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Executive Summary

University researchers have a role to play in working with public authorities to develop effective and efficient approaches to gathering and analysing insights from social media that are useful in public policy development and communication.

This one day symposium brought together academic researchers focused on uses and qualitative analysis of social media in public decision-making, and people working in public policy, strategy, and communication.

The program was designed to present cases and new research, and to explore progress towards better understanding of applications and approaches to the qualitative analysis of passively sourced, publicly available social media data. More than 40 people attended.

This report is a record of the presentations and discussions.

The five cases studied showed that insights gained from research into public comments in social media have already impacted policy recommendations, implementation, communication and evaluations.

The symposium discussions consistently indicated that social media provide a unique opportunity to listen in real time to public debate, to identify changes and trends in public opinion as they happen, and to inform decision making and educational campaigns.

This type of social listening has been associated with controversial and complex issues. Salient among concerns was the development of ethical guidelines required to protect privacy, while simultaneously enabling analysis of publicly available comment, to an extent that affords timely and thorough investigation of perspectives not available when using more conventional methods.

Social media offers policy makers understanding not only of what people think, but more importantly ‘why’. It provides insights into information and misinformation, benefits and disadvantages, lived experience, and emotions and concerns that people have in relation to programmes and policies. Such insights can have wide and significant impacts: financial, social and political.

The findings of the symposium indicated the need for systematic and rigorous research methods to provide the kinds of evidence that policy makers can use to achieve policy goals successfully. Further, there is potential to include a wider range of citizen voices by expanding inquiry into multimodal communication platforms. These types of research can be part of a mixed-methods approach, complementing other sources and types of data.

The symposium evaluation feedback showed that all sessions were well received, and suggest that attendees believe this approach to research can make valuable contributions to public policy. There was enthusiasm for creating a special interest group. The event and venue rated highly.

Analysing social media for better public policy

https://www.csu.edu.au/research/ilws/events/social-media-symposium

Symposium held at Charles Sturt University, Bathurst, 14 November 2019

ILWS report Number 134

ISBN number 978-1-86-467366-1

Organisers and contact:

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Preamble

Welcome to country

The day began with an informal welcome by Wiradjuri elders. Their words acknowledged the significance of the location of the university and the building at the foot of Wahluu/Mt Panorama: a location where women prepared and educated young men before taking them to the men for ceremonies marking their transition to adulthood. The site is now a place for two-way learning, and a place where women and men can work in harmony and with purpose. The elders urged us to keep in mind our purpose, to acknowledge our past and let it inform present and future. In keeping with our mission of ‘yindyamarrawinhangana’ (‘the wisdom of respectfully knowing how to live well in a world worth living in’) their words were apt to the title and purpose of the symposium which implies listening to each other in order to improve society.

Opening address

Professor Sharynne McLeod followed with an equally inspirational message. Firstly highlighting the links between the symposium theme and the Charles Sturt university research narrative centred on creating Resilient People, Sustainable environments and Flourishing communities. Sharynne is a leading researcher in the discipline of Speech Pathology and recently addressed the UN to advocate for the human rights of people with communication disabilities. She also noted the significance of Article 19 of the Universal Declaration of human rights which states:

Sharynne observed that social media enable people from diverse cultural groups to express their views and to listen to the voices of others. Also noted was that Facebook users must be over the age of 13, but that social media were the only way that the voices of some children with disabilities could be heard. She emphasised the importance of listening to a wide range of views in order to inform public policy and urged participants to be inspired to continue to develop and refine these methods.
Why is this important?

**Associate Professor Peter Simmons**, Charles Sturt University

The use of social media as an approach to understanding public opinion acknowledges and respects the way people communicate.

My own interest in social media as a source of diverse views of value to decision-makers began when exploring attitudes to kangaroo culling. The views observed in social media were both outrageous and captivating. Closer analysis was able to show considered and complex responses that pointed to solutions (e.g. if killing kangaroos was found to be necessary then all parts of the body should be used in some way) and values consistent with other evidence.

Attitudes to management of sharks evident in social media have indicated public caution about use of nets, but acceptance of drone surveillance on beaches. These attitudes expressed clearly in social media several years ago ‘predicted’ fine tuning of public policy that today reflects those views.

Developing appropriate approaches to using social media in the public sector is about public governance that is both ethical and pragmatic. In a democracy citizens expect to be heard, and top-down decision-making is too risky. Information and opinions on social media provide a rich data source, and better listening will lead to better public policy. Qualitative analysis of passively sourced comments can capture alternative voices and expose the complexity of views and policy impacts.

Of course we are not the first to see the potential for using social media to aid policy processes. There is some excellent work being done around the world, but most is focused on automation and quantification of sentiment. As my colleague Michael Mehmet says in his presentation, the auto and the quantified are important, but they often lack detailed nuance required by policymakers and communicators.

Here at this symposium we were concerned with the manual and the qualitative. Further, this symposium examines the use of ‘passive’ unsolicited data that occurs naturally in social media, not ‘active’ social media data solicited purposefully by organisations.

If we are going to use social media for better policy, we need new methods that are systematic and acceptable both to citizens and decision-makers. The symposium program included a range of five case studies that emphasise qualitative methods for analysing social media opinions on a matter of public importance. All of the cases have previously been published in peer-reviewed scholarly journals (see Appendix 3 for references). One of the main aims of the symposium is to extend our repertoire of qualitative approaches and techniques for identifying, gathering, analysing and using findings to aid policymakers. So each case presentation emphasises reflection on methodological concerns.

The second half of the day explored policymaker perspectives and ethical issues before the attendees worked together to address three questions:

- What needs to happen for this type of research (Analysis of social media, passively sourced, Qualitative analysis) to be useful to policymakers?
- Most examples have been text based (online comments) and from news sites – what other types of data (non-text?) and sources should be explored? Why?
- What sorts of public policy challenges or questions or stakeholder groups may be best suited to this method of research?

(Slides – Appendix 2a)
Acknowledgements

Special thanks to Rizwan Sharif for calmly staying on top of all the details an event such as this requires.

Many people helped us to make the symposium a success. Thank you for your expertise and generosity:

* Wiradjuri elders warmly welcomed us to their country
* Simone Engdahl expertly designed and ran the ILWS web page
* Becky Russell meticulously designed and set up the venue AV
* Karl Shead generously helped set up the venue
* Joyce Voerman carefully noted, recorded and interpreted the proceedings used for this report
* Sharynne McLeod enthusiastically launched the day
* Greg Windsor thoughtfully participated in the Applications and opportunities in the public sector panel
* James Brann thoughtfully participated in the Applications and opportunities in the public sector panel

Thank you to our excellent presenters from around Australia (see also Appendix 1):

* Michael Mehmet
* Rachael Dodd
* Lucy Farrell
* Jackie Street
* Kelsey Chalmers
* Belinda Curley
* David Cameron
* Kylie Morphett

Thanks also to the event sponsors:

* Faculty or Arts and Education
* Institute for Land, Water and Society
* Charles Sturt University Research Fellowships

And thank you to all our attendees who engaged enthusiastically and thoughtfully with the program and challenges we posed during the day.

Peter Simmons and Kane Callaghan
## 1. Cases, benefits and opportunities for better public policy

<table>
<thead>
<tr>
<th>Case study</th>
<th>Focus</th>
<th>Method/Data</th>
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<tbody>
<tr>
<td>4.</td>
<td>Public responses to media articles about the effects of ecigarettes.</td>
<td>Mixed methods: self-reported descriptive information about posters (e.g. country, smoking/vaping status) quantitative coding of opinion +/-/n qualitative coding of content using thematic analysis using NVivo.</td>
</tr>
<tr>
<td>5.</td>
<td>What to do about sharks?</td>
<td>Mixed methods – social media and focus groups 10 public Facebook and Twitter pages – 4185 comments Appraisal analysis of 13000 ‘sentiment items’.</td>
</tr>
<tr>
<td>6.</td>
<td>Applications and opportunities across the public sector. Panel and open discussion.</td>
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*Table 1 Overview of case studies*
1.1. Reacting to changes in public policy: the case of cervical screening.

Dr Rachael Dodd, University of Sydney

This was one of the first papers to explain the link between social media and public policy with a view to communicating policy changes effectively and educating the public.

- 2017 changes to Cervical screening program in Australia were introduced
- Addressing public concerns about reduction in screening
- Revealed some misunderstanding of medical information
- Random sample from 2000 comments from Change.org petition
- Initially uncertain whether ethics was needed as data was publicly available. Ethics committee noted that comments were not provided with intention of use in research. Seeking consent problematic. Change.org privacy policy also relevant
- Data had to be de-identified. Quotes would be modified to ensure they couldn’t be identified.
- After initially trying to copy and paste comments from the petition, researcher contacted the person who started the petition who was able to provide Excel spreadsheet with all comments.
- Postcode was only demographic data available
- Likely that petition attracted people with prior interest or history
- Total dataset (20,000 comments) stored for further analysis. Ethics concerns addressed by saying identifiers would be removed from dataset but as information was publicly available anyone could still find the comments online and link them with the name of the commenter
- Online comments: timely – connected to petition (people responding); quick way to gather large number of views; press can be powerful way for negative views to be aired

Questions to Rachael:

- How did you manage your own perceptions and attitudes about cervical screening?

Qualitative research acknowledges and accounts for researcher perception. Data were selected randomly. Research perception may influence interpretation of comments, thematic categorisation and examples. Acknowledged in process of analysis.

- How difficult was the ethics process? Did you need to obtain waiver of consent?
- Do you think consent would be an issue now that the NHMRC has changed policy in relation to privacy concerns?
- What sort of feedback did you get (on ethical issues) from journals/reviewers?

(see Appendix 2b slides)
1.2. Public attitudes to government roles in obesity prevention.

**Dr Lucy Farrell, University of Adelaide**

**Dr Jackie Street, ACHEEV, University of Wollongong**

**Context of the study:**
- Public views on the use of regulation and law to prevent childhood obesity in Australia
- Translation of evidence-based preventive health interventions into policy and practice and the inclusion of community values in policy development
- Funded by the Australian National Preventive Health Agency

**Research question:**
What regulations and laws, if any, are socially acceptable, ethically rigorous, legally sound, and cost-effective for the state to use in preventing childhood obesity in Australia?

