

Maureen

The participation spectrum – thinking beyond the box

- Thinking beyond standard two is to think beyond compliance and beyond the accreditation tick box.
- Instead we have to think about why we have standard two what's it for what's its intention?
- To encourage hospitals and health services to increase the level of community impact?
- To offer services that are relevant and useful to the communities we serve? And hopefully therefore improving their experience and ultimately their health outcomes?
- •
- This spectrum for public participation, which many of us are familiar with, illustrates what we need to do to think beyond the tick box
- Currently, most of us, hospitals and health services are comfortable here (column two).
- We are happy to consult with consumers, to show them our services and our products and to ask our consumers what they think.
- There are many reasons for this including; funding models, priorities, resources allocation etc.
- Some hospitals and health services have pockets of activity where consumers are much more influential – but very few can claim to do that universally – and even

fewer can boast a model of engagement where decision making is genuinely in the hands of the consumer.

INFORM	CONSULT	INVOLVE		COLLABORATE	EMPOWER	
Participation goal:	Participation goal:	Participation goal:		Participation goal:	Participation goal:	
Provide the community with balanced and objective information	Obtain community feedback on analysis, alternatives and/or decisions	Work with the community throughout process to ensure that community concerns and aspirations ar consistently understood at considered.	e	Partner with community in each aspect of the decision, including the development of alternatives and the identification of the preferred solution	To place final decision— making in the hands of the community.	

At the Women's we are certainly increasing our collaborative work with consumers and each time we do it if gives us further insight into how a genuinely participatory model leads to genuine improvement of our patients.

Carly and I are going to showcase a piece of work that we have both been a part of to hopefully demonstrate what hospitals and health services can do when we work collaboratively with consumers.

The International Association for Public Participation (IAP2) has developed a Public Participation Spectrum to demonstrate the possible types of engagement with stakeholders and communities. The spectrum also shows the increasing level of public impact as you progress from 'inform' through to 'empower'.

YOUNG WOMEN'S PROJECT



"enhance the health and wellbeing of young women through the provision of high quality clinical services, advocacy, research, and initiatives to build capacity and increase health literacy."



Background

In our strategic plan - the Women's has identified young women as a population that needs a particular focus in terms of our services, our information, our population health efforts and our engagement strategies.

Why?

- Tendency for risky behaviours that can contribute to both short and long-term health and social problems that can persist into adulthood.
- Recognition that health risks for adolescents are different to the broader population and need a different approach.

We developed a young women's strategy with the intention to:

enhance the health and wellbeing of young women through the provision of high quality clinical services, advocacy, research, and initiatives to build capacity and increase health literacy.

We set out to:

 Improve our performance in a number of areas including; service delivery, engagement, health literacy interventions, advocacy for young women and research. Teenage pregnancy one of our central focus points - particularly as it affected young women in rural areas.

Through desk top research and our clinical expertise we started to develop an understanding of the impacts of teenage pregnancy and the various issues surrounding teenage pregnancy.

But the most important piece of this work was talking with and learning from young women.



The Women's has adopted methodology called participatory design - which, as it says here places a premium of the involvement of users and potential users in the design and decision making process.

We started by piloting a program that came to be known as the Advo-cats.



2011

The Princes hill project

Recruited 12 young women through a local high school
They attended weekly for 12 weeks
Introduced them to PAS, NISC, CASA, Social work, women's health services –
extended their knowledge about what we did

At the same time they:

Interviewed their friends about the Women's, sexual health information Did hospital walk abounds with their friends Advised us on our sexual health information – how we provided it etc.

Through their participation we heard from young women in rural areas, from newly arrived and marginalised young women and we were starting to formulate ideas about how we could, as a hospital, provide information that would impact on their lives.

The young women presented to the CE, they also presented at a conference held at the Women's called *In Their Shoes*, where they were able to report on their findings.

One of the key areas identified by this group of young women was the need for relevant, accessible and useful information about contraception designed by young women.

Carly was one of many of the young women was involved in the design process - hand over



Workshop one -

- Held in late 2012
- Workshop with 22 other participants between the ages of 17 and 22
- The purpose of the workshop was for the Women's to gain a preliminary understanding of young women's beliefs and understanding about contraception options especially long-acting, reversible contraception (LARCs).
- The workshop would also help the Women's to understand how young women currently access information and how we would *prefer* to access information.
- We also helped the Women's to develop key messages to help them promote LARCs and emergency contraception options.

At the workshop we learnt that:

- Australia has one of the highest rates of teen pregnancy in the developed world with higher rates recorded in rural and regional areas.
- the use of emergency contraception is regarded with mixed feelings and is linked to guilt and shame and concerns about effects.
- while EC has been available over the counter in Australia for a decade it's had little effect on the actual use of EC.
- young people, despite being skilled users of the internet, struggle on find good info on EC, especially how to get it.

