Telling Your Story in a Meaningful Way

Amy and Emma, Brook Red – Voices for Change

Lisa and Ian, Lived Experience Presenters

Thursday 14 June 1430-1630 - Breakout Room 1

Leonie Sanderson: Let's get going. My name is Leonie Sanderson, I work with Health Consumers Queensland as an engagement advisor mostly in the mental health space. I work on a couple of projects around mental health. Today we have a very exciting session around telling your story in a meaningful way, which I think is like one of the things that is really significant and one of the most impactful things that we can do as consumers and carers and people with lived experience is to be able to tell our stories well and safely. Today from Brook Red we have Amy and Emma who are going to be the facilitators for the work shop today and we also have Lisa and Ian who are also presenting from their lived experience perspective. Just a couple of things, it's a two hour work shop, I'm going to be letting people know when that time is getting close to the end. There was going to be captioning for the session but I think the technology is having a few hiccups so that won't be happening for this session unless they get the technology up and running again halfway through or something like that, we might be able to get something going but at the moment it's down. The networking drinks will be following straight after this session in the main concourse from 4:30 to 5:30 so it would be great to see you there for an hour and have a little bit of networking. There are also a couple of surveys and questionnaires going around so if you are up at the registration desk there's a little lounge area. If you have some time to sit down and do a survey that would be fantastic. There are also some yellow forms which are asking about preferences for training. If you see those things please take a moment to fill those out and give that information to us. I think without further any ado I'll hand over to Amy and Emma from Brook Red.

Amy: Hello. Can you hear me everyone? No? Yes. I should be singing. Welcome everybody to the work shop today. We're very pleased to be here to facilitate the session today. My name is Amy, I'm the program coordinator for voices for change, my role is to support people to tell their story. Which also have Emma here who is a peer worker at Brook Red and we have Lisa and Ian who are going to tell their story about what it's been like for them to share their story publicly and to shape and frame their story within our program. We have a couple of bits that we wanted to go through today. I thought it might be good to give you a background on what voices for change is and then to month on to Lisa and Ian to tell their experience to you of what that's been like so far and then myself and Emma for the last part of the session will do a bit of the writing work shop so we'll give you an opportunity to shape and frame your own story and to do a bit of creative writing so that will probably go for about an hour, maybe a bit longer.

The reason we have asked you to sit in some groups is just because we're going to be having a bit of a group discussion as well. A bit of a background for voices for change. It is a Brisbane-based speakers bureau where sharing the stories of people who have a personal experience of mental health challenges and recovery. Through the program people with a range of lived experiences are engaged in the program. They're trained and supported to become professional speakers and motivators of community change. We focus on addressing stigma, improving mental health services and promoting and understanding of mental health challenges, we also focus on supporting people to explore, articulate and draw meaning from their recovery story.

Our program, we aim to increase a personal and professional skill development of the presenters through regular training, social inclusion activities and peer support so all of the presenters that come through our program engage in if an initial two-day work shop with us where they learn some skills around public speaking and then we have ongoing training sessions as well. That's a bit about our program so far. We began through Brook Red, I'm not sure if many of you have heard of Brook Red? We have three centres, so we're a peer managed and operated community mental health organisation, we support people through a holistic recovery through mental health challenges. We've been running in South Brisbane for 15 years, and we've now got three centres and run a number of recovery programs, one of those is the voices for change program. In mid-2014 Brook Red met with a total of 131 people as part of its voices for change consumer consultation project and within that project we focus on identifying what was the way that people could be better engaged to inform the mental health system and we wanted to gain a clear picture of what consumers both wanted and needed when it came to having their voices heard.

There were two main themes that evolved from that consumer consultation project. The first theme that came through was that it can be very challenging to gets an opportunity to use one's voice and to tell one's story and the second one was that people wanted to upskill themselves so that when they did get an opportunity to share their story and to use their voice that they could do so as powerfully and influentially as possible. So that's why we have that intensive training session at the start, those two days, to get some of those skills around the public speaking and then we do some further training on how to shape and form your story so you can use it as powerfully and influentially as possible. The next year in 2015 voices for change was formed so we've been running for three years now. Once we did a bit of research around story telling, we looked into narrative therapy and we looked into the benefits of people being part of a program where they could come together, have that peer support and to be able to share their story in a public way. There's been lots of research out there about being part of a type of program and forming a story about one's experiences.

