

SYD - Karen Luxford

Our first speaker is from the Clinical Excellence Commission. Dr Karen Luxford is the Director of Patient Based Care at the Clinical Excellence Commission, from 2010. Dr Luxford founded the Partnering with Patients Program at the Commission, to promote patients, family and carers as Care Team Members. And the role of patient based care in improving patient safety and quality in health care services. In 2008/2009 Dr Luxford was a Harkness Fellow in health care policy and practice, Harvard Medical School Boston and studied exemplar patient focussed organisations in the USA and the role of leadership in patient engagement and patient feedback, in improving service quality. Dr Luxford is an ISQUA expert for the International Society for Quality in Health Care. Would you please join me in welcoming Karen.

Thank you very much Leigh. It's a little bit of a change of pace from the rest of today but you're ending with the most important bit, the patient. So thank you very much and I want to also acknowledge my co-presenter, John Stubbs, who has been a colleague of many years and is now also a CEC Consumer advisor, so this is a bit of a tag team between us this afternoon.

As Leigh mentioned, this area within the standards is a very important one. It's one that is also pervasive throughout the standards, when you're looking at the various criteria. Certainly in the circles I move in, there's a lot of discussion about standard two. In terms of partnering with consumers but when you really have a look at the current throughout the whole of the national standards, it's very much about how we do that partnership piece and how we really work with the user of the service to get the best possible experience. This is where when you're starting to look at the work around blood, that there's also some important criteria that relate to that partnership.

I wanted just to give a little bit of context because I think where we're at, at the moment, we often have patients experiencing things being done to them, rather than with them and rather than being in a partnership. It's important to start to think about what are those essential components of partnership and they require a change in the dynamic between the people who are involved in that relationship. One of the things that we've been looking at, at CEC, is trying to get a feel for a shift in attitudes by health care professionals, people working at the cold face, about how they see the patient as a part of the team.

I was really encouraged in the first year of our work that we have slowly being seeing a shift in the views to how integral is the patient and the family as a member of that health care team. So we're making some good but slow, steps. And I think we'd be mistaken if we think that we can really tinker around the edges and look at models that in many ways are provider focussed and think that they're really going to come up to the standard and come up to scratch. Engagement is really a much bigger and integral step than thinking we can just slightly tweak models that really focus around providers.

And with that in mind we founded Partnering with Patients. In the work of CEC, often focussed on the safety and quality aspects but how do we actually get that

true partnership and how do we really listen to the people who are at the centre of that service and think about how we'd do things differently.

One of the areas I wanted to talk a bit about was around the issue of care planning and this is something that is mentioned in the criterion for the bloods standard. How do you do that planning in partnership? What we see when we look at the international literature is often the things that health care professionals think are the expectations of patients and families, indeed don't marry up with what it is that the patients are expecting. Particularly what family and carers are also expecting out of a health care experience. We need to acknowledge that there's a distance between those two sets of expectations. Assume nothing, I think is a good place to start from.

And find out what those preferred outcomes actually are because they're possibly different when you're doing care planning to the things that you as people involved in the health care system, might think they will be. And that involvement and engagement of the carers, the loved ones, the family members, as much as the patient wishes them to be. So how do you do that? How do you really get people as part of that partnership? And then developing further the art of listening and I know that's very hard in our busy world but I think in everything that we've seen, it pays back many, many fold if we can actually just stop and think what it is that the patients are telling us and what they're really trying to get out of a particular experience of care.

We also need to consider that it's not one size fits all. We talk about patients as though they were a amorphous group and we forget about the many differences. There's been some very good work done in Australia and internationally around looking at the area of health literacy quite broadly and thinking about how that impinges on people engaging with the health care system. The Australian Bureau of Statistics did some research a number of years ago looking at the levels of health literacy in Australia and they found that 60% of Australians have low health literacy. So what does that mean? That means that they have difficulty in doing every day health tasks and assimilating everyday pieces of health information, such as medication instructions. So really fundamental low levels of health literacy.