**Primary objectives:**
1. Review evidence for and against the use of regulations and laws to prevent childhood obesity in Australia.
2. Analyse discourses prevalent in the Australian media and on-line forums on the use (potential or actual) of preventive regulations and laws in obesity prevention
3. Through a cross-sectional face-to-face survey, assess public opinion in South Australia on the use of regulations and laws to prevent childhood obesity
4. Through a deliberative citizens' forum, provide informed citizen views on the role of the state in responding to high obesity rates in children and a consensus on the use of regulations and laws for prevention of childhood obesity in Australia

**Data:**
- Reader comments about Australian online news articles: Factiva search obesity related terms in Australian media outlets Jan-Dec 2013.
- Focus groups in socio-economically disparate areas
- Representative cross-sectional survey of South Australians

**Analysis:**
- Thematic analysis
- Affective-discursive analysis

Comments revealed experience of those living with obesity; discriminatory and harsh views

**Comparison of methods:**
Focus groups
- More considered language
- …BUT similar themes

Themes, support for policy patterned differently across high/low socio-economic status areas

**Key finding:** high SES support measures to address ignorance, low SES support measures to address costs of living

Cross-sectional survey
- Hard to design and interpret without qualitative findings

**Key finding:** majority strongly in favour of labelling
Figure 1 - cross-sectional survey results (Farrell & Street, sl.20)

Policy impact

Research led to recommendation that “Commonwealth funding for overweight and obesity prevention efforts and treatment programs should be contingent on the appropriate use of language to avoid stigma and blame in all aspects of public health campaigns, program design and delivery.”

(See Appendix 2c slides)

Questions

Is the harvesting of Facebook comments and the thematic coding too researcher driven?

- broad range of media outlets and comments – pulled out comments not relevant – NVivo grouped comments – manual coding was rigorous and took a long time

Were you surprised by comments supporting food taxes?

- led to reflection on own biases

When you submitted to journals were there ethics concerns about use of comments?

- comments indicated systematic and strong way of collecting and analysing data.

**Dr Michael Mehmet, Charles Sturt University**

- This research compared use of automated data analysis with manual, qualitative analysis using Appraisal theory.
- Found that manual methods could take into account the context of comments and lead to more nuanced understanding.

I am NOT saying that automated practices do not have their place

- They tend to be less expensive
- Quicker, especially with large scale datasets
- Unbiased by human interpreter (this is actually not true and I’ll tell you why)
- Good for a quick snapshot

**Limitations**

- Work in binaries
- Level of expertise needed to use them
- Context. Even AI needs to be trained per context
- Often limited by
  - Jargon
  - Irony
  - Humour; and
  - Nuance or competing thoughts in the same speech act are often miscoded

**Why qualitative?**

The single biggest justification for a qualitative approach is the ‘WHY’ factor.

Automated approaches tell us ‘what’ is going on, but qualitative can delve deeper into the ‘why’

- Pick up on nuance in the FUNCTIONAL language
- Understand explicit and implicit MEANING
- Be ADAPTIVE: you can expand codes if necessary
- All within a specific situation CONTEXT

**Process**

- Understand context
- Collect data
- Cleanse
- Sort/filter
- Determine theme
- Read data, extract themes
- Inter-coder check
- Code
- Appraisal
- Inter-coder check
- Analyse and reflect

**Carp Herpes Virus case**

- Introduced in the mid 1800s carp are classified an invasive alien species or invasive pest
- Explosion in impact since the Boolarra strain of the fish in the 1960s
- They have negatively impacted the environment, particularly the Murray-Darling Basin
- Virus is designed to kill and manage numbers

**Results (automated)**

- More negative than positive.
- Lots of neutral (positive – negative)
- City people were most against it.
- BUT WHY? And why the conflict in the neutral level?
Results (manual)

National

Only 7% of comments were positive towards the virus

- Why the high level of negativity?
  - Fearful of virus and its impact of the environment
  - Did not trust the virus to kill ALL carp (e.g. Cane Toads)
  - Didn’t like politicians and how they went about dealing with the virus

Results (manual)

Capital City

What did we learn?

- Positive reactions at 15%, with a sprinkle of hope
- Why the negativity?
- Again insecurity, potential impact on the environment
- Don’t trust the virus to solve the problem (rabbits)
- Value in carp as a resource or rec species for fishing (fertiliser or sell to Asia)

Results (manual)

Regional

- What did we learn?
- Positive 12%
- Why negative?
  - Insecurity toward impact on local environment, drinking and irrigation
  - Don’t trust government to achieve task or trust the virus to achieve what has been claimed (history of broken promises)

What did we learn?

- The positive figure in the automated was over reported
- Neutral comments were a mix of attitudes that needed to be teased out and examined
- More negative comments
- We understood why, with stories of lived experience, context factors, and historical references.
- We gather a range of emotions, not just positive and negative
  - Hope
  - Fear
  - Insecurity

Impact on Policy

- Policy makers decided to take more time understanding the needs of their constituents, through more active social listening practices
- It resulted in authorities considering alternate communication strategies and channels
  - e.g. Town meeting to overcome communication misalignments and barriers
  - Using social media (then stopping) to communicate with the public. They stopped because of vocal opposition.
- Research insights potentially contributed to the delay of the release of the virus.

Questions

- How did you identify geography? Target audience and self-declared
- Did you consider perception of ‘virus’ as a concept might influence public views?

In automated method comments that include both positive and negative views could be coded neutral (e.g. if words were not in the dictionary)

- Would there be issues publishing now given ethics may not allow harvesting of Facebook comments?
- (see Appendix 2d slides)
1.4. Public responses to media articles about the health effects of e-cigarettes

Dr Kylie Morphett, University of Queensland

Context
- E-cigarettes developed in 2001 to help people quit tobacco. Current evidence suggests much less harmful than smoking but no long term data yet.
- Recent study showing deaths associated with some types of vaping but still controversial
- Benefits: improved rate of success quitting; improved health; long term harm reduction for those who can’t quit; reduce smoking among youth
- Risks: can lead to dual use and higher nicotine consumption; long term risks unknown; can prevent some people completely quitting; another way of normalising smoking and may act as gateway to smoking for young people
- Different policies in Australia (precautionary advice and no nicotine products on sale; online availability); UK/EU – legal but with packaging requirements. USA – regulated as tobacco, but little regulation. Moves to increase regulation
- Growing belief that vaping more harmful than cigarettes. US media more likely to be negative, UK more positive. Experimental study showed negative headlines increased negative views on vaping.

Aims
- Investigate public reactions to news reports about vaping and identify the ways in which people:
  1) Interpret and respond to media articles about e-cigarette regulation
  2) Conceptualise the risks and/or benefits of e-cigarettes
  3) Justify their positions on e-cigarette regulation

Why online comments?
- Accessible and naturalistic data
- Rich source individual comment, opinion, experience and dispute
- Spontaneous, unsolicited
- Insight into how opinions about policy and regulation are framed and justified

Selecting data
- USA due to changing regulations; active debate at the time; e-cigarettes legal and accessible
- New York Times: well-known traditional newspaper; largest circulation; non-subscribed access; anyone can create account and comment
- Two articles met criteria and both presented balanced view, described health effects and regulatory options, included expert opinion and generated robust online debate with lots of comments

Qualitative findings
- People didn’t always refer to the evidence presented in the article and shared their own experience with others – incorrect beliefs about safety
- Confusion about conflicting health advice in different countries; high levels of distrust in the tobacco industry and regulatory authorities – able to identify why people trust or distrust
- Strong concern about young people becoming addicted to nicotine

Implications for policy
- Need to educate to prevent misconceptions
- Acknowledge continuum of harm – relative risks
- Acknowledge and explain conflicting health advice

Challenges
- Deciding what to include or not – need strong justification
- Possibly vested interests at play – not clear who behind comments (eg. tobacco industry)
- Should not be used in isolation but to augment traditional data collection

(see Appendix 2e slides)
1.5. What to do about sharks?

Dr Belinda Curley, NSW Department of Primary Industries
Associate Professor Peter Simmons, Charles Sturt University Research Fellow

Context
- Increased incidence of shark attacks on north coast in 2015 generating media attention and community calls for government action
- Proposed NSW Shark Management strategy worth $16 million over 5 years; trialling new technology while minimising collateral harm to marine life
- Community division over use of nets; need for evidence to support decision making
- Social research relatively new for environmental agencies
- Statewide strategy meant need for understanding broader attitudes across NSW

Aims
- Explore community attitudes to:
  - sharks
  - the Shark Management strategy
  - co-existence with sharks
  - open to other issues and views in the data

Method
- Social Media and focus groups
- Manual coding using Appraisal discourse analysis to capture nuance – resource (time) intensive
- 10 public Facebook pages (balance left-right media: for and against culling) and Twitter
- over 4000 comments made over 13 month period December 2015-2016; 13000 sentiment items

Findings
- Attitudes not strongly in favour of culling or using nets; more in favour of educating people and respecting marine environment as natural habitat
- Respect marine life, but protect popular beaches
- Not black and white; people disliked reactive policy

Outcomes for Shark Management Strategy
- Novel and valid evidence for decision makers
- Complemented DPI social research and feedback
- Helped to inform future trials and identify key issues around mitigation methods
- Informed risk and communications planning (websites, fact sheets)
- Informed design of other social research

Social media growing in importance as data source due to being a major platform for public communication.

More representative of wide range of views.

Passive sourcing of comment avoids survey fatigue or heightening concerns and raising expectations of management decisions.

(see Appendix 2f slides)
1.6 Panel discussion

Facilitator: Dr Jackie Street (University of Wollongong)

Panel:
- James Brann, Director, Student Communications, Division of Student Services, Charles Sturt University
- Dr Greg Windsor, Manager, Administrative Spatial Program, Spatial Services, Department of Customer Service
- Dr Belinda Curley, Manager, Marine Estate Monitoring & Evaluation, Aquatic Environment NSW Department of Primary Industries, DPI Fisheries

Key points in the discussion

James Brann
Changes to ethical concerns regarding use of social media
Seen as a platform for people without a voice in traditional discourses, but still a relatively affluent group of users; internet access not universal or equitable; in global context also weighted to affluent countries and groups
In Australia, many in remote locations still don’t have access
SM may offer platform for those traditionally disenfranchised, but need to actively seek out minority voices.

Belinda Curley
Strengths of social media research:
- lets us listen to concerns of community despite limitations in how representative it might be
- policy makers often interested in a portion of the community and how views change over time
- provides opportunity to evaluate government strategies and monitor long-term effects of implementation.