Looking at the perspective of what have I learnt through my experience and sharing that story with others through that perspective of what have I learned and what wisdom have I gained that I can share with other people. That's the kind of perspective that we work from at voices for change, is we work with people to really kind of frame and restructure their story so that they can tell that from a point of hope and strength and resilience. We've present Dodd a variety of people, Lisa and Ian included, we've been asked and been very fortunate and asked to come out to present to GPs, trainees and psychological medicine, university students in training housing service, counsel workers, community organisations, the general public, prison chaplain, Queensland mental health commission, we've spoken at different festivals, conferences, men's shed, rotary club, we've held a number of events ourselves as well so the context of the type of stories that you're sharing, it varies quite a lot depending on the audience you're talking to, so we've quite a number of people invite us to come out. The feedback's been quite good so far so it is quite a new program, but so far it's been quite good. Especially around talking to GPs.

It's really useful to see things from a patient's point of view to notice the signs to look for and how to help practically. It represented lots of conditions relevant to GP practice, you make a profound difference to these doctors so we've had some good feedback and getting up there and telling your story can be a nerve-racking experience. Nobody really likes public speaking but we do it to make a difference. It's really great that we give out those feedback forms. We might have a bit of a chat with Lisa and Ian about what that process has been like for them so far to engage in that initial training to come forward to the program without any experience of public speaking and to really want to share their story but not really sure how. We thought it might be good to do a bit of a question and answer session to draw out some of those experiences from them, so I might go ahead and do that. If you have any other questionings please feel free to come forward with those afterwards. You've been sharing your story for a while now. Is it possible for you to just tell us a little bit about yourself and why you initially wanted to be part of the program and why you wanted to share your story?

Ian: Yes. With my experience I think it's been a bit unique. I think being part of the voices for change, the preparation started ten years ago, when I joined Brook Red. When I finished working as a peer support worker the voices for change program had just started to commence and that was my next part of the journey.

Lisa: I'm Lisa. When I first got involved with voices for change I was still a hospital patient, still regularly in and out, so Ian and I met with eight other people and every one of us had a different story and it was just so delightful to be normalised in a group that had hope, if nothing else, we certainly didn't - I certainly didn't have the skills to do the speaking. My mental illness still fluctuates, I still go to hospital four times a year, it's all very drab, but I find that by being trained and having someone invest, an organisation invest in us, really was a landmark shift in perspective for me.

Ian: Somewhere deep down there is someone who wants to perform! It's just an opportunity that came around and I thought it sounded exciting.

Amy: You come from an exercise background.

Ian: I used to teach maybe this many people in body combat and body pump.

Amy: Which is why you're all here!

Ian: That's the next session. I came into the voices for change unaware of how unbelievably angry I was and unbelievably unaware of how disconnected I felt to the community, to the world really, and how isolated I'd become with my unwellness because it was very - I had no warning and it was quite catastrophic and it would be eight years in two weeks to go from a loss of a lot of cognitive faculties and stuff to - I couldn't write when I first joined the program, or read, so I obviously have come a long way.

Amy: What audience did you really want to speak to? That's something we asked you when you come to the program first. What are you passionate about?

Ian: My main motivation is to reach out to fathers. My hope in the early days was connected to my boys. There's a bit of a story behind that, so that's part of what I share. That's the audience that I wanted to really connect with and from there it's extended, maybe if you're not a father but you may have a husband or you may have a brother or a neighbour who is a father and they're going through mental health challenges, just help that understanding about the importance of the connection with family.

Amy: Was there a particular audience that you wanted to speak to?

Lisa: I think initially I just wanted to shout and cry at everything and everyone. I quickly realised that that would be utterly pointless. I get a deal of satisfaction in sharing with both professional carers and students and being able to enable them realise that the phrase or term mental illness does not mean that we suddenly sprout little horns and pointy tail. First year nurses, they're such a delight. You can always tell, I'll just show you what happens. They always travel in three. It's really tragic. By the time they get to second year they're starting to walk like this. I have no real interest in that group, because I want to convict with them. They're supposed to be connecting with us, to care for us, how on earth are they supposed to bridge that gap if they have no idea how to communicate with us? So someone's got to put their hand out first and say, "Look I'm just a person actually." And then I go from there. Obviously the peers, we just grab them, get on fab, because we already have that innate understanding but they're my favourite audience, the students and the GPs who are learning as well. They're quite good fun.

