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Youth and the Communication of Risk

Developing Connections between Cancer Council Australia and Contemporary Online Youth Culture

Image by Pink Sherbet Photography

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Executive Summary

Through two focus groups, the project investigated how youth culture perceives online communication of risk. In two 90-minute sessions, investigators gaged the range of online activities that nine 18 - 24 year old university students engaged with. Through a guided discussion the participants explored how they would relate to the communication of health risk more generally and cancer risk more specifically.

Participants' online activity is very high and a range of social media forms are part of their everyday lives. In contrast, their use of traditional media is almost non-existent. Their relationship to accessing and being aware of health information demonstrated a range of views that pointed to quite new and different relationships to health and health professionals. To intersect with their online movements in the communication of health risk demands a sophisticated knowledge of their own searching patterns.

Key ideas generated from the focus groups include: that it might be advantageous to group health risk beyond the specificity of cancer for online success; that an online persona would be useful to provide a face for the communication of risk; that a multi-platform campaign to raise the profile of a persona would be useful; and that success means moving between the serious and the light-hearted in a way that makes the persona a complete person of interest for them.

Pilot Project: Objective and Dimension

The Online Persona Pilot Project (OPPP) was designed to explore how one might improve the communication of risk of cancer to youth. By providing preliminary information and data from members of youth culture, the project explored a central problem that the Cancer Council Australia (CCA) recognised it had in connecting to youth. While the CCA has a history of powerful media campaigns that have communicated cancer risk for decades in a variety of ways and media formats, their online media work was much more circumscribed. CCA's interest was to explore how to connect with youth culture, to convey ideas and information about cancer risks and decision-making to young people through their use of the online domain.

The dimensions of the pilot project focused on the upper end of the youth demographic - that is, 18 to 24 year olds - while recognizing that a larger study would include the younger 12- 18 year olds in a significantly more comprehensive investigation. The key objective then was to develop preliminary ideas for further testing and trialling. Included in the pilot project was the exploration of key health-related web sites by both the researchers and the focus group participants as a means for examining and summarising current and potentially new ideas of connection of young people and information.

Background

The team of researchers are highly trained in media and communication disciplines with an expertise in online communication. Their own research and background has identified that one of the key elements of online communication and digital culture is its personalisation. Where traditional media have operated in a broadcast model of one to many, online communication works in an elaborate layering and networking of interpersonal forms of communication. The social media model means that a message is mediated through friendship networks and personal connections and may ultimately be picked up and disseminated publicly to millions.

The individual or self is foregrounded in the ebbs and flows of public communication online. Marshall has described this intersection between the highly mediated and the interpersonal online social forms of communication as "intercommunication" (2012, 2011, and 2012) and it defines the quite different way that information moves through the culture as well as how significance is attached to particular types of information.

Health and Online Culture

One of the ways to approach online communication is to identify the more popular online sources related to health. In an American context, according to the September 2012 posting of EBiz/MBA (http://www.ebizmba.com/articles/health-websites), the 'top' five websites in terms of visits were Yahoo!Health, NIH, WebMD, MedicineNet, and MayoClinic. Each of these has a different point of iteration on what we would call a spectrum of authority. Thus, NIH is considered to be the most authoritative and the least accessible. While WebMD, Yahoo!Health and MedicineNet make distinct efforts at actively building dynamic content and connections to an audience of general users, the goal of NIH differs as the site is perhaps, constrained by its circumscribed domain of being government sponsored and by necessity has to role in reporting research.

Yahoo!Health has a sophisticated graphic of a body to help navigate the specificity of a complaint. Typing in a symptom is the avenue for greater information, but surrounding its delivery are advertisements, different health experts and other possible clickable spaces. Yahoo!Health does fulfill a general need of ease which would be attractive to young users, but it still has some distance of authority. It does not allow user-generated content, but like its other top five American sources, it links to both Twitter and Facebook.

From this very brief look at popular web sites one of the key elements missing from their approach is that they have missed the personalisation that might be necessary in the construction of identity related to health and health risk. In giving the sense of anonymity for the user, the sites hearken back to a full generation before Web 2.0 and its level of social media even as they integrate a multitude of links to appeal to this different generation of online users and new generation of netiquette.

MedicineNet does facilitate conversations and chats about conditions and in this way approaches what we are imagining as this shifted generation of online use. In our study, we

worked actively in the space of how use has changed and how that intersects with health communication, health risk and health information for these most sophisticated of users.

Stimulating thinking about Health Risk

Sites used in the focus group sessions and as background research

One of the techniques employed in the focus groups was to use online sites and locations that specifically dealt with risk to stimulate discussion. This technique made the fabricated situation of a focus group session closer to how youth might engage with actual content. The group's focus is a common screen and we navigated the web individually in the sessions on their own devices - but nonetheless a screen that showed internet content and had the dynamism of online navigation as a possibility. We also attempted to go to sites when students mentioned them in their own discussions. Our own choices of sites were also designed as potential projections of what might "work" with youth culture. We addressed concepts of shock, humour, and play and captured the generation of abstract information to see how this sector of youth culture would playin those domains. Included below is a list and brief description of the sites we used as "stimulants" to conversation and discussion, and also the sites we used to build comparative models for our own research into the communication of cancer risk to youth.

Focus Group Session 1

Our research focused predominantly on mental health and risk in this session in order to give us a sense of comparative understanding of how difficult information can be conveyed. We included a range of websites in our research and presentation to compare this particular health concern with some other areas such as smoking risk and sex risks. Many of the sites were as much our form of research into techniques of what we might call virality, engagement and play in youth culture. It should be noted that what is listed here is a surplus of sites and not all were employed in the focus groups due to time and the extensive discussions generated.

Youth beyond blue
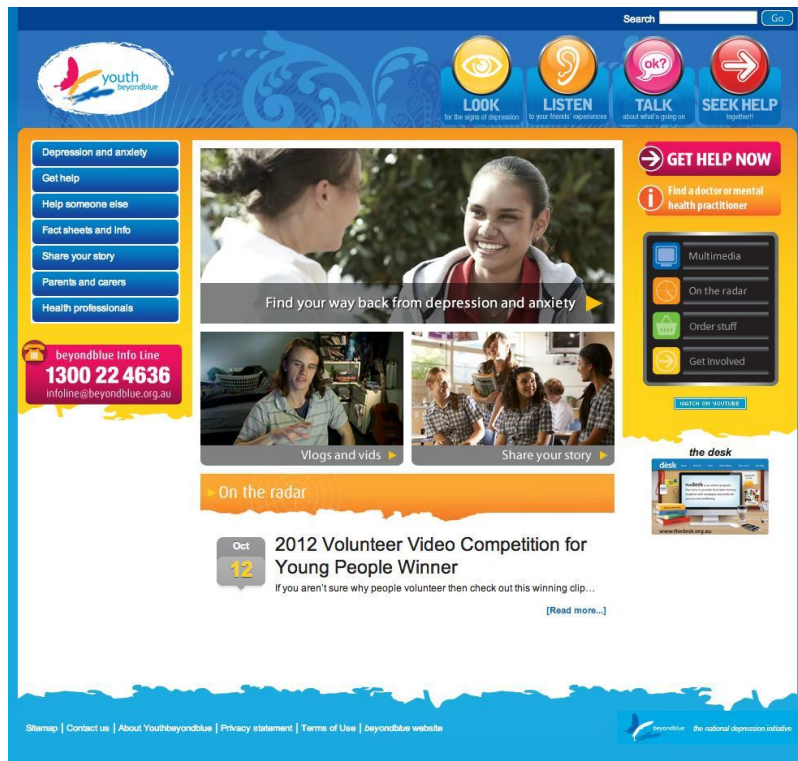
www.youthbeyondblue.com/