Greg Windsor
Provider of authoritative data (spatial information)
- decision makers require accurate information
- need to make policy relevant — input in development and implementation
- good policy can turn bad if it is not in the right community e.g. drought relief misdirected — government out of step
- centralised decisions may fail to acknowledge needs of individual communities
- spatial systems can use information about attitudes to determine what is in the ‘community interest’
- SM technologies enable deeper picture — geography and people’s views
- biggest barrier is in the area of ethics
- Key question: Has government got social license to gather this data e.g. Cambridge Analytica scandal; harvesting and selling public data
- SM policy itself needs to be informed; people’s perceptions of privacy are changing
- Does the government care? Yes. They crave social information to better target policy

BC agreed — there is hunger for information and evidence for cultural and environmental decisions

Jackie Street
- Timing is crucial. They had data [on obesity] but government wasn’t interested. Need to be mindful of purpose and combine with other methods as well as nature of policy and government ideology
- Not just data that is important: analysis and recommendations need to be communicated clearly and in a way that is useable
- Despite contacting every minister in SA to say these recommendations could be implemented with little cost and high impact, they were listening, but not willing to act for fear of election backlash and opposition’s policy position
- Funding body was disbanded so appetite for the research changed
- Nevertheless evidence is there when opportunity arises
- Policy window

GW
- Presenting information key; daily requests for information to help target policy accurately
- Mixed methods useful but barriers to data use
- Policy around social media for research moving – opting in – web providers need to set-up to allow use for research
- Moderators and companies act as passive censor
- Same thing happening in ethics guidelines is happening with privacy policy – getting to stage where use of comments without consent is prevented
- Concerns about safety in removing identifiable components and storing data.
- Need for quality sources – for the good of the community
- Not everyone engages in social media, but low barriers to entry unlike public meetings focus groups
- One tool amongst many; some tools don’t work well; need research on how people engage; more tools we use the better the picture

BC
- SM gives voice to people who’ve been ignored by policy research, previously excluded from decision making.
## 2. Adapting and applying methods to meet policy needs

<table>
<thead>
<tr>
<th>What information aids policymakers and what's available in SM?</th>
<th>Kane Callaghan (Charles Sturt University)</th>
</tr>
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**Publicly available! Ethics and the use of SM data and permissions**

Dr Kelsey Chalmers (Menzies Centre for Health Policy)

<table>
<thead>
<tr>
<th>Workshopping the wicked: facilitated discussions of 3 issues</th>
</tr>
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<tbody>
<tr>
<td>- What needs to happen for this type of research (Analysis of social media, passively sourced, Qualitative analysis) to be useful to policymakers?</td>
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<td>- Most examples have been text based (online comments) and from news sites - what other types of data (non-text?) and sources should be explored? Why?</td>
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<td>- What sorts of public policy challenges or questions or stakeholder groups may be best suited to this method of research?</td>
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Dr David Cameron (Charles Sturt University)

**Table 2 Overview of adapting and applying sessions**
2.1 What information aids policy makers and what’s available in SM?

Kane Callaghan, Charles Sturt University

This research asked: what information or evidence do policy makers need to make policy decisions? Social media provide an opportunity to listen to public opinions; but how do we investigate systematically? What information enables informed decisions; credible and reliable data?

Study
- aimed to understand what types of information are useful
- interviews with staff from Department of Primary Industries
- stakeholders in policy research, organisational communication, policy design and evaluation
- focused on information from community
- scientific information is crucial but so is community support to ensure policy is successfully implemented

Found they desired 4 categories of information (policy development and evaluation):
- Attitudes
- Values and interests
- Understanding of policy
- Lived realities and unintended consequences of policy

Social media can provide policy makers with information in all four categories. Policy makers benefit from hearing community views.

SM data fits these categories across diverse policy areas.

Need to explore various platforms and ask where the required information is present. Importantly, how can we analyse this data systematically?

Questions
- Are the categories useful as a framework for analysis? Not exhaustive but useful.
- Are these categories like themes? Might change with different policy areas (interviews were all DPI but policy areas very diverse)
- Interest in citizen science and crowd sourcing; crowd sourcing can indicate gaps in funding
- Which category stood out? Policy makers worried about understanding and dangers of rapid spread of misinformation (e.g. cervical cancer technology)
- Do categories then lead to responses? e.g. education; design/redesign; communication

(see Appendix 2g slides)
2.2 Publicly available! Ethics of use of SM data and permissions

Dr Kelsey Chalmers, Menzies Centre for Health Policy

Context

- Public versus Private health care; out of pocket costs
- Media coverage: Scott Morrison says all cancer treatment is free – is he correct? Survey of cancer patients; 1/5 had spent over $10 000.
- Has led into a ‘maze’ of ethics applications, ethical and legal issues

Data source

- Online crowdfunding organisation: Go Fund me
- Previous literature in Canada showed that crowdfunding may show gaps in healthcare systems
- Negative is that dangerous treatments that have been ruled out by federal regulation may get funding
- Campaigns need a ‘worthy’ cause thus may discriminate if person or illness not popular
- Gathered information from campaigns in 200 post codes; people asking for funding for medical treatments, accommodation and travel, lost income

Ethics

- Thought it would be OK as data is publicly available
- Advised to check terms and conditions of the privacy policy of the organisation
- Questions about whether all campaigns were legitimate (as some false campaigns had been exposed)
- Ethics about quoting campaigns directly – identity concerns
- Previously approved projects would now not pass ethics applications due to change in NHMRC statement on ethics
- Advised that even though information is publicly available, participants had not given permission for it to be used in research. Expectations people have when using different websites may vary.
- Concerns relating to release for private data in some high profile cases (e.g. Ashley Madison dating; Cambridge Analytica political advertising;)

Discussion

- Spectrum of data from humans
- New study – same design in US was deemed low risk as its publicly available – disadvantage to Australian researchers
- Public benefit of the research should outweigh concern
- Apply for a waiver of consent; consider website terms and conditions; consider privacy by de-identifying
- Shutting down scrutiny of websites not in the public interest
- What’s the difference between newspapers and GoFundMe? – both public spaces. Shifting ground – previously blogs were used, now move to other platforms
- Need principles based approach
- Goal to raise awareness of an issue should therefore be open to researchers; by using GFM people are already sacrificing medical privacy

Questions

- How would you argue the waiver of consent in an ethics application? – Asking for consent might also affect results and who will allow scrutiny.
- How many people are aware of NHMRC guidelines? Are researchers even aware?
- Where will this be in three years’ time? Context is changing in regards to privacy.
2.3 Workshopping the wicked

Dr David Cameron, Charles Sturt University

Focus question 1: What needs to happen for this type of research (qualitative analysis of passively sourced social media) to be useful to policy makers?

Ethics
- researchers need permission
- perceptions of public to collecting the data – even if legal

Build social licence to use the data

Timely – allows us to understand responses to current issues very quickly

To be useful, we need to understand the kinds of questions that SM research can answer.

Social importance – community importance – newsworthy and informative – show the community benefit of the research

Credible – systematic

What is considered systematic research? How do you demonstrate systematic approach to thematic interpretation?

Systematic approach can achieve more nuanced understanding of varied interests

Mix-method approach – complementing other research methods to expand insights – Show value / benefit of social research as a way to LISTEN to communities – achieve two-way learning

Partnerships between government and researchers – Policy makers need to be involved from the start (being invested and empowered). Needs to be in tune with policy cycles. Need to understand what the policy makers are interested in – at present and in the future

Able to be implemented – recommendations – enable ‘quick wins’ and make it sound like it is their idea

Easily understood – ‘digestible’ – must speak to policy makers about what is going on in the ‘landscape’.

Publications – communication conveyed in a way that avoids cognitive dissonance (i.e. be clear)

Must explain context and limitations of the data e.g. policy makers can misinterpret as wholly representative rather than representative of a ‘slice’ of the community.

They must be able to use the data, know how it was collected; “passes the pub test"
Focus question 2: Most examples have been text based (online comments) and from news sites – what other types of data (non-text?) and sources should be explored? Why?

- Images, memes and videos are just as (or more) important as written text but under-researched
- Multimodal research and remediation
- Only old people use Facebook and its use is predicted to decline
- Younger groups use memes and irony to communicate their perspectives; if we don’t investigate their use, we’re excluding their voice
- Need to include people using the source to be included in the interpretation of meanings made.
- Most growth happening in multimodal platforms – question is how to analyse these modes
- Geo-mapping and geo-coding are powerful and important but contain possible privacy issues

Sources:
- YouTube; videos
- Stories (Insta)
- podcasts
- image + text data
- photos
- location/spatial data – drone; remote sensing; webcam
- interactions
- memes e.g. “thoughts and prayers”
- images – facial expression; context; action/vector; body language/gesture
- emojis; gifs
- games
- apps
- citizen science
- metadata on particular issues
- cartoons (e.g. political commentary)
- More research needed on likes, trending, hashtags and how they affect the salience of issues
- Art, theatre and dance
- Humour

Why?
- currency
- diversity of views
- inclusivity
- critical perspectives
Focus question 3: What sorts of public policy challenges or questions or stakeholder groups may be best suited to this method of research?

Those with large financial/health/social impact. IMPACT

Controversial/contentious: Is everything contentious?

Where people have an agenda (multiple stakeholder groups; e.g. patients)

Where it impacts:

- large proportion of population
- minority groups/marginalised – might be their only chance to engage in the debate
- disadvantaged or specialised/niche groups who don’t have a mainstream voice
- difficult to target people who aren’t tech savvy “need to be aware which social media and who is using them”
- issues where there are high levels of misunderstanding; misinformation or lack of information
- issues that required understanding of personal/lived experiences
- questions that are not easy to investigate via other research methods; exploratory questions
- issues requiring change
- sensitive or taboo topics
- suitable for changes requiring broad input – complements other methods of gathering data
- social media itself is a public policy challenge
Appendix 1: Presenters

Associate Professor Peter Simmons
School of Communication and Creative Industries, Charles Sturt University
Peter Simmons is a Charles Sturt University Research Fellow. His special focus is the use of social media in public policy, especially in matters of coexistence and conflict. He has used attitudes expressed in social media to explore several cases of human/human and human/non-human conflict. Peter’s recent research has examined local government communication, sport referee communication, and influences on attitudes to managing sharks.

Dr Rachael Dodd
School of Public Health, University of Sydney
Her research to date has focussed around communication in healthcare in combination with assessing psychosocial impacts of HPV-related cancers. Rachael's current research is looking into communicating key concepts of HPV and cervical cancer in the context of providing reassurance and information about the renewed National Cervical Screening Program in Australia. Rachael completed a Masters in Health Psychology and a PhD in Psychology in London, UK.

Dr Lucy Farrell
Division of Academic and Student Engagement, University of Adelaide
Lucy Farrell is a mixed-methods social researcher, currently working on evaluation in higher education. Her background is in large-scale program evaluation and deliberative approaches to policy-making across a range of sectors and organisational settings. She received her PhD in public health from the University of Adelaide, investigating public attitudes about obesity prevention policy. Lucy also holds a Masters in Journalism and a Bachelor of Psychology.

Dr Jackie Street
Australian Centre for Health Engagement and Values, University of Wollongong
Dr Street is internationally recognised for her research on the inclusion of patient and citizen voices in decision-making for health technology assessment (HTA). She pioneered early work using social media to bring public voices into public funding decision-making for health technologies. Dr Street received her PhD in Biochemistry (University of London, 1985) but made a career change into public health in 2005. Dr Street is a founding member of the Australian Centre
for Health Engagement, Evidence and Values at the University of Wollongong. ACHEEV is a new Centre bringing together leading experts in deliberative practice and community engagement.

**Dr Kylie Morphett**

School of Public Health, University of Queensland
Kylie Morphett completed her PhD in 2016, investigating how smokers understand the neuroscience of nicotine addiction. Prior to this, she worked in a number of health promotion roles in non-profit organisations. Her current research uses mixed-methods research to understand how best to communicate health information about tobacco and nicotine products, as well as emerging environmental contaminants such as PFAS and glyphosate.