That parallels what we see internationally, so it's something that we need to be cognisant of and it's very much brought to the front in the national standards. So when you look throughout the standards there's a stream of criteria that relate to providing meaningful and useful information to patients and families. Often when people are provided information in a health care setting they will get a little bit of that through, in terms of understanding but often not all of that information will be assimilated. How do you actually ...yes, I can see the people who are giggling. Very good at reading backwards.

This is not dissimilar to what a piece of health information can look like to the average patient. And there's a lot of good meaning people who are developing patient information but often it's really not well understood. We do a lot of work in our programs at the CEC with getting advice from our consumer advisors about what we should be developing and what that information should look like. Text based, large text based was not a good idea. Graphic, simple, icon driven, short pieces of information, lay language are the things that really cut through. We were lucky enough to have an expert from Harvard, Dr Rima Rudd, who did some

work with us about a year ago around how do we break down those barriers because I think a lot of people put the onus on the user of the system "oh well they have low health literacy, they don't understand us. If only we could raise that level of health literacy, then they'd know what we were saying". We need to turn that on its head, we need to be thinking how do we break down those barriers for patients to be understanding information and assimilating it as it suits their lives and the things they're really focussed on. And even when people think they're doing the right thing because they think they've understood the information that's been imparted, that can be interpreted in so many different ways and I'm sure you all encounter that in the things that you're doing working, around the precious resource of blood.

There are many techniques that we can use to help our patients, to help our staff, in the way in which they explain information. One of the techniques that we've taken from an educational setting that some of you may know of, is called Teach Back. Is anybody familiar with Teach Back as a technique? It's quite a simple technique that recommends that if you're a health care professional and you're imparting information, for example about risk in this setting, I would have thought that's quite important, that you not only give that information as a one way communication and then say "do you understand" because most patients will go "yes, I do". Nobody likes to look silly "mmm, I understood that".

Teach Back is a more approachable way of saying at the end of a discussion, a dialogue "so Mrs Smith, we've talk about a lot of things today. We've talked about the risks of this transfusion, this bone marrow transplant. Can you tell me what you think is important about the things that we've discussed and what you're going to take home and tell your family members about what we're planning to do with this procedure"? And then letting the patient actually convey that information back is a really powerful tool for picking up on what has been taken on board. And it really will save you time in the end.

And we can't just be thinking about information as written information, so when you're looking at this criterion standards as it appears in many of the clinical standards, it's not just about the written patient brochure. It's really much broader than that. You need to be thinking about verbal information that's conveyed, written information, way finding, signage, what your services look like, how approachable they are, how easy is it for people to navigate their way through that system. We've been working on some simple tools that are electronic to pull a lot of this information together around health literacy. We have a good partnership with the Australian Commission, which has been working on a discussion paper in this area.

We've been focussing on some electronic tools, so we're going to release this on our website so it will be available for everyone to use and it will pull together some of those tips about creating meaningful and useful information for patients. So not using a reading age that's higher than a 12 year old, making sure that there a minimal pieces of information included, not suing complicated jargon, so some very basic information. And also links to some fantastic electronic tools that you can use when you're wanting to scan the information that you're preparing. I particularly like SMOG, the simple measure of gobbledegook. So if you wanted to just run a bit of information past some of these software packages, they'll tell you the reading age and it will help you to think about what you're preparing.

Before handing over to John, I just wanted to touch on the area of informed consent. There's quite a bit of good research around informed consent. We have a number of experts here in Australia. Marie Bismark, based in Melbourne, is a health lawyer who's done a lot of work in the field of informed consent. I think it's very clear from the research that we need to be thinking about not just the written forms that are produced which tend to have a lot of dents of information on them that are hard for patients to actually penetrate, to get cut through in terms of what are risks and benefits of procedures. And it's not one size fits all, again. We really have to be able to think about different people's needs and the information that they want and that trusted relationship with a health care professional is a very important part of that being informed process.

I'm going to leave it there and hand over to John, who is also going to give some of his personal perspective.