solve new problems. And I can give you a concrete example. That's very pertinent to to old aging, to aging and things like that. For last three years, I've been working with a local company on a new medical device, a handheld medical device. That's meant to monitor wounds in particular chronic wounds and the wounds that you'd have other like bed sores, or they could be diabetic ulcers. And these types of wounds don't heal for a very, very long time.

Stephen McDonald ([24:03](#)):

Some people can have them for six months or longer. And in particularly the people who are particularly prone to getting these wounds are the [inaudible] aging population. And the issue that currently exists is

that, you know, you might develop this wound, you'll get a community nurse to come and see you at the community. Nurse might put a dressing on, but you weeks later another nurse comes, it's hardly ever the same person that comes to see you. And they have to make a judgment to see you, is the wound getting better or not there, but to make a lot of different assessments, this is supposed to determine how deep as you weren't. How shallow is it? What's the area, what's the volume? What percentage of the tissue is dying? What percentage of it is healing? And it's a very subjective thing to assess. If I draw it an arbitrary shape and ask you what percentage area is that, plus we'll know how to do it, except if it was a circle or a rectangle, but these are the types of things that people are expected to do.

Stephen McDonald ([24:59](#)):

And what's supposed to happen is if I can determine that your wound has gotten bigger. Well, I know that treatment is not working. And so I might try a different dressing. I might try a different interpretation. What we know is that a lot of people could actually heal a lot better if the world's best practice was applied. When a practice is very difficult to apply because of all of this subjectivity. So the purpose of this device is to automatically assess the wound. So we develop algorithms that take a picture of the wound and then assess the picture and predict or quantify what percentage of the wound is dead. What percentage of it is healing automatically determined? The volume automatically determined the depth and things like that. And we can only do this. So the key ingredient for this type of work is a lot of examples.

Stephen McDonald ([25:43](#)):

So imagine the way you train a nurse, a witness, you take this person and you show them lots of examples of wounds. And you say, here, this is an example of necrosis, and this is an example of slough. And they study for several years. And after a while they become proficient, you need to do something similar with computers. You need to do something similar. If you want to teach a machine to automatically detect things, you have to show the machine. Lots of examples. So what we've been doing, been working with people who have had wounds who have volunteered their data and said, they've effectively said I consent to you using my images of my wound to the system. And the system can only work. If a lot of people do that, that because of, we need to, like, everyone's word is slightly different. You know, you'll have a bigger wound, a shallow wound, different cut, et cetera.

Stephen McDonald ([26:33](#)):

So you need to have the variety. You need to eat, to see all the different ways in which something can manifest. And then what's incredible about this process is that in some sense, like by the wounds of other people, other people are getting healed. So your own, in some sense, your own suffering can be turned into something very positive because you effectively volunteered your information, which can then develop a system, which in 2, 3, 4 years time can help treat other people's wounds. And I think that's in many ways, the spirit of what we try to do with big data, it's really about tapping into what, what the current issues are in our society. What the current elements are that plague us all and try to devise interventions, new methods, new algorithms for solving those issues for the future generation. The way I think about it is like, like supposedly you're sick and you go to the doctor at the, at the moment, you're pretty much at the mercy of the experience of the doctor.

Stephen McDonald ([27:31](#)):

Know if you go there and if I have a problem, that's maybe a bit unusual and I have a doctor that's only good five, his experience that person might not be able to determine what's wrong with me. Maybe

though they are pretty well connected. And so they tap the shoulder of another doctor and they say, Hey, I've got this patient. He's had these particular blood results. But they don't seem to indicate anything to me. Do you know what might be wrong? And that person might have more experience. And so they might have some other cases too, that they tap into and they realize, oh yes. You know, 20 years ago I had a patient that had some similar symptoms. Perhaps you should consider doing X, Y, or Z, but now imagine a different scenario. Imagine you, you go to a doctor and the doctor's able to work.

Stephen McDonald ([28:09](#)):

The doctor doesn't know what's wrong with you, but through some technological intervention, this person can query in a faster, rapid manner database of different patients across Australia and say, well, show me, show me the data of people who have very similar symptoms, maybe a similar age, maybe have a similar medical background. And suddenly you end up in a situation where you get information from two patients in Queensland. And one, it has mania, both of which have had similar symptoms and those cases have been resolved. And so this particular doctor can be kind of inspired us to know what might actually be wrong with you. And I think that's us in the, in the, this is more in the spirit of what happened with charters. Mcdata, it's really about using pooling the experience from a variety of different people across Australia to improve medical decisions, to improve diagnosis and improve treatments.