Amy: Was there an important message that you particularly wanted to share?

Lisa: That I'm a real person. None of us choose mental illness, not one. Everybody has lost an idea of what their life should be. Everyone is broken hearted and hurts. You can stand there and feel good about telling someone how to fix it, you know something about bootstraps and get over yourself and stuff like that, and it’s so helpful.

Amy: What about you Ian, was there a particular message?

Ian: My message is evolving. It's a process. It takes, I think with each opportunity it's just refining that message and that message for me I think as I move forward in my life is just the equality that we all deserve and the right, it doesn't matter - our ability or disability, it's just refining that and then having the confidence to assert that, because I think in my experience of one of my conversations or more than that with groups and so forth, it's captivating capturing your ears. If I can have confidence within myself, to assert that, it will be received with that message. Have you found any benefits at all to your own life in being part of the program and being able to share your stories, made any changes at all to your own recovery?

Lisa: When we were invited to reframe our story from a recovery point of view, I was angry because I was not recovering in my mind. We had a fantastic brain storm of what recovery actually meant. It didn't mean we were going to revert back to what we were before because there's no such thing as turning back time but I need to move forward. It was a pivotal shift for me to be able to say, "Look your story has a whole bunch of information there. When I become more feature focused and become more present focused, then I have something to carry, have something to share." My sense of purpose was born, reborn because as I say I lost everything when the breakdown occurred, the whole kit, so and community status, even permission to have an opinion. Just permission to have an opinion. Someone could actually ask. That just stopped, no-one asks me for my opinion, just find it really annoying.

Ian: My co-presenter represents part of my growth development with telling my story, my own personal benefit and that's kindness. She represents kindness.

APPLAUSE

Lisa: For myself, thank you for that. Getting up here, it's always comes back to the notion that I need to trust myself so that I learnt how to do in my first presentation which I was a nervous wreck and I still get nervous but that's that journey to trust yourself. That's the main benefit. The second part would be working alongside come great people, the other presenters, Amy, with Monique who started the program, have all been great, extension of that peer support that I've received in the past and it extends out at the opportunity to talk to people like yourself and I think for that I'm learning now more as I go through the this journey, it's somehow the essence of trying to consider what is important to the greater community as well.

Amy: I think that was something that you mentioned, Lisa, about if you don't say anything then nothing will change and that you found that that was adding to the resentment. It was important to at least say something.

Lisa: If we could... I've experienced a lot of verbal suppression so I know that to get someone's attention that don't do it that way, we really need to be very clear about that connection where we feel connected. It's so important, you have a story, everybody has a story, and resentment is allowed to be in it. It's perfectly legitimate. It's part of the journey. It can prop up in all manner of places, doesn't have to be a mental health thing. I'm sure you'll all find a source. I was very disempowered to - sorry, I have aphasia so I'm learning my words. I'm just going to stop talking.

Amy: How has it been for the both of you to reframe your story, to work together in the peer support group and to work with me and to look at sharing your story as a point of hope rather than a point of recovery rather than just telling an endless story?

Lisa: Unbelievably exciting. It's just exciting. I rant in my head a lot. It's really boring, never inflict it on other people. Goodness, hope stories, at night where you'd have no idea where someone's candle is just so close to the edge and hope is probably the thing - when we did a work shop, do you remember when we made a gift to each other? And hope is what we take so when we go into a presentation it is with a view of helping people understand that when we are very unwell and we are now lower than the lowest class of citizen in society with mental illness that there's hope because it's pretty miserable when you're in it but if we can say that we have been there, and still am, it's the only reason why I do it and the only reason why I'm prepared to be incredibly nervous, very uncomfortable, putting on lipstick, you have to be.

Ian: To continue the voice of hope, as I mentioned before, my family representing that hope for me. I think the empowerment that I receive through telling my story and you mentioned earlier within some of the research and what you did before and talking to different audiences or to different individuals that come into the context of our story is changed so I think that's very empowering to learn, that this was my experience and these are the words that I attach to that experience and then reshaping that, putting it in a different context. And learning that broadening your language capacity, provides that hope within me in my social life, I have established a lot of relationships now so once it was just hanging on to hope, now I have a lot more relationships that are meaningful to me now as well.