This site actively encourages contribution by its users affected by depression in some way. Youth depression has a complexity about it that makes it valuable in searching through how users might intersect and then engage with such a site. One of the elements we were testing is how self-identification works and how over-identification can actually make youth avoid sites even with the best intentions in the world by their creators and managers. Youthbeyondblue also encouraged the development of vlogs by individuals that are posted on a related Youtube channel. This in itself presents an intriguing way to allow users their individual space and networked form of expression.

Rotorua and Brisbane Zombie Walk

In 2010, an individual organised a charity for Brain Injury that linked to similar good-humoured efforts in other countries. The connection to Zombies and brain injury occasionally initially generated negative criticism, but the event was a notable success, concluding with a Michael Jackson Thriller and attracting a large number for a small New Zealand town. A similar event occurred in Brisbane and corporate sponsors were connected to the event. What was intriguing about this particular structure was the connection to the individual response to the contentious start-up that was embraced by a community through the events connection to a major health injury issue.

The strength or fecundity of the viral nature of a popular, if gruesome figure, the zombie walk features a capacity for personalisation in the crowd in the accoutrements and costume, much like Facebook and other social media sites that enable sometimes quiet extensions 'options' in how the self can be represented via their profile, avatar, site or Twitter account, but consist of a homogeneous group in terms of the software and platform capacities: despite being able to customise avatars and backgrounds and assemble unique networks every Twitter account is identical. The zombie and the zombie walk, and other flash mobs and internet memes seems to have a persistent but idiosyncratically and individually networked degree of individualised origins and extensive community participation around the planet.

It's All right - (Part of Sane: A charitable foundation)

It's All right is a website communicating to youth through an interesting avatar system presented visually in comic-style (with links to Manga aesthetically) with issues on youth mental health. Three of the four avatars developed are female and each avatar's image links to a series of diary-like posts from the characters. There is no question this site has tried to personalise the experience of the stories while maintaining anonymity. Other parts of the site include links to information around mental health and a helpline online for users to post questions. The sites challenge both the research team and the focus groups on how to present quite personal information in a way that connects to youth and maintains the dynamism of social media in its form of communication. The research reading of this particular site is the attempt is a partial success that may have different ways of anonymous engagement with youths because of the particularities of mental health issues.

Likeitis

Likeitis.org.au

The Likeitis website is designed around providing very frank information about sex and sexual health issues. Apart from lists of keywords that define sex 'risks', the site pushes strongly towards revelation and thereby enters into the way youth might relate to these issues. Billboarded across the homepage is what is called the "SexFiles" where you can find out more, by entering information about oneself. There is no question that the site is aimed at girls and very much less oriented towards boys. Two interesting features of this site are the celebrity fans of the site - almost like goodwill ambassadors - and a Dr. Phil advisor for questions from users and site visitors. They have also loaded the site with a game entitled Love Bugs Battle which uses a spaceship shooting condoms at advancing STIs. The look and the feel of the site hearkens back in time, but it does have an edge, a kind of humour and a personalisation of information that is worth further investigation and study.

OxyGen

Oxygen, run by the Cancer Council South Australia, works to engage younger children in the risks of smoking. It is cross-linked with simple flash games, YouTube videos that are commercials related to the risks of cancer. Via bright colours and an animation style that intersects with those found on contemporary television networks such as Disney or Nickelodeon, the site targets a demographic perhaps younger than the core focus of this pilot project. It is obvious - by a prominent link - that this site is meant to integrate into school programs. However noble this may be, it will be relatively ineffective at intersecting and engaging with adolescents and young adults and their methods of using online culture. Perhaps most interesting from this web site is the use of spot polls for instant engagement and communication of information.

Reach Out
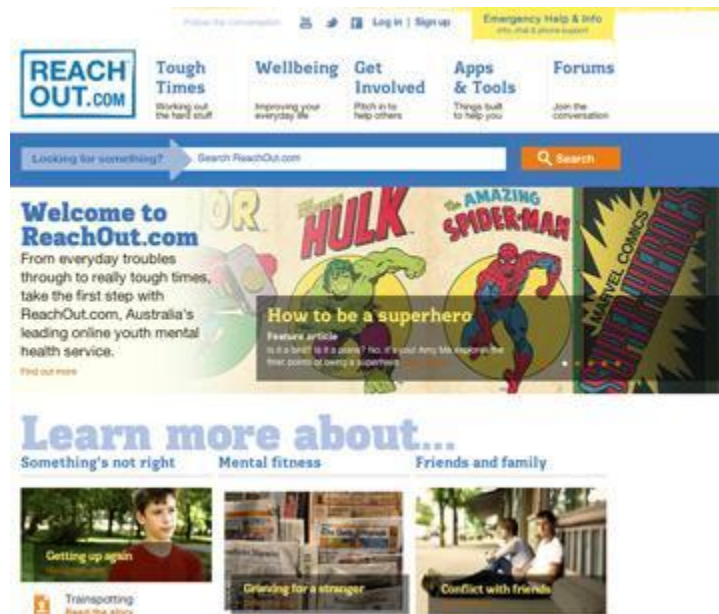
The Reach Out site heralds itself as "Australia's leading online youth mental health service". It's strength is its interconnection across platforms. With a strong Facebook and Twitter presence as well as an active direct text messaging application that is sent directly to subscribers, Reachout at least identifies the different ways in which youth engage with contemporary media.

Focus Group Session 2

Sites researched and displayed in Session 2 of our focus groups looked at specific risk related behaviors of young people and concentrated directly on issues of the older demographic of 18 to 24 year olds, including eating disorders, sexually transmitted diseases and drug use.