Jane Mussared ([29:03](#)):

We never got an opportunity for you to ask questions. So I I'd invite you to formulate questions. Then I think we have a mic and that'll do the food around. The first thing I wondered with our panelists would would mind talking about it from your perspective, what's the really coolest thing. Perhaps in your experience that big data is helping us with right now. Let me just tell you the coolest thing I saw was what's the best joke of all time. They apparently big data has enabled us to make a breakthrough and learn what the best joke of all time was. So it seems a bit, I mean, there must be more,

Stephen McDonald ([29:44](#)):

I'd tell you if I can remember it. Well, one of the incredible things that I've seen, there's some research that's come out of our research group and partnerships with some collaborators in the U S has been some studies where they've taken. And I think it was, it was a full body scan. I don't know if it was a MRI scan or some kind of full body medical scan of people that had presumably nothing wrong with them. And they followed these people for several years, maybe 10 years or so. And what they then were able to do is they were able to train a system that just analyzes as this image, the image that was taken a few 10 years ago and was able to predict at this stage about 70, 70% accuracy, whether you'll actually die. Now, that sounds very morbid, right? But what's really impressive here is that with this big data analytics, there is, there has been some pattern that's been detected in the people 10 years ago that we, the medical community doesn't know how to characterize yet.

Stephen McDonald ([30:44](#)):

We don't know what was all of them, but what the system did. And this system can predict quite accurately that there is something wrong. That's a really good screening tool. Like if you think you go there and if we can get beyond 70%, but maybe, you know, 90 something percent, that's a really good indicator to say, well, we shouldn't send this person home. The system is saying there's something wrong and it's really investigate. And it's really dive into and figure out what could be the cause. Why

does the system think that this person might not be alive 10 years from now? I think that's quite incredible.

Stephen McDonald ([31:18](#)):

Availability of big data is driven for me to changes in the philosophy and the way we think about evidence and research. And the change in the way we do research is, is this is that we many people were my generation of Steve's generation. When I started my PhD last century, it was going to find a research question, find the protocol, go and collect the data, analyze the data. So question first design data analysis answer. And one of the things that big data has done is allow that process to be inverted so that the data is out, that that is being collected anyway, for other reasons. And so the not the incremental cost to answer new questions is just ask random questions. If you like, what's the best joke the, about the incremental cost has, has shrunk wise, so that the potential to to get a positive answer from a question is much greater.

Stephen McDonald ([32:23](#)):

The other change is an, it relates to the traditional model of research, which still is very valuable in terms of setting up a trial, which is the traditional way to demonstrate that a new medication or a new intervention works. You do a trial, you recruit a number of people and you might randomly give half of them treatment. And half of the treatment, they, by their nature, those trials generally only include a very tightly defined range of people. And so if you ask what's the evidence for use of a particular type of drug for a high blood pressure, I would say, look, there's great. Evidence in the general population is very little evidence for, I put that in my particular group of people who have, might have chronic kidney disease. And I need to make a guess about whether that evidence really applies to, to you who are afraid of me or not. And what big data allows you to do is actually look at the whole population. And, and out of that, draw the groups of people that and experiences that are similar to the question that's confronting you at the moment. So it's about being able to look at whole populations rather than, and look at the evidence from that rather than the, just very tightly defined segments that may not actually be all that closely related to the problem confronting you.

Steve Graves ([33:46](#)):

I was actually going to say a very similar thing really in that I think what is really, really cool, it is actually changing the science of medicine and that but the coolest thing about it and being involved in it now for over 20 years is actually seeing the real benefits from doing and that that you can have extraordinary impacts on the delivery of healthcare and the quality of healthcare. And there's just so many, many people that are benefiting by this connectivity of data and looking at the data in a detailed way, and being able to interpret it by those people who are knowledgeable in the area of the practice that you're looking at. And it's just been quite extraordinary, the benefits that have actually been achieved. But the other really exciting thing is the things that we're starting to discover that you can do, which we never even really thought about.

Steve Graves ([34:46](#)):

It's looking at things like, okay, certain devices, joint replacements, I behave differently depending on which drugs patients are off. And so it's, there's interaction of all that health care that a patient is under and how you can optimize the total package of milk for people in a whole variety of diseases, because there are different practices that work better in certain situations. And one of the things that Steve and I are doing actually is, is linking our registries because from our perspective from Jordan provides, but

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there are very special problems associated with joint replacement in people with renal disease. And people just don't have enough information on that, but by combining the registry it's, we can actually start to look at that in much more detail and we can start to identify and optimize the way people are cared for and Arctic.

Jane Mussared ([35:44](#)):

Okay. We've got time for a couple of questions. We've got one.