Lisa: The back of your palm cards, the last one said eat and this one says the tiger.

Amy: These were cue cards that were used for an adult learning program. I just got these second hand cards. Thank you for that!

How do you tell your story safely and make sure that you're OK afterwards and that you're sharing something that you feel comfortable in sharing? Or how do you look after yourself if it doesn't feel very comfortable?

Ian: I've often taken someone with me and I've always debriefed afterwards. When we share our own story, you know how we have memory - you just access memory, when the prefrontal cortex goes down, I have to access memory through emotion so when I share my story I have opened all those charming little boxes and I have got superglue there so we have coined a lovely phrase, a disclosure hangover, you get to the end and yourself think what have I done?" Debriefing, extremely important. The other thing is the feedback form, very important, self-compassion, I know that I'll be tired tonight and tomorrow and probably the next day. It's part of the healing. It comes at a significant hangover.

Lisa: At the training we kind of give permission to people to only share what they're comfortable in sharing and that's one of the first times we speak about to ensure that you have a look inside yourself.

As a human being we do have the right to say, "Thank you for the question. Today is probably not a good idea otherwise we may get side tracked but a good question and whether you need to ask it, I'm not the best person to answer it today”, and really important boundaries to discover, that we as individuals have the right to say thank you but no thank you. There was something else...

Ian: I think also if you choose to talk one-on-one, if you see me at the end of the presentation.

Amy: What part do you find most difficult about sharing your experiences?

Lisa: Panic attack in one. An absolutely classic. The feedback was amazing. I felt the sensations start in my centre and you know how that's things. You know what? You're all GPs, I'm going to describe some things here. I don't want you to move. I'm just going to share with you exactly what it feels like for me to have my panic attack so I'm going to walk you through it and I'm going to show you why I'm now diving into my handbag to get my Gav, circumstances con and my daughter has gone to get me iced water because I need that to keep the temperature and that was fantastic because as I got near the end of it I then had a minute or two just to read through it, but we found that the feedback afterwards was "gee that was fantastic. You showed us more than we could have understood if you'd chosen to leave the stage and hide the truth or the reality of the experience." Panic attacks by their very nature do tend to come a little uninvited. I think that's the trickiest, emotionally very triggered.

Amy: What would you say to others if they feel that they're not ready to tell their story yet?

Ian: I think that story telling is going to happen naturally. When somebody might want to understand what that's like for you with some of the challenges or the experiences you have with your condition and that has a ripple effect as well. If someone's inclined to feel the need to share their story on a public thing, it's the emotional support that I've learned is important for me because it's a lot of work that goes into having to prepare it and we have this program that is a privilege to be part of with Amy doing so much great work with that and we have each other to support each other, we get the opportunity to tell our stories through the training as well, shaping our stories and exploring that part of story telling as well and that's pretty good position or privilege to have as well.

Amy: Would you have any advice for others about to start to frame and shape and write their own story?

Lisa: Your story is inside you. Only you. We can stand here and see all of you and we will have completely different experiences. So when we share our story it's through my eyes, own it. It's really really awesome to hear what the world is like through your eyes, because it's always an extreme case and it's real and I want to hear it because I feel closer to you when I know how the world operates for you and so have a psychologist appointment shortly after. I'm not him. Amy has some very superior psychological training and skills, and letters to prove it and she helps us enormously. It is so important because to open your inner most closet to one other soul, let alone a room, it's intimidating. You have a goal, a purpose, and you anchor on that, even if it's just simply to prove that you can survive the experience and so as to encourage others to take a risk as well. I think it's really important.

Ian: Great words, have to follow up. What was I going to say? Got to do our cool-down now, our stretch. It's just part of the process. I suppose good to have in your mind what that vision of what that might be like to tell a story starts within, as Lisa eloquently expressed, starts within, we all have that story. It's telling that story in a meaningful way, you need to find that meaningful way within myself and trust yourself and trust the process as well.

Lisa: And always be aware, your audience may not be ready for the vulnerability you disclose alright? That's not your problem and it doesn't mean that your presentation is wrong, it just means that that person or that couple of people just weren't ready and you just bless them and say thank you, but do not judge yourself by that. That is absolutely relevant.

Amy: How do you tell your story in a way that's meaningful to you? That's something we'll work on later but just from a personal point of view?