The Butterfly Foundation

www.thebutterflyfoundation.org.au

The Butterfly Foundation is focused on eating disorders. In many ways, its site is very institutional and perhaps appealing to support and donations as much as those personally at risk. One of its strengths is the Foundation's close connection to the commercial world via the clothing chain Sportsgirl. It is not that this in itself is surprising or unique; nonetheless it underlines the way that youth culture intersects with consumer culture and in this case clothing itself. As online presence and connection is developed for the CCA, it is worth bearing in mind that the online culture is a culture of connections and intersections and a site that works on these relationships breeds success in achieving its core mandate.

Eating Disorders Victoria


www.eatingdisorders.org.au

EDV works with a peer support model which presents another interesting variation of personal connection that is worth exploring in relation to health and risk. They offer prevention and early intervention strategy, non-clinical support throughout the recovery process and relapse prevention and recovery maintenance. The website is bright and colourful and while it has many fact sheets and very good information, it is very easy to navigate and is easy to read. The information is aimed at sufferers, parents, carers and friends of people with eating disorders.

There are tabs which relate specifically to eating disorders and children, and eating disorders and adolescents under the 'quick links' section. As with many other sites, Facebook and Twitter are part of their links. Perhaps most useful to investigate further from this site is that they have a satellite site entitled Real youth, which is linked from this institutional home where a blog that allows the posting by youth of their own personal stories as well as inspirational stories are

relayed and connected to an open invitation for users to submit their own creative works and writing to the site.

 In a flash centrepiece of the Real Youth site, something called the Melbourne Girl project is profiled, where submissions in raw handwritten forms are posted and scroll by for the user to peruse. Although by colour and artwork, the site is aimed towards girls there are gestures by links for boys to explore their relationship to eating disorders. As with many elements that deal with youth and health, it is also worthy of exploring the importance of gender-specific content and interaction in the development of connection to youth and cancer risk specifically.

The Looking Glass Foundation
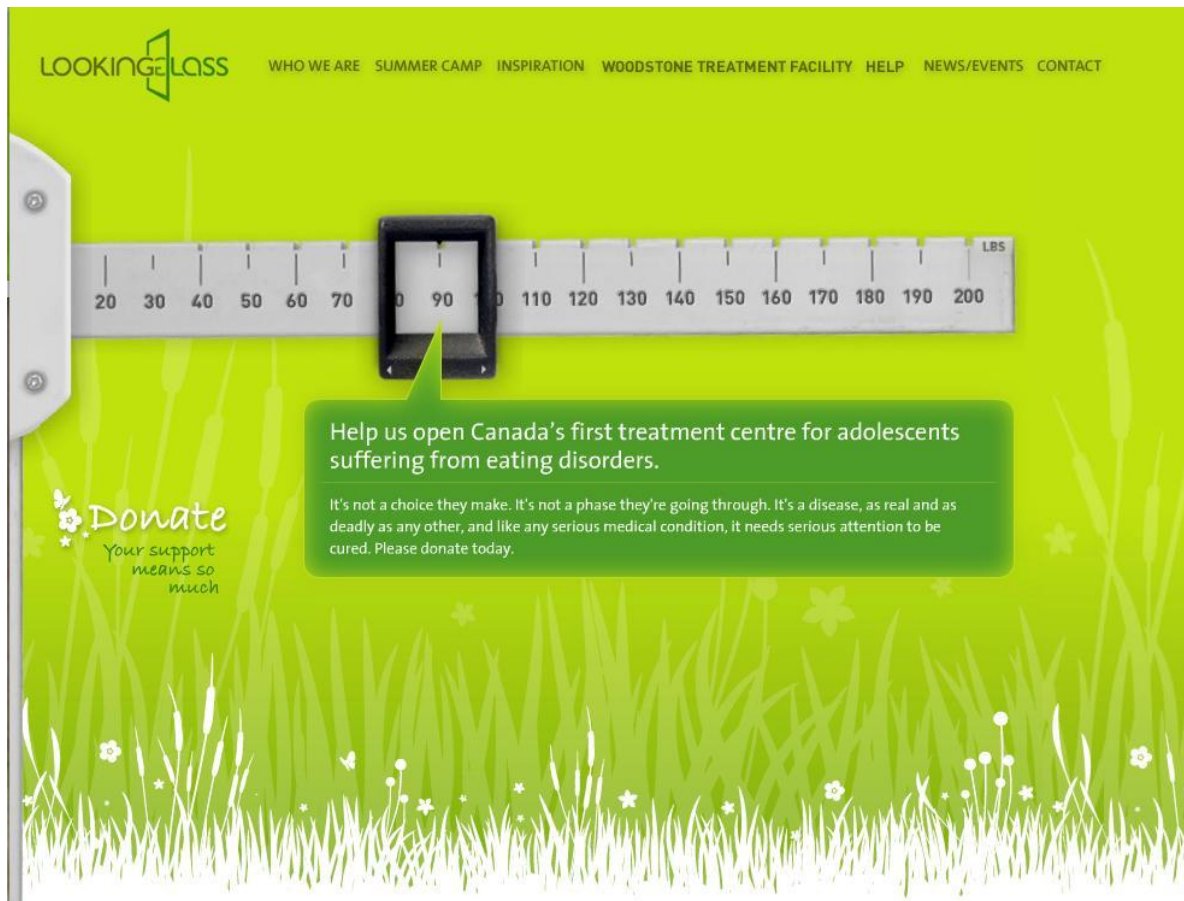
The Looking Glass Foundation is a Canadian-based treatment centre and organisation that is included in our sample because of how it has drawn people to its services and sites. By posting a series of promotions via YouTube that were originally television commercials broadcast in 2008, it has built a significant following. What can be learned is that content - visual content - can live on quite effectively online as long as it is well-linked to current sites and information. YouTube is one of those locales to organise CCA's content so that it moves through online culture for greater periods of time than it is possible to do through traditional media. Looking Glass Foundation's linked web site is very much modelled on an expert/authority serving a wider community and thereby parallels the needs of an organisation such as CCA in being an authority but perhaps a connected authority to youth culture.

The website **Above the influence** is a youth-focused American site that works to cultivate a culture of resistance to peer-pressure and recreational drug use. What can be learned from this particular site is that the frame around information can also make a particular site mocked by youth culture as is evidenced by comments on their linked Facebook and YouTube videos where their emphasis on " just say no" may hearken back to the long but unsuccessful war on drugs initiated in the Reagan era. What can be taken from this is that working in social media and youth culture requires that an organisation has both a thick-skin and recognises limited success as important an achievement as unanimous success - after all, it lists 1.7 million likes on Facebook which identifies some kind of connected influence in the debate with and among youth. Above the influence has had many who have viewed their material and no doubt gained important information. It has also successfully branded itself with the clarity of its logo on all its links and this is also important: to make a logo that makes finding and connecting online the simplest and the most direct.