**Dr Kelsey Chalmers**

Menzies Centre for Health Policy
Kelsey Chalmers received her PhD in public health from the University of Sydney, and investigated the measurement of low-value procedures using Australian private health insurance claims. During her PhD, she worked with government and industry stakeholders, and was a visiting Queen Elizabeth Scholar at McMaster University in improving health systems. Her current work at the Menzies Centre for Health Policy focuses on value and financing in health care, including out-of-pocket costs.

**Dr Michael Mehmet**

School of Management and Marketing, Charles Sturt University
Dr Michael Mehmet specialises in social media social listening. He has pioneered a multimodal method that can extract meanings and sentiment from a range of social media sites. His background in marketing and communication has allowed him to apply his skillset across a range of policy, business and community contexts.
Dr Belinda Curley
NSW Department of Primary Industries
Belinda’s career has focused on applying strategic social and ecological research to policy and communication in coastal environments. She currently works on the development of the Marine Integrated Monitoring Program for the NSW marine estate, with a particular focus on the social and cultural components of the initiative. Previously, she led the social research program for the NSW Shark Management Strategy and conducted ecological research on Marine Protected Areas.

Kane Callaghan
PhD student, Charles Sturt University
Kane Callaghan’s research focus is on ways that online citizen commentary can be collected and analysed for use in public policy decision making. Kane’s PhD uses the policy space of human-shark coexistence to explore systematic approaches to capturing and making sense of citizen thinking expressed online. Kane's PhD research is funded by both the NSW Department of Primary Industries and the CSU Institute for Land, Water and Society.

Dr David Cameron
School of Communication and Creative Industries, Charles Sturt University
David Cameron is a Senior Lecturer in Communication at Charles Sturt University. His professional background includes broadcast and online media production. His PhD examined shared conventions between educational drama and game-based learning. David’s recent research and publication has examined ways in which live performance and media arts interact with digital cultures to create new forms of multimodal and transmedia storytelling.
Appendix 2: Slides

a) Why is this important?

Why is this important?
Associate Professor Peter Simmons
Charles Sturt University Research Fellow

Overview
• Pioneers, FoAE, CSU Fellowship, ILWS, ScE, DPI
• An exploration - discovery
• Morning – cases – story with focus on method
• Panel
• Afternoon – context, application and development?
• Outcomes – understanding, issues, paper, initiatives, chapter book, repertoire, collaborations, better research, better listening, better policy

Outrageous, direct, insightful. Data!

"[Referring to Barnaby Joyce] What a pathetic waste of oxygen this vile creep is. I despise him." (Wilkie, 2015)

"[Referring to the Greens] Fuuuck heads. Salad eating miss informed twits. All of them." (Rhiannon, 2015)

"I don’t kill them for profit. I kill them for fun...there’s a difference you know." (Rhiannon, 2015)

"[I hope that the meat will be butchered for consumption...and the hide is also used]."
(The Canberra Times, 2015)
Social media ‘predicted’ policy

<table>
<thead>
<tr>
<th>Common social media attitudes 2016</th>
<th>Policy 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>No to nets, Yes to drones</td>
<td>No to nets, Yes to drones</td>
</tr>
<tr>
<td>‘Mesh nets don’t work; kill marine life/ expensive’</td>
<td>Cease North Coast net trial 2018 – no more planned</td>
</tr>
<tr>
<td>Trials of alternatives - SMART drumlines/</td>
<td>More trials of drones, now with drones and signage</td>
</tr>
</tbody>
</table>

Why is this important?

Acknowledging and respecting the way people communicate

Governance that is both ethical and pragmatic – In a democracy citizens expect to be heard, and top-down decision-making is too risky

If we are going to use SM for better policy, we need new methods that are systematic.

SM is already influencing policy

“There was another shark incident 10 days ago in the same location,” Fisheries Queensland executive director Claire Anderson wrote in an email to senior officials...

“There are comments on social media about it so it will likely be picked up by media,” Ms Anderson wrote.

“This reinforces the need to get some drum lines in the location as quickly as possible.”

Citizens and authorities need SM for full picture

‘Traditional media is heavily enmeshed with the racing industry but on social media the potential for animal abuse is slowly overtaking glossy glamour shots in coverage of the day’ (Horse racing, 2016).

... governments first used their own accounts in various social media, in which they provide information about specific problems and policies, and solicit citizens’ feedback on them (active citizenship). Recently, they attempt to take advantage of the extensive public policy related content developed beyond their own social media accounts, in various political forums, blogs, news websites, and SM accounts, by the citizens, without any stimulus (passive citizenship). (Loew et al. 2015)

Questions for today

- What needs to happen for this type of research (qualitative analysis of passively sourced social media) to be useful to policymakers?
- Most examples have been text-based (online comments) and from news sites - what other types of data (non-text?) and sources should be explored? Why?
- What sorts of public policy challenges or questions or stakeholder groups may be best suited to this method of research?
References


Social media use – Roy Morgan May 2019


Facebook recently Australia’s most widely used Social Network at early in 2019 with over 12.1 million Australians aged 14+ (83.3%) visiting Facebook in an average month, an increase of almost 4.2 million (+32.4%) from four years ago according to the latest research from Roy Morgan.

YouTube is in a clear second place and the popular online video sharing site has an estimated 13.3 million visitors in an average month, up by over 3.5 million (+28.7%) from four years ago.

Although both Facebook and YouTube are clear market leaders in the Social Networks and Online Communities market, it is the primarily image sharing sites Instagram and Pinterest that have grown in recent years.

Instagram, Facebook’s photo and video sharing subsidiary now has over 8 million visitors in an average four-weeks, up by over 5.6 million (+238.1%) from four years ago.

And Pinterest, with over 7.3 million visitors, has grown by over 4.6 million (+194.3%) since 2015 with both sites now have more than doubled.

Other sites that have impressive growth include Twitter, now with over 6.8 million visitors has increased by over 3 million (+83.1%). LinkedIn which now has almost 4.6 million visitors, up by over 1.4 million (+40.0%) and Reddit which now has over 2.9 million visitors, up by over 1.2 million (+71.0%)

These results are based on an in-depth Roy Morgan Single Source interviews with more than 50,000 Australians over the 12 months to March 2015 compared to four years earlier in the year to March 2015.
b) Reacting to changes in public policy: the case of cervical screening

![Image of Sydney University logo]

Reacting to changes in public policy: the case of cervical screening

Dr Rachael Dodd

rachael.dodd@sydney.edu.au
@rachael_dodd85

Penetration of the Australian Population

- Approximately 6 in 10 Australians use Facebook on a daily basis
- 1 in 3 Australians use Instagram

Key Points to Note:
- Facebook has been shut down
- Instagram has been shut down
- Twitter has been used by the Australian government

Social Media Use in Australia - July 2019

[Links to social media statistics]

Background

In December 2017, changes were made to the cervical screening program in Australia. These changes were:

<table>
<thead>
<tr>
<th>NOW</th>
<th>WAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical screening test:</td>
<td>Pap test: cells from the cervix tested</td>
</tr>
<tr>
<td>cells from the cervix tested for HPV</td>
<td>for HPV infection</td>
</tr>
<tr>
<td>examined under a microscope, if HPV is</td>
<td>examined for physical changes</td>
</tr>
<tr>
<td>detected</td>
<td></td>
</tr>
<tr>
<td>Every 5 years</td>
<td>Every 2 years</td>
</tr>
<tr>
<td>Start: 25 years</td>
<td>16-20 years</td>
</tr>
<tr>
<td>End: 70-74 years</td>
<td>69 years</td>
</tr>
</tbody>
</table>

2014 survey (Yap et al., 2016)

- 40% accepted HPV testing, 38% delaying screening to 25 years
- 50% concerned cervical cancer in younger women would be missed
Background

- Understanding how to communicate reductions to screening effectively without raising public concern in an important area for research
- Opposition from the public in other countries in response to a change in guidelines for cancer screening programs
- Following the changes announced to the cervical screening program in Australia, similar opposition has been met
Methods

Primary study
- Downloaded all comments to online petition on Change.org: Stop May 1st Changes to Pap Smears – Save Women’s Lives
- Feb 16 2017 – March 19 2017
- Of 20,000 comments, analysed a random 2000 (10%)
- Analysed using content analysis

Secondary study
- Concentrated on the 615/2000 comments which reflected concerns about the specific changes to the cervical screening program
- Analysed using thematic analysis

Reacting to changes in public policy: the case of cervical screening
Methods

Ethics (early 2017)

- Uncertainty whether ethics was needed as publicly available data
- Ethics office said:
  
  Despite the information being ‘publicly available’, the comments made on the change.org petition were not provided with the intention of being used in research. Also, I note that you want to publish your findings, and many journals require ethics approval for publication.
  
  The main thing to consider in submitting an ethics application for this research project will be the identifiability of the data you’re proposing to use and the matter of consent i.e. whether or not it will be sought.
  
  You might need to consider change.org’s opinion on using their data for research purposes as they do have a privacy policy.

Reacting to changes in public policy: the case of cervical screening

Methods

Data retrieval

- Data collected from Change.org, identified as this was the platform for the petition
- Had to consider how many to code
- May have to consider Change.org policy and also ethics policy
Methods

Ethics (early 2017)

- Uncertainty whether ethics was needed as publicly available data
- Ethics office said:

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  You might need to consider change.org's opinion on using their data for research purposes as they do have a privacy policy.

Sampling

- Due to large volume of comments (almost 20,000) we chose to include a random sample
- We included all comments micro in a months time period: Feb 16 2017 (day the petition started) to March 19 2017
- All comments recorded chronologically in Microsoft Excel and assigned a number
- Comments ranged from 1 to 712 words (average 22)
- Comments chosen using a random number generator in Microsoft Excel
- Chose to code 10% of the complete dataset as 2000 was deemed an adequate sample size

Data collection

- Access to all the comments caused some difficulty as slow process and the number of comments was increasing each day
- Started as manual copy and paste
- Ended up contacting the woman who started the petition and she could send an Excel spreadsheet with all comments – would do this straightaway in the future
- As student project, we restricted the time the comments were sourced from i.e needed to set an end date
- No demographic data available, only postcode
- Likely petition attracted responses from persons with a greater interest in health policy or women’s health/increased personal or family history of cervical cancer
- Stored total dataset – further analysis in an additional paper


Methods

1) Content analysis
   - Combines qualitative and quantitative methods
   - Can report both frequency and content
   - Appropriate for analysing text data
   - Frequently used to analyse social media comments
   - Have used before and familiar with methods

2) Thematic analysis
   - Flexible approach
   - Enables a rich and detailed account of data
   - Enabled further insight gained from commenters
   - Have used before and familiar with methods

Both methods: important to recognise theoretical values and positions of coders

Reacting to changes in public policy: the case of cervical screening

Methods

Ethics of reporting quotes
   - Ethics approval required and a waiver of the requirement of consent
     requested given that it is impractical to seek it
   - Using direct quotes in publication - important to note that theoretically it
     may be possible to infer identity by entering a direct quote into a
     search engine
   - Said to ethics:
     ‘While some comments may be published, those will be modified (e.g.
     shortened) to ensure they are not identifiable.’
     Each comment will be de-identified, by removing the name and any other
     identifiable data of the commenter associated with the comment.’