Ian: That would wrap up a lot of things I've said myself. I'm a very methodical person. I think a lot of in the back of my mind, even as I'm talking, the aspects of my life, I wrote down in a way for me to understand my relationship with things and the three things that I look at with the aspect of hope is with families so if we can change the relationships between families and to extend ourselves further into the community, if we can possibly create that ripple effect of change, future generations, which I have to believe in, that's what we're doing and the last part being myself, it's just increasing my understanding by continuing to ask Myers the questions that I seem to always ask of myself or curious to ask others.

Amy: That's great. Thank you very much for sharing.

APPLAUSE

Amy: For the next part of the work shop we wanted to give you an opportunity to start to write your own story. There's lots of difficult ways that you can shape and give meaning to your own experiences. I suppose what we'll use as a bit of a framework for change, so when we tell a story at voices for change, this is the kind of framework that we use, you might have seen this before. This is the story arc or the hero's journey. And for us, this is writing a story of hope and writing a story from a perspective of strength and resilience and learnings. The way that we start to tell that story is to look at our key messages and our purpose for why we really want to share our experiences with an audience and we use those key messages and that purpose to shape and frame our purpose of writing our story.

The only other time that someone can access a My Health Record record in the legislation is in an emergency, a clinician can exercise a break glass facility and that means that you're unconscious, they want to know if you're on any medication they can see that information there but this is an instances that carefully monitored and reported to a person. For example if a carer is not available to give consent, that's when the clinician can access it only in that emergency. There's an audit log so whenever someone logs in the details when they're there their status, their approved access is recorded, there are fines of up to $160,000 for unauthorised access plus two years in jail. This access to privacy is pretty serious. All instances are monitored and recorded. Matthew will call out some of the functionality later.

The information in the My Health Record is for the patient and their health care providers and it's governed by the Australian privacy commissioner and they're the independent regulator of the privacy aspects of the My Health Record. They provide advice to health care providers and assess data breach, the commissioner can also conduct an investigation without receiving a complaint if there's mishandling of personal information in the My Health Record suspected and as the consumer you have a right to call that out and contact the commissioner if you're concerned. The commissioner's office can help health care providers and understand their privacy obligations as well as answer questions individuals might have around handling their private and personal information.

As the agency we are committed to ensuring every Australian benefits from having a My Health Record. However we do know that not every individual want to have one and I've said that and that or that is part of the reason why there is an opt-out period. This is why every Australian will be given the opportunity this year to opt out from having a My Health Record created for them. In closing, our message is your health record is your hands and as Harry called out around having information around his mobile he takes it with him whenever he goes. He and many are embracing this concept placing themselves in the driver seat of their health care journey. Thank you.

APPLAUSE

I'd like to hand over to Christine. Just turn the mike down a little bit.

Christine: To begin, I would like to firstly take this opportunity to acknowledge the traditional owners on whose land we meet today and pay our respects to elders past present and emerging, my first question is who here has a My Health Record? Hands up? That's very impressive. Well done everyone. Who here obviously doesn’t have one but has heard about a My Health Record? That's pretty good and out of who here that's heard about it is thinking that it's a good thing or doesn't know? So there's a mix in the audience. One of the rows that we're doing at the moment is a significant national community engagement and awareness campaign to we want to reach all Australians and let them know about the fact that everybody by the end of this year will have a My Health Record set up for them unless they choose not to have one. So obviously it's a huge job for us to make sure that we at least let people know about what a My Health Record is and the benefits and then people can make an informed choice about whether they want to then have that record set up for them or opt out.

Basically, the way we're going to engage the community and this has already begun in the last two or three months, which will increase as we move to the opt-out phase which James mentioned will start on 16 July and we basically are going to be involved in a multifaceted, multilayered and hugely targeted campaign. So basically we have a number of target groups that we want to reach so obviously there is the general public which is you and I and everybody, pretty much but we also want to ensure that we reach a number of other specific groups and there's a lot of work that's being done at the moment around the planning of information and activities to specifically reach those groups and as I've explained up here we're really targeting rural and remote communities, multicultural communities, Aboriginal and Torres Strait Islander people, people with a mental illness, people with chronic conditions, the disability sector and older Australians. What's happening is I work for Gold Coast primary health network and we're the Queensland hub for communication and engagement activities across the State for My Health Record. So what that means is that I'm basically working with all my PHN colleagues across Queensland to make sure that all of our engagement is targeted and localised so that we can basically have the best chance of reaching local communities.