The National Drugs Campaign

In contrast to the missive of 'saying no to drugs", the Australian National Drugs campaign that is part of the Commonwealth government websites, attempts to provide similar information, but in an attempt to allow youth to make informed decisions rather than preach the desired outcome. What can be garnered from this comparison is that any organisation has to work out an appropriate spectrum of registers and tones in online culture - from the official to the informal, from the expert to the personal stories, from the hip to the serious, and from pathos to the potential for humour.

The Meth Project
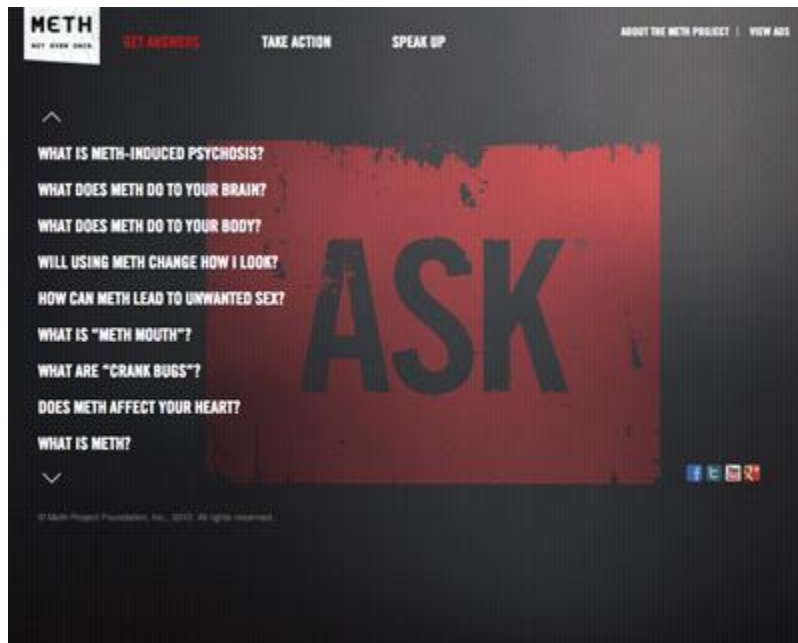
What one would call a powerful site, The Meth Project, works to stimulate interest and sense of risk with a strongly constructed graphic interface of images and information. A privately funded site designed to get youth to think about their relation to an epidemic of methylamphetamine drug use, it uses interesting and disturbing backdrops to key questions: rolling the cursor over the question "what is meth induced psychosis?" a visual of a bedroom appears with an invitation to use flashlight/torch to see via a directed beam of light the different parts of the darkened and grotty bedroom. Upon clicking on the lightswitch, the whole bedroom is illuminated revealing different aspects of meth-induced psychosis, from hyperactivity to delusions and a soundtrack of empty wind. The project is both well-funded and well-linked with Facebook, Twitter and a series of public service advertisements or commercials that are still on YouTube that have steered traffic no doubt to the site. It does provide locations for the generation of user content, but expertly develops ways to make these brief in both text and visual forms. Private foundations have some of the flexibility to invent themselves related to a specific public health concern: this demonstrates the power of this kind of development of public discourse online.

Chlamydia

Sometimes with particular illnesses and risks the key problem in connecting to youth is providing a substantial connection online. With the awkward-to-spell STI chlamydia, it is difficult to make the links apart from through school programs and other related STIs perhaps that have more popular names.

In Australia, a search for chlamydia will push you towards one site - http://www.sti.health.gov.au/internet/sti/publishing.nsf/Content/chlamydia - which has it as a tab along with other STIs. As a government site, informationally it is strong; its capacity to connect to youth culture, weaker.

Searching chlamydia via YouTube is perhaps something that might intersect with youth culture more directly. With this objective, what one finds are a number of commercials or what are often called Public Service Announcements (PSAs); but there is also an attempt to put humour into the mix with a parody of a recent popular song with transformed lyrics and a song title that plays with a different kind of risk.

Hey there Chlamydia

http://youtu.be/dcaqS2eDmRs.
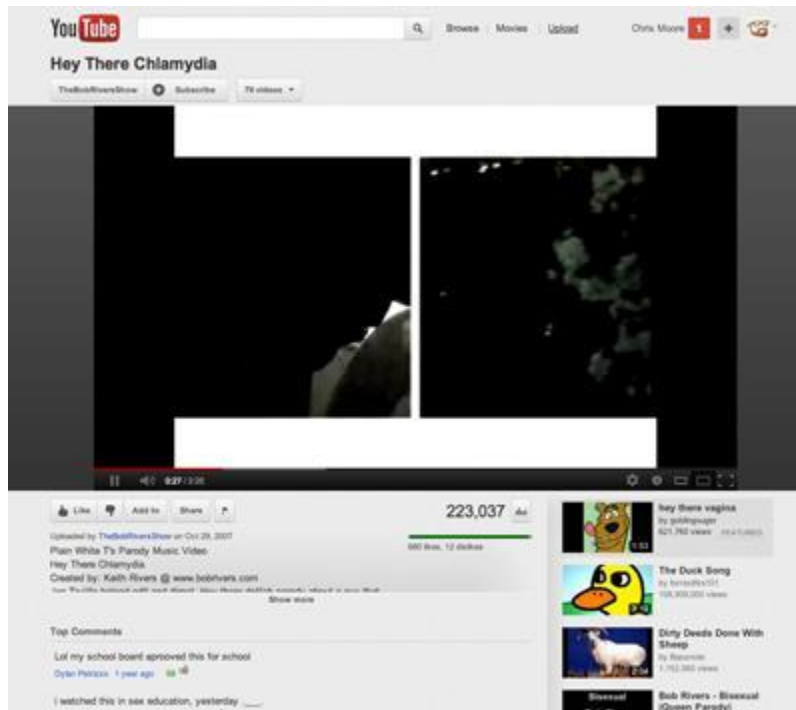
Other videos play with contemporary club scene images and encourage the use of condoms because of the hidden fear of STIs.

The approaches are ways to intersect with youth culture and to underline the urgency of the risk. Cancer generally involves communicating risk over time; nonetheless, the strategies of the currency of risky behaviour are very similar to STIs such as chlamydia.

Focus Group Results

Two focus groups were undertaken as part of the pilot project. The first (Focus group A) was held in October 2011 with one male and one female participant. The second focus group (Focus group B) was held in September 2012 with seven participants, with two male and five female participants. The participants from both focus groups were students at Deakin University, ranging in age from 19-24 years old, many of whom are studying the media or public relations. As a result, their insights and opinions may not represent those of younger high school students who may, for example, watch more television. As students of the media and public relations these young people are in a unique position to be able to offer suggestions for strategies that the Cancer Council Australia might use, while also having an understanding of how such strategies work to engage young people.