Reacting to changes in public policy: the case of cervical screening

Methods

Reporting
   - Two journal articles published, another accepted
   - Presented at national and international conferences

BMJ Open
It has saved thousands of lives, so why change it? Content analysis of
objections to cervical screening programme changes in Australia

A Thematic Analysis of Attitudes Toward Changes to Cervical
Screening in Australia

Journal of Medical Screening
"A Pap smear saved my life": Personal Experiences with Cervical
Abnormality Shape Attitudes to Cervical Screening Program Changes
Methods

Ethics of storing re-identifiable data

- Why necessary to store information in identifiable or re-identifiable form, given this poses a potential risk to participants privacy and the confidentiality of data.
- Response:
  
  As this data comprises comments available on a website and linked to the commenter's name, it will always be available publicly in re-identifiable form, even if all efforts are made to remove identifiers from the dataset. The identifiable information is publicly available and commenters have agreed through the terms and conditions of the website to post this identifiable information. Identifiers will be removed in the stored dataset by the researchers. However, as any member of the public has access to the data set website (change.org), they can see the comment with the name and location of the commenter on this website.

Methods

Reasons we chose online comments

- Timely
- Connected to petition
- Quick way to gather large number of views about the changes
- Pros very powerful, especially negative

Advantages of using online comments

- Quick way to gather a large number of views about the changes
- Rich data

Disadvantages of using online comments

- Vocal minority
- No demographic data
- Emotive accounts

Reacting to changes in public policy: the case of cervical screening
results

Petition: 70,000 signatures and almost 20,000 comments

Main themes from content analysis of 2000 (10%) comments from the petition:

1. valuing women's health and rights;
2. political statements;
3. cost and health care funding;
4. opposition to specific components of the screening program changes (e.g., interval and age of onset of screening)

Reacting to changes in public policy: the case of cervical screening

Results

34.7% of comments reflected concerns about the specific changes
- worry about the increased screening interval (16.7%);
- worry about missing cases of cervical cancer in younger women (9%);
- want to keep the current system (4.7%);
- disagreement with the change in test technology (2.6%);
- worry about missing cases of cervical cancer in older women (1.6%)

Reacting to changes in public policy: the case of cervical screening

Results

- Mismatch in what policymakers think women will be most concerned about and what they are concerned about
- The biggest focus of cervical screening programs worldwide is the change to primary HPV screening – renewal based on evidence of potential harms with the cytology (Pap test) program and development of new (more sensitive) screening technology
- Our findings showed only 2.6% of comments disagreed with the change in test technology
- Could be due to not understanding the difference between Pap smears and HPV test
- The comments demonstrate what the community is concerned about (interval and age increase) in order to focus communication to alleviate those concerns
Example comments

- The current system works very well, don’t try and “fix” something that’s not broken to save money instead of saving lives.

- 5 years is far too long for something as quick progressing as cancer, and given that young people (well under 25) are sexually active, they have a right to the protection that pap smears offer just like everyone else.

- How far could a cancer progress in the five years between testing. This is so ridiculous, just leave things that are working well alone.

- A Pap smear detected pre-cancerous cells in my cervix when I was 20 years old. A delay of years could have compromised my survival.

- Not all cervical cancer is caused by HPV and there are many types of cancers caught by the Pap smear testing. So far testing for HPV isn’t advanced enough. And doesn’t cover all cancers.

Comparison with other research

- Consistent with survey studies conducted in Australia prior to the announcement of the changes that identified women’s concerns about age of first invitation to screen, screening intervals and cost-cutting.

- These issues could have been addressed in advance through better communication.

- Findings from this study demonstrate these issues were not addressed prior to changes being implemented.

- Findings highlighted women need to be educated about the purpose of the HPV test and the accuracy of the test.

- Developing an understanding of the public’s awareness of the benefits and harms of screening is crucial in the development of information about these changes.

Reacting to changes in public policy: the case of cervical screening

Faculty of Arts and Education | Analysing Social Media for Better Public Policy
One day Symposium
Policy impacts/implications

- Findings demonstrated where women were misinformed about the rationale for the screening changes - need communication to increase understanding and potentially alleviate concerns
- Communication must acknowledge emotions involved in this screening change
- Developed recommendations for issues to address with concerned patients
- Not direct link to policy but has led to further research in this area to consider ways best to explain the rationale for the screening changes
- Cancer Australia - using to develop ways of communicating about this policy renewal

Reacting to changes in public policy: the case of cervical screening

Policy impacts/implications

- Findings demonstrated where women were misinformed about the rationale for the screening changes - need communication to increase understanding and potentially alleviate concerns
- Communication must acknowledge emotions involved in this screening change
- Developed recommendations for issues to address with concerned patients
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- Cancer Australia - using to develop ways of communicating about this policy renewal

Reacting to changes in public policy: the case of cervical screening

PREVENTING OVERDIAGNOSIS

The conference will explore the challenge of overdiagnosis and overuse within genetics and precision medicine, musculoskeletal conditions, women’s health and more, as well as commercial drivers.

Online registrations open at...

www.preventingoverdiagnosis.net

Speakers include:
Dr. Anne Bernard
President, WHO World Organization of Familial Cancer
Professor Sanchez Aranda
CDA, Cancer Council Australia
Dr. Anne Grilkes
Editor-in-chief, BMJ
and many more...
c) Public attitudes to government roles in obesity prevention

Public attitudes to government roles in obesity prevention
Lucy Farrell, University of Adelaide
Jackie Street, ACHEEV, University of Wollongong

@LucyOFarrell
@JackieMStreet

Context – The HealthyLaws Project

- Public views on the use of regulation and law to prevent childhood obesity in Australia
- Translation of evidence-based preventive health interventions into policy and practice and the inclusion of community values in policy development
- Funded by the Australian National Preventive Health Agency
Research Question

What regulations and laws, if any, are socially acceptable, ethically rigorous, legally sound, and cost-effective for the state to use in preventing childhood obesity in Australia?

Healthy Laws Multi-Sectoral Advisory Committee

- Systematic review of evidence for and against regulations and laws to reduce childhood obesity
- Legal and ethical aspects of regulations and laws to reduce childhood obesity
- Survey of public opinion on the use of regulations and laws to reduce childhood obesity
- Analysis of public discourse in the media and online forums

Deliberative Citizens’ Forum:
Under what circumstances is it acceptable/unacceptable to use regulations and laws to prevent obesity in children?

The Healthy Laws team

University of Adelaide:
- Agata Krokowska (public health law)
- Jackie Street (community engagement)
- Vivienne Moore (social epidemiology)
- Megan Wurm (social anthropology)
- Vicki Kelle (project manager)
- Elle Moss (health economics)
- Tracy Meint (systematic reviews, clinical epidemiology)
- Genevieve White (health services epidemiology)
- Rebecca Tooher (systematic reviews, communications)
- Drew Carter (ethics)
- SA Department of Health and Ageing:
  - Danny Bird (law & policy)

Flinders University:
- Chris Haycock (public health law)
- Elizanthe Hambro (media law)

Doctoral Theses:
- Lucy Hamon (public administration)
- Ema Bicanski (public policy)

Masters Thesis:
- Ali Harwood MPhil (ethics)

Honours Theses:
- Lauren Clarke (public health law)
- Erna German (constitutional law)
- Jackie Lau (international law)
Public attitudes about obesity policy

- Reader comments about Australian online news articles
- Focus groups in socio-economically disparate areas
- Representative cross-sectional survey of South Australians

Why reader comments?

Don’t read the comments. I never do.

I was surprised. These comments weren’t anything I didn’t hear regularly. These are words that strangers will readily say to me, face to face… snap “fat bi*ch” at me with startling ease… These comments are as ubiquitous as the air that I breathe. And like the air, they are invisible to you.
Emotion in reader comments

- What type of problem is obesity perceived to be when readers express anger about it?
- In what contexts is obesity something to be sad, rather than angry, about?
- What is offended when obesity is presented as disgusting?
- Who or what is threatened when the ‘obesity epidemic’ is feared?
- In what contexts are these emotional constellations used to argue for, or resist, policy reform?

Data sources

Factiva: obesity, obesity prevention Jan – Dec 2013
- The Australian news.com.au
- The Conversation
- ABC News
- NineMSN
- Daily Telegraph
- Sydney Morning Herald
- The Age
- Herald-Sun
- Courier Mail
- The West Australian
- The Advertiser
- Hobart Mercury
- NT news
Sampling

Factiva: key words relating to obesity, obesity prevention, Jan – Dec 2013
965 articles returned
296 in scope, available online
83 with reader comments
3,636 comments (n= 1 to 568, average 44)

Ethics

Posted by: P***ed Off Voter & Taxpayer of Northlakes 03:49am Sunday 3rd March
Comment 3 of 29

The fashion of wearing “Muffin tops” is all the rage at Crossälle, why stop now?

JAMES HAPARAHAN

I can’t wait for all the obese people to start defending themselves by blaming everything other than themselves for their situation.

Reply Share

Meris Hempel

Fat kids definitely come from fat parents unless there is a legitimate medical condition. Go anywhere these days and fat people rule while thin and slim people are getting fewer in between. Shops have huge plus clothes sections now with smaller sizes disappearing. I don’t blame just mothers, fathers too are to blame. At the end of the day you diet and exercise are what you eat.

Reply Share

Analysis

1. Thematic analysis (Bacchi)
2. Affective-discursive analysis (Ahmed, Wetherell)

This makes me so mad! Given the high percentage of fat and sugar “Maccas” is probably one of the worst foods you could eat. Prior to Mascals and all other JUNK foods people actually ate well and at home. Now everyone’s FAT an has the potential to get diabetis and heart problems. This is the WORST JUNK FOOD YOU COULD EVER EAT, IF IT WAS UP TO ME, I WOULD BAN MACDONALDS. The government MUST act.
Analysis

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This makes me so mad! Given the high percentage of fat and sugar “Maccas” is probably one of the worst foods you could eat. Prior to Maccas and all other JUNK foods people actually ate well and at home. Now everyone’s FAT and has the potential to get diabetes and heart problems. This is the WORST JUNK FOOD YOU COULD EVER EAT. IF IT WAS UP TO ME, I WOULD BAN MACDONALDS. The government MUST act.

I am so sick of the constant complaining about what are perfectly legal and well run private businesses... Using McDonalds as an example, why can’t they have a community spirit and provide support to young kid’s sports?

(neon of parish, ABC, 14/12/2013)

If you don’t want to be bigger than beached whale eat like a sensible person, not a comfort eating emotionally deprived low self esteem alcohol guilt washing orally fixated victim of food sellers and advertisers greed.