So one of the pillars of our campaign is local grassroots engagement and when I say that it's things like this, it's being able to come to forums and be able to talk to consumers and people, to obviously inform you about what is going to be happening this year but also from our perspective to get feedback from you about ways we might be able to better reach and target people to provide information as I explained so that they can make an informed decision about their health record. It's a great opportunity for us to be here and we will be answering a number of questions straight after this presentation and we have a panel discussion so that you can do just that. As part of that, we basically, every primary health network has dedicated community engagement staff that have a mandate to get out in their local communities and engage, in other words talk to people about My Health Record. There are a couple of trial sites that were done around the opt out process, and that was Cairns and also North Queensland and the Blue Mountains and some of the research and findings from that which was significant engagement activities was that grassroots engagement and face-to-face engagement as a significantly important part of the campaign because talking to you face-to-face you can ask questions, you can discuss your concerns, your feedback can be fed back through the system and we can also make sure that obviously there is significant involvement engagement with consumers and it's just a critical part of our campaign so I don't think there's be many other campaigns that I can think of where such a lot of time and resources have been implemented across all of Queensland to get out and into the communities and talk to people. Just out of interest, how many people here are from Western Queensland? We have a couple. What about central Queensland? We have a few more. Sunshine Coast? Got quite a few more. Very nice part of the world. But basically we have primary health networks in seven different regions in Queensland, including all the regions I just mentioned. And they're basically getting out into the communities and they're going to a range of different things, as I mentioned here, they're going to your local shows, to events they're liaising with all your key stake holder groups, basically the advantages of the primary health networks getting out and doing engagement is that they're already doing it and most primary health networks have consumer advisory committees a, a number of those committees are also being consulted around My Health Record and a number of consumer champions are come from those committees as well so that they can go out into the communities as well and at least talk to people about what a My Health Record is.

We estimate that we are going to literally reach hundreds of thousands of people through these engagement activities, on the Gold Coast alone, for the last three months we've had engagement staff basically stationed there and all she's done literally is meet people and setting up meetings, going to events and so far she's probably engaged face-to-face directly with well over 2,000 people and she's potentially reached another 20,000 at the event and when I say face-to-face you might have 2,000 at the event, people can get information and take it but it's the people to whom she gives her time to also provide feedback because obviously communication is a two-way street and we value that feedback, so it's a very important mechanism for us and that's basically what's being rolled out on an even bigger scale from July right through to October. As we obviously continue to inform people about the initiative. As I mentioned here there's also a lot of engagement happening through the PHNs and also I'm also meeting a lot of peak health organisations for example across Queensland, we're also meeting consumer groups, Government organisations, a whole range of different groups to again get our message out so anyone who has any influence in the community or is out and about in the community we basically want to inform them so they can inform their clients or their consumers as swell so again this is a significant part of our engagement campaign. Supporting that campaign, as I mentioned which is a very diverse, that we have a wide range of advertising options, that are basically being developed by each State. As I said, one of the huge things we're doing with this campaign is it's tailor made for each region, this isn't just an initiative billion rolled out nationally, it's tailor made, what that means is that all local staff at their PHNs have all completed these regional plans which also outline a number of options on how to best reach all consumer, that includes your advertising options as well as your meeting and activities planned for the next few options and basically that's fed into a state-wide plan and that means that hopefully the advertising that we will be doing will be locally tailored for the local audiences and hopefully also using local people.