The focus group discussion centred around four main areas of inquiry. Participants were asked about their current uses of social media, including approximate time spent online and what they did online, what sites they visited and which social media sites they engaged with. They were asked about their awareness around cancer risks, and the ways in which risk is communicated online; what worked, what didn't and why. They were also shown video clips and websites related to health and social issues in order to elicit discussion and potential directions that Cancer Council Australia could take with future online campaigns.

Current Uses of Social media and online culture

"I wake up every time I get a notification"

The amount of time spent online ranged from one participant reporting 2-3 hours per day to another who described her time online as "excessive" and stated that she was never offline and would even wake during the night when she heard notifications come through on her phone:

"I'm more of an excessive user. I don't think I really go offline ever. Probably not even when I'm sleeping. I wake-up every time I get a notification, usually it's Twitter" (C 2012).

Taking into account these two extremes, the average amount of time online is around 6 hours a day which includes both personal and work or study related use.

Table 1. Frequency of different sites used by focus group participants

Participants used a mixture of laptops and phones to conduct their various online activities. A number of participants stated that the different sites they accessed dictated to some extent, whether they used their phones or laptops. For example they might check their Facebook or Twitter accounts on their phones because the interface was good, however they would conduct a Google search on their laptops, due to the ability to quickly read and access all of the sites that might come up in response to their query.

Facebook was used by all of the participants to varying degrees however one used it reluctantly and had only begun using the site in 2011. He appeared to be resisting joining the Facebook community:

"...now everyone is using Facebook...it is hard for me to accept that social media is controlling my life and those around me…so I am resisting Facebook, although I use it" (male participant 2011 f/g).

Twitter was the next most popular site, with all but one participant using it. The only person not to use Twitter was the participant who was also reluctantly using Facebook. A number of participants mentioned that they actively 'manage' their Facebook and Twitter accounts by regularly culling friends and followers and the people they follow and pages that they had 'liked' from their accounts.

"Recently I just went through all the pages I 'liked' and just 'unliked' everything because I got so sick of the constant notifications that they send through… now if you go onto my profile, I only 'like' 1 thing and that's my work. So, I just got really sick of the constant notifications and really pointless stuff" (Nadine 2012).

This echoes the sentiments of the participant who did not like to think of social media controlling him, and speaks to an attempt at being in control of their social media use and making it manageable.

The other most popular sites were YouTube, Skype, LinkedIn, DSO (Deakin Studies Online) and personal email. News sites such as BBC, CNN and a variety of online newspapers and magazines were also cited as sources of news and information. Facebook and YouTube are used mainly for social activities, while Twitter and LinkedIn are used more for professional and informational uses by these young people.

Frequency of different sites used by focus group participants

"Facebook games – social games – I am playing the Sims online and I love it"

Online games were not a big feature of the online activity for these young people. Both members

of the first focus group noted that they played online games, with the male participant stating that

he liked to play games of strategy such as Ages of Empire and Star Craft. Facebook games such as The Sims Social were more popular with the female game playing participant. Almost all of the participants of the second focus group cited lack of time as a contributing factor, however many also viewed online game playing as an activity associated more with high school students or the older generation. Interestingly though, while discussing strategies that institutions could use to engage young people; competitions or interactive games were identified by the focus group participants as ones that would work.

"I'm just a Facebook person. I don't like straying away from it…"

The participants used different sites for a variety of reasons. The majority of Facebook use, for example was for purely social reasons. "I just like Facebook. I'm just a Facebook person. I don't like straying away from it… Yeah, completely social element. Makes sure I'm up to date with all my friends and no-one forgets about me…" (Nelly 2012). Others, however, used Facebook for social and as an information seeking resource by 'liking' or following pages of institutions or companies as well as having 'friends'. "I use Facebook as a personal platform more or less and also information seeking. I follow quite a bit of companies and campaigns and pages that interest me and tend to keep more interested in pages I follow than most people I'm friends with because sometimes it's more interesting information coming from pages" (Charlotte 2012).

Twitter was regarded as very much a professional or information seeking platform rather than specifically social service.

"Twitter is somewhat personal mostly professional. I use quite a bit of it. I don't tweet as much as I read tweets and follow up links that I find on twitter" (Charlotte 2012).

Twitter is also seen as a way in which participants could build a 'professional' identity online, while still allowing some of their personality to come through:

"I would still post photos and things on twitter, whereas I wouldn't put photos and things on LinkedIn" (Mary 2012).

The participants reported a feeling of need to divide their online identity between the personal and the professional:

"I divide my identity in some online media, on Facebook it is about me - myself and my private life. On Twitter my engagement is much more about my subjects and my degree (communication) and I like to follow experts in communication" (FP 2011).

LinkedIn is seen as being the most professional focussed of all the social media sites discussed, and there is a very distinct sense of not allowing the personal to cross over into this site.

"I use [LinkedIn] to connect with people that are in the same industry as I'm in whereas my Facebook is purely basically for socialising" (Mary 2012).

YouTube was used almost exclusively for entertainment purposes:

"Youtube for example. I would use that mostly for entertainment purposes. So for something … that's funny, or music or something like that" (Mary 2012).

Skype was used as a way of keeping in touch with family and friends. Particularly those living some distance away or those who were travelling:

"my family is about 3 hours away from me so I Skype them usually once a day, sometimes if mum misses me a bit more it's more than that" (Francine 2012).

Television and radio use was minimal amongst the participants. They reported that radio was only listened to in cars, while in the home they preferred to listen to music on their Ipod/mp3 players or streaming on sites such as Spotify. One participant noted that she did not watch television at all:

"I never watch TV. Never, ever, ever" (Nadine 2012).

Others noted that if they did watch, it was whilst also doing other activities online:

"...if you have the TV on, you'd have like your laptop on your lap and YouTube and you'd be muting the TV and just have the TV sitting in the background" (Francine 2012).

Generally if they wanted to watch something in particular, these young people would go directly to the corporate website such as the ABC iView site or SBS-on-demand to watch it. There seems to be no sense of sitting in front of a television and watching it as an activity in itself. This would seem to minimise the possibility of engaging young people with a television campaign that they would 'come across' while engaging in general television viewing.

Health, Risk and Online use

"...If I thought something was wrong with me…I'd probably, the first thing I'd do is Google"

Almost all of the participants stated that they used the internet as a source of information for health related queries. Some use online sources to confirm or double check their medical professional's opinion, while others attempt to self- diagnose before going to the doctor, or to ascertain whether or not they need to go.

Francine went to online forums to discuss advice given to her about her wisdom teeth after being told she would need to have all four of them removed. The general consensus online was that she should seek another opinion. Francine did this and was advised that she need not have her wisdom teeth removed. Francine also states that she uses Google to ascertain whether:

"...something … should be followed up. Like, you know…oh is this little twitch you know is that something that I should go see a doctor about because like when you think about it you're like oh…do I want to go to the doctor? Do I want to sit in a waiting room with sick people for about an hour waiting for the doctor?"