(Lane, Sydney Morning Herald, 20/12/2013)
"...a special section of the supermarket where only people with low bmi's are allowed to shop. Driving licenses should not be issued to fatties- to force them to walk and use public transport.

What right does the public have to impose draconian measures on the obese? Because figures show the amount of public funding (from taxpayers) being spent on pandering to those unwilling to manage their own health with this preventable condition.

Bill Heather of Fairfax, Courier Mail, 14/2/2014"

"Time to Super Tax junk food, proportionally to how unhealthy it is... Seems to be working for smoking....."

Randy, Sydney Morning Herald, 12/4/13

I couldn't agree more! As an ex smoker, the anti smoking campaign increased the guilt for smoking unbelievably. People felt they could comment openly to my face about the 'filthy habit'... Do we all start making rude comments to fat people eating in front of us, to shame them to stop their 'filthy habit'? Seems to me, what's good for the goose is good for the gander.

Jon Jon, Sydney Morning Herald, 12/4/13

I agree @Jen jen. Naming, blaming & shaming has worked to reduce smoking why cant the same work with obesity?

King, Sydney Morning Herald, 12/4/13"
Comparison of methods

**Focus groups**
- More considered language
- BUT similar themes
- Themes, support for policy patterned differently across high/low socio-economic status areas

**Cross-sectional survey**
- Hard to design and interpret without qualitative findings

**Key finding:**
High SES support measures to address ignorance, low SES support measures to address costs of living

Policy impact?

**Recommendation 1.**
The committee recommends that Commonwealth funding for overweight and obesity prevention efforts and treatment programs should be contingent on the appropriate use of language to avoid stigma and blame in all aspects of public health campaigns, program design and delivery.
d) Why manual, qualitative analysis over automated? The carp release program.

Clarification

I am NOT saying that automated practices do not have their place

- They tend to be less expensive
- Quicker, especially with large scale datasets
- Unbiased by human interpreter (this is actually not true and I’ll tell you why)
- Good for a quick snapshot

But they do have limitations

- Work in binary
- Level of expertise needed to use them
- Context. Even AI needs to be trained per context
- Often limited by
  - Jargon
  - Irony
  - Humour; and
  - Abstract or nuance or competing thoughts are often represented in the same speech act and mis-coded

Why qualitative?

- The single biggest justification for a qualitative approach is the ‘WHY’ factor.
- Automates approaches tell us ‘what’ is going on, but qualitative can delve deeper into the ‘why’
  - Pick up on nuance in the FUNCTIONAL language
  - Understand explicit and implicit MEANING
  - Be ADAPTIVE; you can expand codes if necessary
  - All within a specific situation CONTEXT
Carp Herpes Virus

- Introduced in the mid 1800s carp are classified an invasive alien species or invasive pest
- Explosion in impact since the Boolarra strain of the fish in the 1960s
- They have negatively impacted the environment, particularly the Murray-Darling Basin
- Virus is designed to kill and manage numbers
Results (automated)

What did we learn?
- More negative than positive.
- Lots of neutral (positive – negative).
- City people were most against it.
- BUT WHY? And why the conflict in the neutral level?

Results (manual)

National

What did we learn
- Only 7% of comments were positive towards the virus.
- Why the high level of negativity:
  - Fearful of virus and its impact of the environment.
  - Did not trust the virus to kill ALL carp (e.g. Cane Toads).
  - Didn’t like politicians and how they went about dealing with the virus.

“what if they can’t control it, what will happen to the river and the Murray Cod”
Results (manual)

**Capital City**

<table>
<thead>
<tr>
<th>Sentiment</th>
<th>Capital City Sentiment Tokens and Results</th>
<th>Corp</th>
<th>Vir</th>
<th>Impact on Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affect</td>
<td>Insecurity</td>
<td>15%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td></td>
<td>Hope</td>
<td>3%</td>
<td></td>
<td>92%</td>
</tr>
<tr>
<td>Judgment</td>
<td>Negative Capacity</td>
<td>7.3%</td>
<td></td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>Insecure Positive</td>
<td>5%</td>
<td></td>
<td>14%</td>
</tr>
<tr>
<td></td>
<td>Neutral Negative</td>
<td>8%</td>
<td></td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>Value Positive</td>
<td>5.5%</td>
<td></td>
<td>12%</td>
</tr>
</tbody>
</table>

*They said the same thing about controlling rabbits... that worked out well.*

**What did we learn?**
- Positive reactions at 15%, with a sprinkle of hope
- Why the negativity
  - Again insecurity, potential impact on the environment
  - Don’t trust the virus to solve the problem (rabbits)
  - Value in carp as a resource or rec species for fishing (fertiliser or sell to Asia)

---

**Regional**

<table>
<thead>
<tr>
<th>Sentiment</th>
<th>Regional Sentiment Tokens and Results</th>
<th>Corp</th>
<th>Vir</th>
<th>Impact on Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affect</td>
<td>Insecurity</td>
<td>23.7%</td>
<td></td>
<td>12%</td>
</tr>
<tr>
<td></td>
<td>Hope</td>
<td>12%</td>
<td></td>
<td>88%</td>
</tr>
<tr>
<td>Judgment</td>
<td>Negative Capacity</td>
<td>9.7%</td>
<td></td>
<td>91%</td>
</tr>
<tr>
<td></td>
<td>Insecure Positive</td>
<td>17%</td>
<td></td>
<td>83%</td>
</tr>
<tr>
<td></td>
<td>Neutral Negative</td>
<td>14.8%</td>
<td></td>
<td>85%</td>
</tr>
</tbody>
</table>

*We rely on that water for irrigation and drinking. What if they poison it; you can’t tell me they have a plan to collect the dead fish.*

**What did we learn?**
- Positive 12%
- Why negative
  - Insecurity toward impact on local environment, drinking and irrigation
  - Don’t trust government to achieve task or trust the virus in doing what has been claimed (history of broken promises)
What did we learn

• The positive figure in the automated was over reported
• Neutral comments were a mix of attitudes that needed to teased out and examined.
• More negative comments
• We understood why, with stories of lived experience, context factors, and historical references.
• We gather a range of emotions, not just positive and negative
  • Hope
  • Fear
  • Insecurity.

Impact on Policy

• Policy makers decided to take more time understanding the needs of their constituents, through more active social listening practices
• It resulted in authorities considering alternate communication strategies and channels
  • e.g. town meeting to overcome communication misalignments and barriers
  • Using social media (then stopping) to communicate with the public. They stopped because of vocal opposition.
• Research insights potentially contributed to the delay of the release of the virus.
e) Public responses to media articles about the health effects of e-cigarettes

Public responses to media articles about the health effects of e-cigarettes

Kylie Morpeth, Lisa Herron & Coral Gartner
University of Queensland, Faculty of Medicine, School of Public Health

Overview

1. Context of the research – what are e-cigarettes and why study public attitudes towards them?

2. Methodology. Why online comments?

3. Our findings. How are they different from interviews or focus groups?

4. Discuss challenges of analysing online comments on news stories, and recommendations to others.
What are e-cigarettes?

- Developed in 2001 in China by a chemist to help smokers quit smoking
- Heating element
- No tobacco
- Nicotine solution
- Different formats (e.g., refillable tank or sealed cartridge)
- Looks like smoking with fake smoke
- Current evidence suggests harms much less than smoking — no long term data

E-cigarettes in public health: Controversies and conflicts

Anti-smoking groups butt heads over Melbourne vaping conference

Can vaping save the world from smoking? Health experts may not agree

Doctors at odds over value of vaping, as study finds it’s just as harmful as cigarettes

[Image: Introducing NicoSheen, the smoking celebrity]
Benefits and risks of e-cigarettes

Potential benefits
- Improve quit success/reduce relapse to smoking
- Improve the health of smokers who switch to vaping
- Provide long-term harm reduction option for those who find it difficult to give up nicotine completely
- Reduce youth smoking prevalence

Potential risks
- Lead to dual use – smoking and vaping at the same time
- Cause unknown long-term health risks
- Prevent individuals who would otherwise have quit nicotine completely from quitting
- Renormalise smoking/act as a gateway to tobacco smoking in young people

Policy context
- UK/EU – legal to sell as a consumer product with consumer safeguards (e.g., packaging requirements, sales to minors prohibited, no advertising of health or efficacy claims, limit on nicotine concentration).
- USA – Regulated as tobacco products. Little regulation currently, but moving to increase regulation e.g., banning flavours, some cities have banned their sale.
Public knowledge and understandings of e-cigarettes

• An increasing proportion of smokers and non-smokers believe vaping nicotine is equally, or more harmful than smoking cigarettes

• In the US news stories more likely to be negative about VNP's (Wackowski et al, 2013, 2018), in the UK positive stories more common (Rooke, 2014).

• Experimental study in US; participants who viewed negative headlines about VNPs had increased negative views on VNP harms, and decreased positive views of benefits (Tan et al, 2017).

Our research aims

To investigate public reactions to news reports about vaping in order to identify the ways in which people:

1) Interpret and respond to media articles about e-cigarette regulation
2) Conceptualise the risks and/or benefits of e-cigarettes
3) Justify their positions on e-cigarette regulation.
Why online comments?

- Easily accessible public forums
- Rich sources of data: individuals can comment on content of a news story, state their opinion, describe their experiences, dispute opinions of others
- They "reflect spontaneous, unsolicited opinions not affected by study demand characteristics or researcher bias" (Regan et al, 2014)
- Naturalistic data that can reveal the issues that matter most to commenters (Cho and Hung, 2009)
- Can provide insight into how people frame their opinions and justify their views about policy and regulation.

Our method – selecting data

- **Country**: USA because:
  - Shifting regulatory environment
  - Active public debate at the time
  - E-cigarettes legal and accessible

- **Media source**: New York Times, because:
  - Well-known traditional newspaper
  - Largest circulation among metropolitan newspapers in the USA. 2.13M digital subscriptions
  - Non-subscribed have access to limited number of articles each month
  - Anyone can create an account to post a comment.
Selecting articles

- Systematic search of NYT website for articles about e-cigarettes published between February 2016 and July 2016 to identify articles open for public comment.

- Two articles met criteria. They were:
  o Published closely in time – validate themes between articles
  o Both presented information about potential harms and benefits of e-cigarettes – balanced view
  o Described health effects and regulatory options
  o Presented information from various expert sources (rather than just opinion)
  o Resulted in robust online debate with significant number of comments.