We are also targeting a wide range of publications where we'll be doing some advertising in editorial examples of that might be a bowling magazine that goes out to 40,000 people, we have just done a seniors magazine where we have a two page editorial and specific examples from seniors ABS how that record will work for seniors, and basically that's gone out to 110,000 publications across Queensland. Again it's all being underpinned by additional strategies to try and get the message out there. And then there's as I said, specific strategies for targeted group, nacho for example have been involved with Aboriginal and Torres Strait Islander strategies as well as a huge body of work to specifically target the best ways that we can reach those communities working with AMSs and a whole range of different options and so the same with the multicultural community as an example, we're looking at translating our brochures into at least 20 different languages, we're looking at a whole range of publications, radio and different mechanisms whose community leaders and events to reach those events. Most recently on the Gold Coast we had Japan and friends today, we have a consumer champion who is Japanese, so she was able to go along to the day and speak to people in Japanese, because obviously that's not something that we have the expertise in but they do so we want to use every mechanism we can think of to engage consumers and as I said there about community champions we do have a number of people who are champions who are able to sort of - who are known in their local communities and can talk to their communities about this. And also supporting our strategies of course is media and events so we're looking at, you know, your local papers and your regional communities running a story and a bit of an interview and things like that so that again with all these other options if you missed out hearing it here hopefully we'll pick you up somewhere else and you'll hear about it through the local press. The local media stories will be important. Regular information that's promoted at key stages of the opt out process so we keep this things current as we progress, case studies are a really useful tool around people's experiences from different groups and backgrounds, and recently the CEO of the Kathy Jackson health agency Tim Kelsy did a presentation to the press club and the reason he did that was to again brief journalists about the fact that this is coming, everyone will have a record and we need to let people know that you're going to have a record unless you choose not to have one, and if your a record we would like you to also learn how to use it effectively. As in the modern age, probably for people a wee bit younger than myself, we have a social media strategy so this strategy will look at a range of different things, including your Facebook, Twitter, Instagram, we'll be sharing posts and videos, we'll make it interactive and interesting and then we'll have social media influences, who have a number of followers that also can help promote it for us there's also a new dedicated website that the digital health agency has rolled out for further information. That's probably it for me and I might now hand over to to Anne.

Anne: Thank you. Can we pass over the questions and thank Christine. We move on to the next slide. We don't keep that one? Again I'd like to introduce Matthew Ame, many of you may know his story and we're very lucky to have him with us today. He'll talk about his role but also bring the consumer perspective to the value of having a My Health Record. And during this time there will also a sense of how to access and start up a My Health Record. Thank you Matthew.

Matthew: Thank you Anne. I won't use the lectern otherwise you won't see me. I'm out this side. Thanks, it's fantastic to have be here to talk to you about My Health Record. My involvement in this particular project started a couple of years ago now, when the digital health agency contacted me probably at a fairly fortunate time, just before they had contacted me I'd had about a week or so before that had to travel down to Melbourne for some specialised surgery. So that particular trip down to Melbourne really sort of stuck in my mind, for a number of different reasons, but the things that came to my mind when the digital health agency talked to me were that I had to go to Melbourne a day early to get scanned for a couple of bone things inside my body, but the reasons

I had to go down a day earlier and get a whole heap of scans unfortunately those scans were exactly the same scans that I had actually had in Brisbane only a few days earlier which is why the reason I had to go down there but I had to repeat, go early, pay extra money, just to go through the whole process again simply because the system down in Melbourne didn't talk to the system up here in Brisbane, so they got to same thing over again. That stuck in my mind and then following on the next day as I waited patiently, I think that's why they call it patients when we go to hospital, patiently in hospital doing my admission paper work, I'm sure many of you would have gone through this process and admission paper work is not one of my most enjoyable processes, to give you context I'd lost count of surgeries by this stage, I have basically health records spread, I've had surgeries under five different hospitals here in Brisbane, four in Melbourne and Victoria, and one in Chicago and I've also had multiple visits to - so many specialists, I think I've seen every specialist there is to see except for maybe a gynecologist, an observation, but I haven't quite worked out how to get to them yet.

Needless to say my records are spread everywhere, there I'm sitting and doing the admission paper work, history, great, how long do we have? And I myself could not remember what I had had when, I didn't have that information with me, I didn't - if I'd gone and called everybody, I go to that place of what is it important for these guys to know, I'm triaging myself at that point because I don't want to spend two hours writing history so I found myself just basically writing a very short amount of information for my history.

Writing Stories Session

Amy: Any ideas, of what sharing a story of hope?

Audience Member: I just wrote a general experience. A story of hope and courage in other, it highlights how far you've come in your journey and lets people know that hope is worth holding on to. It would remind people of how far they've they've come.

Audience Member: I think stories of hope, they're encouraging and they release positive emotions or just emotions and I think - I'm a true believer in positive energy and message whereas if we focus on the sad parts of the story or the negative sides that will transfer. We need to encourage people to get our message across and demonstrate how resilience is nice.