Ian also states that he would go to Google if he had any medical concerns:

"If I thought something was wrong with me…I'd probably, the first thing I'd do is Google… you get a lot of online forums but …I'm never going to act on it purely just because I have no idea what they know" (Ian 2012).

So for Ian, while there might be an array of information available online, he would still seek a medical professional's advice, rather than simply rely on medical information online.

Google seems to be the first place most of the participants would go if they had any concerns; before going to see a doctor. Nadine went looking for advice online about a mole that she was concerned about:

"I've got a mole that's passed down from generation to generation on my neck…My father, his father and all that, we all have it in the same spot, on my neck…I was concerned that because I surf a lot, in the sun I could possibly …it could be black. You know how you can tell the difference between black and brown? So I went onto Google to search exactly what colour it should be and what I should do about it. And it just gave me where I should go …what it should look like, how to tell and how to protect it and all that kind of stuff…I essentially wanted to know if I should keep it or get rid of it if it's a risk and [Google] could inform me of that" (Nadine 2012).

Ideas for Connection and Communication

The focus group participants had some great insights and ideas regarding ways in which
Cancer
Council Australia could engage young people with messages around risky behaviours. Both
groups were adamant that there needed to be an interaction between the institution and young
people in some way, rather than simply delivering a message or talking to/at them.

**"We don't like to just be told, just to be informed – we like to experience something that
is fun or deep" (female participant 2011).**

The 2011 group put forward online games as a form of engagement.

**"When you want some continuous attention it has to be addictive. Social games have
those interactive elements involving you with others… please help me do this and that. A
cure for cancer game … would be interesting. We learn so much from games – my
husband is learning to drive in games – but I think in terms of cancer we could have
some participating in – online game, thinking in terms of the Sims and participatory
media" (female participant 2011).**

The Need for Persona: "Dr Steve"

The 2012 group had a number of ideas regarding ways in which Cancer Council Australia could
convey health messages to young people. The overarching theme was that of having a persona
who represented the institution, but was not always seen in a health related context. They gave
this fictional persona the working name Dr Steve. It was important for the group that Dr Steve be
fun yet seen to be an authority about cancer. He should not speak 'youth speak' for example
LOL, OMG etc as this was seen to be an attempt to appeal to a youth audience in an insincere
and unauthentic way.

**"You can't be too…sometimes you see ad campaigns where they're trying so hard to
have that LOL, OMG and all that kind of stuff …and just think, …I'm not going to take
anything you have to say properly" (Ma 2012).**

"...you know, an ad – a pop up that's just text …you know,something like 'worried about sunburn? Ask Dr Steve.'"

There was discussion around ways to introduce this new 'expert' character. Summer was identified as an ideal time to launch this new character as there are many sports such as cricket and tennis as well as a number of music festivals that many young people attend.

"In terms of the advertising, if you do it over summer period where like there's you know, there's going to be cricket, there's going to be tennis and a few other things that, music festivals, a lot of that …and on those sites you might like just have, you know, an ad – a pop up that's just text …you know, something like 'worried about sunburn? Ask Dr Steve.'" (Ian 2012).

Nadine suggested using the cricket and other summer events as a way to introduce the character and build interest:

"you have to do the groundwork and give the character a background, so slowly introduce the character through the cricket, …have the character appear at events or whatever that kind of stuff. So people think who is this person?"(Nadine 2012)

Rather than simply have one personality who represented Cancer Council Australia, there was a suggestion that a number of health related organisations might collaborate and join together as a 'go-to' site for a variety of health related queries.

"[if] a few of these organisations sort of joined together and you kind of have this,…almost like a health person that you're following on Twitter, …if there's a particular interest and you know the first person you go to on Twitter…to find advice from. You're going to go 'oh you know, this has got, you know, the Heart Foundation, it's got the Cancer Foundation, it's got all of this if I want to know something, I'll put that on there and that also makes it more likely that people will follow them because it's not going to be this constant hammering of cancer or heart, there's going to be a mix and information[…]" (Ian 2012).

Competitions which involve young people, such as inviting participation to come up with a caption to a picture or to upload their own pictures were seen as effective ways to engage young people with an institution:

"...when an organisation is reaching out to us as opposed to posting something and expecting us to go click on a link. So giving us an opening to be a part of the organisation is where certain people get involved and from then on other people … It's sort of like if they posted a photo and said 'caption this'" (Charlotte 2012).

Nadine also suggested:

"...engaging exercises or little competitions or something. So say, how would you best caption this? How would you best explain this? Because the winner will have theirs posted upon the site or something like that" (Nadine 2012).

Looking at online communication of Health and Risk

As indicated above, the focus groups considered a range of online content and what follows are the focus group participants' comments on some of the sites we were able to present to them. For greatest effect in the context, we presented several videos to gather responses on the ways that they 'play' with youth culture. What was fascinating to observe and determine through our focus groups is whether they would pass content on to others - the basic key to success in online culture.

The most successful of our online sites was the humourous, *Hey Chlamydia* song (http://youtu.be/dcaqS2eDmRs) which most in Session 2 - despite its content related to STIs - felt comfortable in discussing and would pass the link on to other people. In Session 1, we played the "Pictures of you" commercials (a campaign started in 2008 with stories from 10 families) that related to losing loved ones through traffic fatalities- a TAC-sponsored television advertisement series with follow-up content online. Although the message was powerful, it appeared that unless it had a personal impact or explicit connection to the individual, it was unlikely to be a source for a viral spread in the youth culture according to our focus group.

We presented a video in the second session on Eating Disorders that displayed the cognitive dissonance between a young overly-thin woman and her perceived mirror of herself as rounded if not obese (http://www.youtube.com/watch?v=mXimYVNf5C8). This video was in every way powerful and the focus group acknowledged this through silence and an inability to work out how they would "use" such a video for sharing purposes with the only way of passing to someone would be with a warning about the shocking content. Generally, the group felt that if there was an issue that they felt relatively informed about, then the 'shock' begins to lose it's value. N. used the analogy of clips of starving African children. He stated that he felt that the message had been overdone and that it was a case of the same thing over and over again. Francine stated that shock is used most effectively when it was a 'clever' form of shock or something that was shocking because it was more a twist in a narrative, than a visual shock.