Smokers Urged to Switch to E-Cigarettes by British Medical Group

E-Cigarettes Are Safer, but Not Exactly Safe
Our method – analysing the data

Mixed methods approach:

- Self-reported descriptive information about posters, where it was available (e.g., country, smoking status, vaping status)
- Quantitative coding of whether the overall opinion of the poster was positive, negative, neutral about e-cigarettes (double-coded)
- Qualitative coding of content of comments using thematic analysis
- Used qualitative coding software NVivo 11 to collate and code data

Our findings

- 424 comments by 241 unique posters
- Most comments posted on the same day as article was published
- Majority wrote one (34.4%) or two (23.8%) comments
- Varied in length from a few words to several paragraphs
- Nearly all reported being from the USA (location nominated by user when registering)
- 66 identified as current vapers, but the majority did not disclose smoking or vaping status
Qualitative findings – Debating the safety of e-cigarettes

- Revealed incorrect beliefs about nicotine
  
  "Do not trust anecdotal evidence. Nicotine, by itself, causes vaso-constriction, pulmonary hypertension, coronary artery disease, hypertension. You are not afflicted with the far but the nicotine is a health hazard. It is an addiction with known harm and white cancer takes longer than 7 years to become symptomatic, certainly the evidence of COPD is becoming irrefutable. Lung disease? Yes that is a lung disease."

  "As a neurotoxin, it kills neurons in the brain and elsewhere."

- How e-cigarettes are framed: relative risk versus absolute risk
  
  "No one claims that vaping is harmless; that's practically impossible for anything, even water. But we have proven, time and time again, that vaping is massively, hilariously, less dangerous than lit tobacco."

- Concerns about young people taking up vaping

Qualitative findings: Interpreting evidence

- Many people didn’t reference the article or specific evidence presented in it
  
  Person 1: "Common sense and studies have already proven e-cig negatives"
  Person 2: "No, the research has not proven the negatives... did you even bother to read the article? Or are you just parroting what others have told you?"

- The primacy of personal experience and sharing advice with others
  
  "I don’t need the FDA, or studies, or other’s opinions to tell me what is good and bad in regards to smoking/vaping, as there is something much closer with a far more compelling messages, the message my body is sending me. And it is a good one."
Qualitative findings: Trust and vested interests

- People are accessing a variety of information on internet—crosses national borders
- Expressed confusion or distrust over conflicting health advice between countries
- This conflicting health advice between the UK and USA led to accusations of vested interests
  
  "This sounds like evidence that the C.D.C is in the pocket of big tobacco. If e-cigarettes are getting off of regular cigarettes, and they are only 5% as harmful as traditional cigarettes, why would the C.D.C be against that? They are compromised."

  "The FDA is ignoring science and common sense here and going with the emotional ‘for the children’ rationale because they have become a culture that cares more about exercising their own power than actually serving the public or protecting health."

- Many expressed high levels of distrust in the tobacco industry, tobacco control researchers, the FDA, CDC, and medical groups.

Implications for policy and health education

- Identified incorrect beliefs about the safety of nicotine
- Identifying why people trust or distrust certain information or organisations
- Strong concern about young people becoming addicted to nicotine

Implications for policy:

1. Correct misperceptions about the harms of nicotine
2. Acknowledge a continuum of harm for nicotine products and differentiate between relative risk for smokers, and absolute risk for non-smokers
3. Acknowledge and explain conflicting health advice
Challenges and methodological recommendations

Since 7am this morning, people have left 18,162 comments on the Guardian. About 324 were blocked by our moderators.

- Deciding on what to include and what not to include. Need to have a strong justification.
- Using data that is technically feasible to extract

- Who is behind the keyboard?

- Rowe et al (2008). Method should not be used in isolation, but used to ‘augment traditional data collection methods.’

Thank you

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f) What to do about sharks?

Analyzing social media for better public policy
Bathurst 2019

Dr. Belinda Curley NSW Department of Primary Industries
Associate Professor Peter Simmons CSU Research Fellow

Research support from:
NSW Department of Primary Industries
CSU Institute for Land Water and Society

What to do about sharks?
Using Facebook to listen to ocean user thinking on shark management

Outline

• Small increase in incidents – community demand action
• Shark Management Strategy – some options divide community
• Aims
• Method chosen to listen to community
• Findings – how do they help policy?
• Reflections on SM analysis and DPI
Catalyst for the NSW Shark Management Strategy (SMS)

15 interactions off the far north coast in 2015 (6 serious, 1 fatal)

Generated:
- Ongoing media attention
- Impacts on local community

COMMUNITY called on government to take action!

The 20 kilometer stretch of Northern NSW saw 11 attacks between February and August. Ballina which sits in the middle of the area served as the focal point. If these statistics weren’t a reality they’d be unfathomable. “Something has to be done,” Mr. Wright said back in August. “People have to be protected and we’ve got to get on top of this thing quickly so that Ballina does not become a byword for shark attack.” The way Reunion Island is... and for Ballina it may be too late for that.

NSW Shark Management Strategy (2015-2020) - $16 million, 5 years

Key focus: to trial new technology to increase protection for beachgoers while minimising harm to sharks and other marine life.

Community division over some strategies (e.g. nets): need for evidence base to support decision making (Social research program initiated)
Social Research still relatively novel for agencies - traditional focus on environmental research

Social research by DPI focused on the far north coast
• Community surveys to track attitudes to nets over time, and towards other mitigation methods
• Important component of evidence-base to inform policy decisions in the region

What about the rest of NSW?
• State-wide strategy – trials of new methods at other locations
• Strong engagement program – provided anecdotal information
• Need for stronger evidence base

CSU grant proposed - systematic analysis of social media across NSW

What was the appeal for DPI?
• Polarizing views capture most attention on SM
• Formal way of analysing SM
• Novel method

DPI supported grant & PhD
Aims of the study

- Explore community attitudes to:
  - sharks
  - the Shark Management Strategy
  - coexistence with sharks

Method chosen to listen to community

<table>
<thead>
<tr>
<th>Social Media</th>
<th>Focus groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Kozinets’ (2015) 12 stages for understanding digital space – where talking?</td>
<td>• 8 groups with ocean users (surfers, swimmers, lifeguards, small business, conservation etc)</td>
</tr>
<tr>
<td>• 10 public Facebook and Twitter pages discussing sharks - balance</td>
<td></td>
</tr>
<tr>
<td>• ABC News, The Australian, Guardian Australia, Coastwatch, Injust Magazine, Surfnet, NS</td>
<td></td>
</tr>
<tr>
<td>Shark Council, Sea Shepherd Australia, NSW DPI Fisheries, and Premier Mike Baird’s official site</td>
<td></td>
</tr>
<tr>
<td>• 4185 comments became 13,000 ‘sentiment items’ (13 months 12/15-12/16)</td>
<td></td>
</tr>
</tbody>
</table>

Appraisal discourse analysis (Martin and Rose 2014) - reasons, lived realities, nuance

- 39 topics
  - Eg Politicians, Nets
- 28 meaning codes
  - Emotions, Judgements, Appreciation
  - Dimensions of ‘negative’
  - Capacity (‘they don’t keep sharks out’)
  - Propriety (‘it’s wrong to kill other species’)
  - Value (‘they’re expensive to operate’)
  - Composition (‘no use in heavy seas’)
  - Normality (‘they are old technology’)

- Multiple dimensions in attitudes – not just ‘negative’ ‘positive’
Findings

Respect marine life, but protect popular beaches

<table>
<thead>
<tr>
<th>FINDINGS</th>
<th>RESPECT MARINE LIFE</th>
</tr>
</thead>
<tbody>
<tr>
<td>People do not like mesh nets</td>
<td>I don’t like the bycatch, something like 50% of the catch is bycatch, and many of these animals are rare and endangered or threatened species.</td>
</tr>
<tr>
<td>Humans should respect the ocean as a marine home</td>
<td>Respect the marine life! It’s their only home!</td>
</tr>
<tr>
<td>Have patrolled and unpatrolled areas</td>
<td>I drew a little bit of a distinction there. If you want to go to protect yourself from sharks, then you go to a beach where there’s an area patrol and the surf lifesavers are keeping a look out and sounding the alarm.</td>
</tr>
</tbody>
</table>

HOPE FOR RESEARCH AND TECHNOLOGY

| People expect technologies to improve | Drone technology and associated intelligent, interpretive software will only get better and will ultimately be a perfect solution |
| Future more effective, lower cost, less invasive | I like the Cleave Buoy concept... because it’s non-invasive... Drone leaves the sharks alone... doesn’t cost much to put a drone in the air, but it costs a lot to put a helicopter up. |

ANGER AT THE MEDIA

| Media feed community fear | You are over 290% more likely to drown in Australia than be eaten by a shark in Australia in 2015. Don’t be played by the media |

DISLIKE OF KNEE-JERK POLICY

| Stop stop stop! No nets!!! You have lost my vote if you put nets out!!! Listen to the experts! It harms more sea life than deters sharks!!! More People die from car accidents! So are you taking cars off the road. Ridiculous knee jerk reaction. You have lost your way Mr Barn!! |
Outcomes of the CSU study for the SMS

Novel & valid evidence-base for decision makers

Complemented DPI social research & feedback from engagement to:

1) Inform direction of future trials (e.g. SMART drumlines, drones)

2) Identify key issues (+ve/-ve) around mitigation methods
   - Risk/comm planning & language (website, fact sheets)
   - Design of social research - “how many people think this way” and “where do they reside?”

Frequently asked questions
- Do SMART drumlines attract sharks?

Reflections: Social Media analysis

- Social research increasingly valued in coastal management
  (e.g. DPI Strategic plan, Marine Estate Management Strategy)
- Current internal capacity for SM limited - contract or collaboration

Some Pros of Social Media analysis for policy and communication:
- Utilises a major communication platform
- More representative view of social media conversations (vs polarized)
- Passive listening:
  - no survey fatigue
  - avoids raising concerns/expectations of community of management decision
Thank you

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Associate Professor Peter Simmons CSU Research Fellow psimmons@csu.edu.au

References


Method

- Kozinets (2015) 12 stages for understanding digital space – where discussions were taking place
- Decisions about ‘balance’ – left and right; cull and no-cull
- Sample and time period
- Analysis – Appraisal – Reasons, Emotions, Appreciation
- Across time showed spikes in sentiment
g) What information do policy makers need to make good decisions?

What information do policymakers need to make good decisions?

Kane Callaghan

Content

- Project background
- Study One – What information do policy and decision makers need and want?
  - Aim, study purpose, method
  - Four types of information useful to policy and decision makers
  - Testing the model with today’s cases

Project Background

- Analysing social media is an opportunity to listen to communities
- An opportunity, but how do we use it systematically?
- Project developed with the aim:

  “Contribute to policy decision makers’ ability to use social and online media citizen commentary systematically”
Research Design

Study one – What information do policy and decision makers need and want?

- **Aim:** to understand what categories of information are useful for policy and decision making
- **Method:** Interviews with 12 Dept. Primary Industries staff
  - Stakeholder engagement, policy research, organisational communications, policy design and evaluation – various levels of seniority
“Pap smears need to stay at two years…how dare a male run government make these decisions…It has been proven that age does not matter in these circumstances...” – Dodd et al.
Attitudes to Policy

Like/dislike Support/not support Approve/disapprove Agree/disagree
What are their concerns?

What interviewees told me

“Before we go plunging into that decision, we really do need to understand what the response of the community would be.”