Amy: That's really brilliant because what we look at it is hope is something that's inherent to people. It's a point of looking forward, looking back on an experience that's happened to you and using that go forward and share with people that you can go do it, you can change and you can get to somewhere where you'd like to be and an illness story is negative and people don't really get anything from that story. The next parent is purposeful story telling.

Emma: One of the things we focus on is making sure that we have a purpose for our story. As we spoke about in the research, getting a meaning from telling your story, often comes with putting your story in a purposeful organised format where you're being really clear about those messages you'd like to share and the calls to action of how you'd like the audience to change. One thing we look at is ensuring that when telling your stair it will be beneficial to people and also to others as well. Not just replaying a series of negative events but making sure it has a clear path and purpose for why you're sharing your experiences.

Amy: You want it to be distinctive, something that people will take away “that's awesome. I can do this." You want it to be something that you can connect with others, you want to connect with them on a difficult level so people can understand in a different way and why else would you share your story?

Emma: Going back to the stories arc is take some time now to start to write your story. It doesn't have to be your own personal journey, it can be a journey of somebody that you're supporting or it can be a journey about someone named Freddy, anything. We're getting into the notion of starting to write a purposeful story. We first wanted you to take five minutes to write down what the purposes of your story are, so think of an audience that you want to speak to and have a think about what your purpose is, why do you want to tell your story, why are you passionate about this. What future are you trying to create and why should the audience care. Take a few minutes to write that down and we're going to take some time to discuss that in groups as well.

Group Discussion

Amy: We'll get someone to share with the room.

Audience Member: I just got created a list, educate and inform, start a conversation, promote and drive change, challenge thinking, let others know that they're not alone.

APPLAUSE

Audience Member: I thought the audience for my story was health policy-makers and the mental health clinicians in training as well as Government. My why is to create better mental health outcomes for everybody, but especially vulnerable young people. I have ten years lived experience of caring for two young people with severe and complex mental health issues and I've seen the good the bad and the ugly and I want to effect change for those young people and why people should care about my story is because mental illness does not discriminate.

Amy: Thank you for sharing your stories as well. It's really great. We've done some things in our community, yarning circles and the benefits of sitting down and yarning, we are big story tellers so we always tell stories and things like that. We have a medium of where people tell their stories and say what is going on with them. We were talking about being health advocates and we were quite willing to share these personal stories, in the hope that that's going to help someone else, that it's going to improve the health system or the care that they would get or the quality of health care that they're going to get. We are willing to share those stories if it's going to help someone else and it's going to help effect change in the community and things like that, yeah.

Audience Member: I think Stephanie summed it up really nicely. We were having our conversation and we were also discussing about how it can be hard to share your story but if there's positive benefits to it, it feels good.

Audience Member: I'm amazed because every decade of my life I thought what is happening in the next decade and having had a grandfather who topped himself and my father topped himself, a bit of history in that direction and I've had severe depression since I was in my teens, and somehow I sort of staggered through to the next decade and a bit of work on myself and appeared to get better and also get worse. Then about 30 years ago I came to Brisbane having lived all around Queensland and something in the water has fixed me. I'm 75 and I'm going strong. It's amazing what can happen. I never thought I'd get through. Every decade I don't think I'll last another decade, maybe not another year or week, but somehow I did. I hope it's encouraged come other people to keep staggering along.

Audience Member: I think we've got to realise that every time we access health care we expect to tell our story to get proper treatment. It is the rapport or it's the expectation that clinicians have that we will tell our story that we will tell it truthfully so that they can conduct proper assessment and treat us appropriately. I think it's really important that we understand the importance of health literacy, if we're going to tell our story we need doctors to respond by telling us what the treatment is about, how it's going to affect us, what's the benefit of complying with the treatment. It's not just about mental health. It's about any illness at all. There is a story that's told every time and that's the premise for good assessment, so I think that the story that's told will - if it's told accurately will enable better treatment and better understanding of what we are dealing with within our own health.

Amy: The next bit is your story and how it can be beneficial. It's really important to know what part of your story you want to keep private. What part of your story do you want to share, that's beneficial for others? Also depends on who you're telling your story to. I'm going to share something now. Because I'm a peer worker obviously our job is to share that experience, obviously I don't go around every day to telling people their story. It comes from a place of recovery, from a place of hope. I do it when it's only needed, when I feel like someone is reaching out to me and I hear parts of share that are similar to mine and I can contact with them and I have this experience and this is how I was able to work.