Other web sites were also shown, but they inspired little engagement by participants. What became clear is that web sites are not the starting point and may not be the direct link that

people make with issues and health. For instance, the group briefly discussed the Cancer Council Australia website. The feeling was that unless they wanted hard facts, they would not go to the site and they did not find it engaging. They did feel that as cancer was a serious issue that there still needed to be an 'official' and authoritative site that delivered facts and important information; however there was seen to be a definite need to have a section or parallel site and online forum that engaged young people more. It is interesting to note that while the group cited a real benefit in having posts or clips that could be shared among their networks, the CCA website has a policy around sharing information from the site that would appear to dissuade young people from doing so. Unlike other organisations such as Eating Disorders Victoria or the National Drug Campaign websites, the CCA website does not have any section relating specifically to young people. While having a presence on Facebook, again, the CCA page does not have a very youthful feel or a section for users to post anything other than wall posts in response to items uploaded by CCA.

Conclusion

Because of the nature and dimension of this pilot study, what can be concluded from the analysis and observation of the focus groups is very tentative. The sample population was quite specific and could not be generalised. It did not cover the entire youth range we need to explore - from 12 to 24 - with only 18-24 year olds in our focus groups. It also focused on university-educated participants which presented us with new opportunities as well as limiting their representativeness. It must be understood that online culture has generally skewed towards a university demographic in terms of leadership: this is no more graphically emphasised than when we look at the university origins of the social media giant Facebook. Nonetheless, we must recognise that we have discovered some interesting findings related to health and risk and their intersections with the uses made of online and social media culture.

Personalisation

We have tested the relationship of online culture to the personal and it appears with youth culture that the key to the movement of content and the effective taking up of information relates to the organisation's ability to allow for the personalisation of information. What this means is that what is produced by the CCA must get into the networks of circulation that youth culture employ with something approaching naturalness despite the insistence on the urgency of the message. There is no question that this is difficult and such a development must be done with care.

Personalisation also means that CCA may have to consider a number of platforms of contact. From the preliminary study, it appears connecting to the older demographic of youth culture might be quite different than their younger counterparts. There was some evidence of the use of online culture shifts somewhat with age. Connecting to mobile delivery of content should be seen as something to work towards. Where much of youth culture looks to shorter messages and forms of written connection, such as tweets, status updates and texts, and it may be possible to effectively engage this demographic through this avenue, but once again care in how communication is established and then maintained is essential.

Intercommunication

As described earlier, intercommunication refers to the new relationship media and communication forms now have in facilitating the movement between the interpersonal and the highly mediated. What appeared to develop from our discussions particularly in our second session is that making an impact requires using other media beyond the online. It also means making links between video content and online forms and it means giving all of these currency and contemporaneity, both aesthetically and in terms of information. A web site loses its dynamism if it does not have strong connections to YouTube and further strong cross-links to social media such as Facebook and twitter. Although other forms of social media were mentioned less, it is important for the CCA to remain current with the shifts and flows of youth online culture and therefore other social media pathways need to be explored and fed with information. Also, it must be acknowledged that various forms of user-generated content not only have to be housed through the CCA online, but have to be well-integrated and cross-linked beyond the CCA web site to have any impact or possibility of having the **vitality of online virality.**

Constructing Persona(s)

In our focus groups, our participants revealed that building a **relationship** to a provider of information and content is crucial. It is evident that social media forms the hub of the online entertainment/recreational activities and the informational activities of young Australians. Like most users of the Internet, youth employ media and communication applications simultaneously for a variety of activities. The pathway of connection to youth culture is constructing a form of mediated and networked **personal connection**. A particular web site is not the primary means of connection, but maybe secondary or even tertiary in terms of how youth navigate the fields, windows and links of online culture. The filters and gateways are interpersonal in nature: information is passed from individual to individual and some level of affective engagement leads youth to feel the need to express themselves through what they have found to others.

How does an organisation with a desire to enter these flows of information movement intersect with this effectively? Axel Bruns, in describing earlier generations of the Web, described some people and their associated web sites and connections as resource centre sites and gatewatchers: that is, resource centre sites as gatewatchers, not keepers were locations online

that were the most likely place for people to go to either connect to others or build their own knowledge about a particular interest (Bruns, 2005). In the era of social media, the larger pool of resources may be a particular web site, but the *portal* is something quite personally delivered.

The focus groups related very strongly to the idea of a particular person somehow embodying the relay of information about the risks of cancer. They were also very astute at identifying the need for perhaps ways in which this person is very individualised as an entity and not some cartoonish avatar that represented an organisation. What needs to be developed is a technique of a particular **persona** or **personas** that allow the CCA to speak to online youth. These personas have to engage in the various ways that youth play and work online and with mobile applications.

To intersect with youth culture of different ages, it may be useful to have a very high social media presence and have that intersect with multiple iterations across media formations, such as an online or mobile game presence particularly for younger users.

Here are a few preliminary recommendations, all of which require greater research to advance:
- Persona(s) should be used for primarily social media avenues to the CCA such as Twitter, Facebook, YouTube, Instagram, Reddit, Flickr and others as they emerge
- Links should be made across social media and web sites effectively and to sublocations that relate to youth when it makes the most sense
- Blogs make sense to move information from the authority to the personal - they represent an intermediate strategy of advice and information that is updated regularly. See below for further development of this site.
- Attempts should be made to make the persona a real person who is not necessarily youth in age, but genuinely connected to youth in an age- appropriate way. Examples of how this is done is probably best expressed through teachers and university lecturers who work out an identity or persona that is cognizant of youth's interests in popular culture.
- A second persona - perhaps the CEO of the CCA - would also be developed more fully. This would be used for more authoritative messages - these will be retweeted by what we call at this stage *Dr Steve*.
- Managing the general to the specific identities (Dr Steve, CEO) needs to be developed with an awareness of how the **Intercommunication Industry** now operates.

- Videos and public appearances by Dr Steve would be needed to build a profile and to build a reason for youth to "follow" or "friend" Dr Steve.
- Generalising across health issues would be useful for Dr Steve's online persona even if it is primarily a return to the issues of cancer and cancer risk.
- Register and tone of address is exceptionally significant in the development of all personas. The range of emotional registers must be part of the repertoire particularly of Dr Steve. Humour must be well-developed and thought through, but also how to construct seriousness and also how to link effectively to messages that are interesting but not quite aligned with CCA.
- A comfortable distance from the CCA - but a necessary link must be developed for Dr Steve to have integrity

TheHealthClinic.com.au

Our second focus group provided us with the insight that perhaps it is smarter to work collaboratively and cooperatively across health organisations to develop an online culture that works well. One of the most remarkable facts that the focus groups provided about youth culture is their readiness to explore health issues online *first*: That moment of searching has to be fostered, nurtured and directed.