Find out “if they are concerned, and then, what is it that they’re concerned about?”

Examples from today’s cases

“I personally think they’re a waste of time, money and effort” – Simmons & Mehmet

“The current system works very well, don’t try and “fix” something that’s not broken” – Dodd et al.

Values and interests

Deeper principles and interests

What interviewees told me

“I mean 100 percent it’s about the values base of people. It’s about their drivers and about their struggles, and about what’s critical and what’s important to them.”

“there’s some fundamental principles that are driving them to arrive at that conclusion”

Examples from today’s cases

“Back in the 1950’s gluttony and laziness were still considered to be a sin and a moral failing. Now it is mainstream and acceptable to eat like a pig and sit around idle. Let’s face it. We must return to those old values for our own sake and that of our kids if we wish to live health and fulfilled lives” – Farrell et al.

“It shouldn’t be the rich get treatment and those less fortunate die as they can’t afford necessary tests” – Dodd et al.

“I’d much rather see a school built or a hospital funded and money going into that” – Simmons & Mehmet
Understanding of policy
How do citizens understand/misunderstand policies or proposals? Where to direct communication and educational resources?

What interviewees told me

“What is their understanding of the current shark management methods? … Is there an opportunity for us to be targeting some campaigns around how to improve that knowledge?”

“People might say I don’t like my SMART drills because they kill dolphins, and so they think I don’t want to wear them… and then we say well actually we haven’t killed a single dolphin… So yeah, it’s [opposition] born with this misunderstanding of what it actually is”

Examples from today’s cases

“5 years is far too long for something as quick progressing as cancer, and given that young people (well under 25) are sexually active, they have a right to the protection that Pap smears offer just like everyone else” – Dodd et al.

“Not all cervical cancer is caused by HPV and there are many types of cancers caused by the Pap smear testing” – Dodd et al.

“Will it affect other species?” – Mehmet et al.

Lived realities and unintended consequences
Understand policy impacts in the words of citizens impacted, or just an opinion?

What interviewees told me

“How is this going to affect you? And then how do you think it’s going to affect your community? And to assist you… with that peripheral examination of impacts”

“the relative impact for different parts of the community. So it’s a classic isn’t it? You might get some very vocal people from Burke making a lot of commentary on an issue that really has nothing to do with them and won’t affect them”

Examples from today’s cases

“I smoked a pack a day for over 40 years. I tried every trick in the book to quit… One year ago I bought an e-cig and completely quit tobacco that very day” – Morgan et al.

“I have a Pap smear every 2 years. I’ve needed to have abnormal cells removed. I changed to annual Pap smears for monitoring - nothing in 1 year to high risk in the next. This has happened to more women I know. It’s extremely common. This change to 5 years makes no sense.” – Dodd et al.

“I go to the gym several times a week and do my best to eat healthy. I also like to reward myself with a cheeseburger or a packet of chips every now and then. I’m fit and healthy, so why should I have to look at disgusting images that ruin my appetite?” – Farrell et al.
Findings and Future Directions

- Policymakers benefit from information about citizen's:
  1. Attitudes to policy
  2. Values and interests
  3. Levels of understanding
  4. Lived realities and unintended consequences
- SM data for categories appears across diverse policy areas
- In what platforms is this information present? ...and to what extent?
- How can we collect and analyse this data systematically?

h) Publicly available! Ethics of use of SM data and permissions

Publicly available!
Ethics and permissions for social media data

Presented by
Kelsey Chalmers
Menzies Centre for Health Policy
Policy issue: Healthcare OOP costs

Scott Morrison says all cancer treatment is free in public hospitals. Is he correct?

RMFT ABC Fact Check [2019]

Policy issue: healthcare OOP costs

OOP costs over two years reported by participants in CHF survey

Crowdfunding may show ‘gaps’ in healthcare systems

People overstate the benefits and downplay the risks of treatments

Potentially dangerous treatments are funded on the platform

Campaigns need ‘a worthy narrative’ in order to be successful
...More to the story? Proposed GoFundMe study

What does online crowdfunding for healthcare costs say about the Australian healthcare system?

- What are the funds being used for?
  - Medical treatments?
  - Accommodation and travel?
  - Income loss?

- Why are the funds being sought?
  - Not covered by Medicare?
  - Issues with private health insurance?
  - Experimental treatments?

augofundme.com/medical
Campaigns from ~200 postcodes

HREC: Conditional approval

The research team is prompted to consider whether the use of a purpose-built web crawling program to scrape user data is consistent with GoFundMe AU’s *terms and conditions* as well as their *privacy policy*. This will be a condition of approval. If this cannot be confirmed, it is suggested that a letter of support be obtained from GoFundMe AU to use the proposed information for research purposes. Please comment.

The committee noted that the collection of data in this way assumes that all campaigns posted in GoFundMe AU are legitimate. Have the researchers considered the impact of fraudulent campaigns on research outcomes?

As highlighted by the researchers, GoFundMe AU campaigners will have posted information on a public platform and direct quotes may render those whose data was used in the research identifiable. Is it necessary to directly quote campaign text in the published results? Although posted on a public forum, these comments were not posted for use in research. In the case of fraudulent activity, victims of identity theft may be misrepresented.

Why is this an issue now? Ethics and internet data

*National Statement on Ethical Conduct in Human Research*

Data or information available on the Internet can range from information that is fully in the public domain (such as books, newspapers and journal articles) to information that is public, but where individuals who have made it public may consider it to be private, to information that is fully private in character. The guiding principle for researchers is that, although data or information may be publicly available, this does not automatically mean that the individuals with whom this data or information is associated have necessarily granted permission for its use in research. Therefore, one of such information will need to be considered in the context of the need for consent or the waiver of the requirement for consent by a reviewing body and the risks associated with the use of this information.

3.1.5: Researchers should take account of any terms and conditions applicable to social media platforms when using data or information from these sources or platforms and other web-based communities that do not permit the removal of the name of the author or a post or any changes to the wording of a post.
Why is this an issue now? Ethics and internet data
Unethical research and impacts of internet data use

Discussion: where does this leave us now?
It is important to protect the privacy and rights of individuals online. Everyone is just trying to figure this out.
Discussion: where does this leave us now?

There is a spectrum of ‘internet data’ generated by humans, and also a spectrum of ‘internet research’. We can’t let the same rules apply to everything.

Great progress on healthcare. Improvements being made - Republicans coming together!

@realDonaldTrump

11,274 70,316
Our project now...

- Submission to NHMRC + discussion piece
- Waiting: HREC response
- Next step: ask permission from GoFundMe?
- Next step: collaborate with Canadian group?
- Final resort: same study, different data (newspapers)

Thank you

Co-investigators:
Dr Rochael Dudd, University of Sydney
Dr Stephanie Mathiessen, University of Sydney
Appendix 3: Case articles


### Appendix 4: Evaluation

**Feedback on 'Analysing social media for better public policy symposium'**

n=22 (17 University; 5 public sector)

<table>
<thead>
<tr>
<th>Morning: How would you rate the case sessions and panel? (1=Low and 5=High)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>Afternoon: How would you rate the presentations and workshop? (1=Low and 5=High)</th>
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<tr>
<td>What information aids policymakers and what’s available in SM? (Kane Callaghan)</td>
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<td>Publicly available! Ethics of use of SM data and permissions (Kelsey Chalmers)</td>
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<td>Workshopping the wicked (David Cameron)</td>
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<th>Which sessions did you find most useful for work? (1=Low and 5=High)</th>
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<td>Panel -</td>
<td>Applications and opportunities across the public sector? Panel and</td>
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</table>
Briefly, please tell us something you gained from the symposium. 17 answered, 5 skipped.

- Interesting perspectives
- Ways to talk about social media discourse and how it applies in my role/organisation
- Thought-provoking ideas and motivation
- More insight into how to conduct this research
- The knowledge that policymakers are interested in using this type of research in looking at policy
- Insight into how social media can be used to think about policy and communications
- Connections to researchers working in field
- Great to hear the very latest ways that researchers are using data collected from the internet.
- Methods for analysing SM data
- The case studies were very helpful for understanding the range of ways that we can conduct this type of research. The discussions around ethics were very interesting and relevant to anyone conducting work in this area.
- An insight into the academic perspective or social media research.
- Ethics discussions and challenges
- Insight into common issues for this type of research
- People interested in the results and methods
- Very challenging and rewarding to see what is happening in this space
- Insights into ethics and other challenges on data harvesting via social media
- Microphone needs to be upgraded.
Do you see any applications of the method for your own research or work? 18 answered, 4 skipped.

- Yes
- Not for research, but how the outcomes of your research can be used to inform organisational policy and governance
- Absolutely
- I think this is a valuable research approach and compliments many other approaches in gaining insight about attitudes around policy decisions
- Yes
- Yes, but I fear that the world I live in is too reactive and decisions about direction will continue to come out of ministers offices.
- research issues very applicable
- Put sentiment analysis/online data harvesting into some perspective for me as a statistician.
- Yes! I have a million ideas now!
- Yes. I gained a good understanding of how to avoid some of the pitfalls involved in this type of research, and how to discuss and present the methods in a systematic way.
- Yes
- Yes
- yes .. learning form insights to do similar research better in the future
- Yes, I think it's great data for policy input
- Yes
- Yes, once ethics are worked out
- Somewhat
Do you have any comments or ideas about future activities that might emerge from this symposium?

14 answered, 8 skipped

- Loved the breadth of input and voices. More Kane presenting too please. He's a megastar!
- Updates about the case studies; new information about this ever-changing environment
- possible collaborative research
- A methodology paper would be good to write
- I think there's a place for government, research partnerships to discuss and develop on the value of using social media
- "How to deal with ethics - step-by-step guide *Using R to collect internet data."
- Run it again next year!
- Ethics was a recurring theme that could be explored further
- Would be interesting to re-gather to talk ethics and also more around the practical issues/methods to actually do this research
- A special interest group online - FB page? Collective Blog? chapter book of cases?
- Yes - a discussion piece on where this can fit into policy evidence, as well as the methods
- Perhaps more time for questions?
- Nil
- none
Finally, do you have any additional comments about this symposium?

the only reason I rated comms badly is I couldn't find a program in the lead-up to the event...

It was great, I enjoyed every moment and stayed engaged the whole day which can be challenging for all day events!

None

No

It was a shame the vC didn't work so well for the shark lady. Also, special props to Kelsey for making a presentation about ethics fascinating

The symposium was very well run, very professional; Peter was exceptionally welcoming and friendly! Thank you!

Great symposium, many thanks for all the hard work putting it on.

Great symposium, many thanks for all the hard work putting it on.

It was great - I was interested the whole day. Thanks

Charles Sturt was a great venue, had a wonderful time. Thank you

Nil

none
## The event

**How important or unimportant was the symposium to you for meeting people face to face?**

(1=very unimportant; 5=very important)

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22 4.5

**How satisfied were you with the logistics?** (1=very dissatisfied; 5=very satisfied)

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