We made the following recommendation to the Women's

- To make info that is **relevant** and **targeted**
- To create "youth pages" where young people can find info relevant to them
- Offer ways for young women to chat online anonymously
- Make info that would help parents and teachers to talk to teenagers about sex and contraception
- Make info that explained the risks, benefits, should address myths and tell women's stories



The Women's then held a series of focus groups and fed back the results. I participated in a focus group.

- There were 5 focus groups held in all
- 39 women and 1 man, 17 21 yrs
- 6 participants were mothers, one father
- 10 from northern Africa
- 20 Anglo/European
- Recruited through internal and external sources

We were asked:

- Our opinions, concerns and views about EC and the possible myths around using EC
- How we had been informed about EC where did our information come from
- What we thought about some of the information out there already
- We were shown other videos and information produced in other parts of the world and asked to feed back on it.

WHAT THE FOCUS GROUPS REVEALED

- Poor understanding of EC operation, effects and regulations
- Myths and misunderstandings about emergency contraception
- Technology is central to the lives of young people early adopters and heavy users of social media and internet
- Technology is good for engaging with young people in the area of sexual health information - anonymous, interactive and accessible
- · Young people want information that is:
 - Trustworthy (endorsed by a trusted source)
 - Engaging
 - Conversational and relaxed
 - Uses uncomplicated language.



- Nearly all participants had *a little* awareness of emergency contraception; only a few were quite familiar with it.
- Those least likely to know about it were relatively new arrivals from Northern Africa and some younger students in high school
- Most thought they needed to have parental permission to get it if they were under 16
- Participants felt it had a reputation, it makes you sick and it caused an abortion, it will stop you from getting pregnant in the future.
- Many felt that the their privacy was an issue because they had to fill out forms to get it from a pharmacy
- · They felt judged
- We endorsed the use of social media and offered a range of strategies for making information available.
- Most of are savvy users of social media- generally cynical about what is good and trustworthy information and what is trying to sell us something.
- Most said that info had to be from a trusted source for us to trust it, it also had to be engaging, relaxed and use language that could be understood.



The 'style'

Video

Entertaining is good (song, good graphics etc.)

One-on-one communication preferred – blog style

Fun and funny delivery works but be careful not to lose the message



Collaboratively with the Women's, we arrived at the idea of producing **a video** that would be:

- Entertaining
- One on one blog style
- Fun and funny

BUT

It – it was also important to the us that the video:

- Wouldn't trivialise or downplay the issues
- That we see something of ourselves in the person that delivers the info
- Had a sense of believability not a doctor or a medical person necessarily so
 that we could trust the information that was being delivered to us.
- We thought that if the Women's produced the video, that would provide that credibility.

We decided that the Women's should make:

- A video for social media, short, sharp
- Using a performer with whom young women would relate, identify with
- Elements of entertainment but otherwise quite straight in its delivery

Script development



- Language
- not too complex
- keep it simple
- Avoid too much info



The next stage in the process was to workshop the script.

The comedian Nelly Thomas was brought in to help us to develop the script. In the workshop there were young women who had been involved throughout the process and some new members as well. There were also Women's staff; a gynecologist, a pharmacist, a sexual health educator and other staff to ensure that the information was evidence-based.

We worked together to develop ideas and key messages that needed to be in the video.

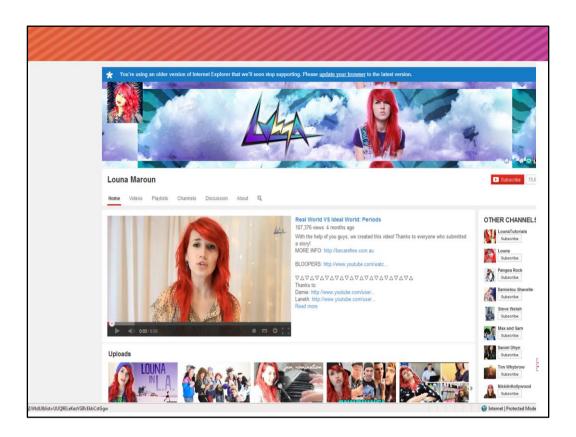
These are some of the key messages:

- Young women need to be empowered to seek out emergency contraception
- You women need information about services to help them if they need it
- There are things that pharmacists can ask us about and things they really shouldn't ask us about
- · Not all pharmacists are evil
- If they refuse to give me EC its not my fault
- · EC is not an abortion
- Its not harmful to our health
- Its safe and effective in protecting us against pregnancy in this one instance
- Common side affects are minor and what to do if we had side affects
- Timing is crucial to the efficacy
- If I'm pregnant it won't affect the pregnancy



We even got to choose the actor for the video.

Four actors were screen tested and Ultimately we decided to ask a performer called Louna Maroun.



Louna has her own very strong social media presence with 74 thousand followers and 100,000 views on average for a single video clip.



And this is the final product

REFLECTIONS

- From the Women's perspective
- From the consumer perspective



Maureen to give her perspective

Carly – what did it feel like to be involved? What benefits to young women who were involved, to young women in the community? To me?