In order to develop a portal, the research team is trialling their own idea of a portal concerning health as a blog. A clinic as a virtual physical space with different experts seemed to be the metaphor that would allow us to explore a collaborative model for health organisations to employ to get the information both available and used by youth culture. We will trial through our own researchers something entitled the TheHealthClinic.com.au

Future Directions for Research and Collaboration

There are a number of directions that can be explored:

ARC Linkage

It would be useful to develop an ARC linkage grant that expands on the directions of the pilot project. It would include:
Further focus groups and in-depth interview research.
Development of experimental online forms for primary research
Development of the project for focus groups aged 12-18

Other collaborations

Further mandated reseach would analyse collaborative relationships with other health organisations to develop a more comprehensive health literacy and risk communication strategy through the Healthclinic.com.au initiative. This may lead to mandated research funded across the sector.

Direct expansion of Pilot Project research by CCA

Direct funding of research to generalise the preliminary findings of the Pilot Project to develop an online communication of risk strategy and implementation of strategy.

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Relevant Literature on Health Communication

Green, M C 2006. Narratives and cancer communication. *Journal of Communication*, **56, S163-S183.**

Throughout history, narratives have been used to share information, change beliefs and inspire action. In health communication, narratives range from a public service announcements or PSA (commercials) to multi-episode telenovela (soap operas).Their engaging stories convey cancer-related information for various ends such as to reduce counter arguments to help individuals overcome barriers to treatment-seeking; facilitate the mental simulation of unknown, difficult or frightening procedures such as screening, seeking treatment for behavior change such as quitting smoking; provide role models for behaviour change; and create strong attitudes that are based on both cognition and emotion. (p.163)

Hesse, B W 2009. Cancer communication: Status and further directions, *Journal of Health Communication*, **14, 109-127.**

A meeting of Directors of the National Cancer Institute's' (NCIs) Comprehensive Cancer Centres held on November 7, 2005 examined ways to improve the outcomes of their work fighting cancer using current knowledge. They found that cancer communication needs to be the focal point of research in order to extend the benefits of cancer knowledge throughout the population. The three foci of cancer communication identified were: i) research designed to extend the awareness of prevention and early detection, ii) research designed to improve the accuracy and usability of cancer science as portrayed in the national media and iii) Research designed to support behaviour through individual and community-level interventions. The paper points out that within the context of a fast changing communication environment, these foci take a new meaning and imply that behavioural science must keep up with them and offer new evidence – based approaches for extending the reach, effectiveness and efficiency of cancer communication. (p. 109)

Institute of Medicine of the National Academies, 2004. *Health literacy: A perception to end confusion.* **Washington D C, National Academies Press.**

Definition of health literacy: Health literacy is the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make

appropriate health decisions. Health literacy is the result of multiple, complex social and individual factors. These individual factors include education, culture, language and communication skills while social factors are made up of educational systems, health systems and the media.

Kreuter, M W, Green, M C, Capella, J N, Slater, M D, Wise, M E, Storey, D, Clark, E M, O'Keefe, D J, Erwin, D O, Holmes, K, Hinyard, LJ, Houston, T and Wooley, S 2007. Narrative communication of cancer prevention and control: A framework to guide research and application, *Annals of Behavioral Medicine***, 33(3), 221-235.**

The authors argue that narrative forms of communication such as entertainment education, journalism, literature, testimonials and storytelling are important and emergent tools for cancer prevention and control and propose several applications of such narratives for cancer control. They see narratives as having four distinctive capabilities-namely overcoming resistance, facilitating information processing, providing surrogate social connections and addressing emotional and existential issues. The authors further assert that these capabilities apply and relate to different outcomes across the cancer control continuum such as prevention, detection, diagnosis, treatment and survivorship. However, they point out that that these applications may involve several variables that may impose moderating effects on the narratives and are likely involve ethical issues when used in efforts towards cancer prevention and control. (p. 221)

Kreps, G L 2008. Strategic use of communication to market cancer prevention and control to vulnerable populations. *Health Marketing Quarterly***, 25(1/2), 204-216.**

Complexities related to health information as well as those of health communication pose challenges to those communicating relevant cancer prevention and control information to their publics-especially to those belonging to vulnerable populations. Such communication and information about cancer relates to cancer risks, early detection, prevention, care and survivorship. The author examines the challenges of communicating relevant information to vulnerable populations who often face difficulties with health literacy, cultural barriers, and economic challenges to accessing and making sense of relevant health information. Therefore, effective health communication that carries messages that are clear, accurate and motivating can help such individuals and populations identify and recognise relevant health risks.

The effective strategic communication strategies to be used in such as setting should involve a planned application of key social marketing principles such as carrying out in-depth audience

analyses to learn about and segment one's target audiences so that a persuasive message design and suitable mode of delivery may be used to reach them adopting consumer-oriented, culturally – sensitive and culturally –appropriate processes of communication and health information.

Park, H, Rodgers, S & Stemmie, J 2011. Health organizations' use of Facebook for health advertising and promotion. *Journal of Interactive Advertising, 12* **(1), 62-77.**

Sullivan, H W & Rutten, L J F 2009. Cancer prevention information seeking: A signal detection analysis of data from the Cancer Information Service. *Journal of Health Communication, 14,* **785-796.**

Communication and health information seeking play a significant role in the promotion of cancer prevention behaviours that includes screening. An exploratory study using a 20,412 person sample of information seekers who contacted the (US) National Cancer Institute's (NCI) Cancer Information Service (CIS) found that younger and older adults were less interested in seeking cancer prevention information even though cancer prevention was important to people of all ages. (p. 794)

Viswanath, K 2005. The communication revolution and cancer control. *Nature and Review,* **5, 828-835.**

Increased public demand for health information has been directly related to the advances in communication technologies during the past few decades as these technologies have allowed for greater access to information through a variety of channels.

Yip, M-P 2012. A health literacy model for limited English speaking populations: Sources, context, process and outcomes. *Contemporary Nurse,* **40(2), 160-168.**

Health literacy that helps individuals to function within the healthcare system traditionally used to consist of reading and numeracy skills. But today, they have moved much further to include several others such as critical thinking, problem solving, decision making, information seeking and communication. Health literacy is also linked to health behaviours and health outcomes.

Today, health literacy is further complicated with the proliferation of information and communication technologies as these technologies have changed the way people obtain and disseminate health information and increasingly emphasises an individual's ability and need to navigate the healthcare system and obtain the necessary information. Therefore, health literacy

is an asset as well as an outcome of health education and communication that allows a person to be empowered to manage, promote and maintain good health through their own efforts. Health literacy is within the specifics of specific communication platforms or channels such as social media (smartphone applications, telemedicine, socials networking sites and web-based applications), interpersonal encounters (interactions between individuals and networks of friends, family members, healthcare providers) and written forms (printed materials such as brochures) at the individual (including families) and system (including healthcare settings) levels. Some communication platforms have the potential to enhance an individual's health literacy.

Since health literacy is dynamic and receptive, it can change based on changes taking place with an individual's skills and communication platforms he or she uses.