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News and social media: Windows into community perspectives on disinvestment
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INTRODUCTION

There has been increasing focus on the use of HTA to inform both investment in and disinvestment from technologies. Understanding the social aspects of a health technology may be particularly important when considering disinvestment from an entrenched and valued technology or service.

However, the cultural beliefs and values associated with a technology may be difficult to measure or assess. Furthermore, in the same way that social meaning and 'best case' promise of a new technology may work against evidence of safety, efficacy and cost-effectiveness, strongly held beliefs, values and interests with respect to an existing technology may frustrate disinvestment initiatives. (1)

In the context of disinvestment, in-depth analysis of the socio-political environment using theoretical frameworks is important but empirical collection of community perspectives may also be useful, if potentially expensive and time-consuming. (2; 3) Web2.0 (interactive social media) offers an opportunity to collect a range of community views in an inexpensive manner. (4)

Through its universal health insurance program, Medicare, the Australian Government subsidises assisted reproductive technology (ART) procedures – including in-vitro fertilisation (IVF) and intracytoplasmic sperm injection (ICSI) - for all citizens and permanent residents. ART services are also covered by the Extended Medicare Safety Net (EMSN), which can be accessed once an individual's medical costs reach a threshold amount in a given financial year. As ART services are primarily private sector based, there remains a variable additional patient-borne 'gap' payment, dependent on: procedure undertaken, treatment stage and billing policies of individual clinics. The Australian Government has periodically entered into policy debates around the introduction of access criteria for IVF services, most notably in 2005 when age and cycle limits were proposed but not enacted. However, after a change of government, the 2009/2010 Federal budget included a cap on EMSN rebates for ART services to counter purportedly inappropriately high provider fees. This policy change took place in a context where the Australian Government provides a 'baby bonus' paid to all new parents.

We have analysed relevant peer review literature, media articles and associated on-line public response, to provide insight into the socio-political implications of disinvestment from ART public funding in Australia. This method is based on the assumption that the media both reflects and forms community views and that it was the primary information source for the public of the proposed disinvestment.

METHODS

Peer reviewed, grey literature and published documents detailing media and community response to the 2009 proposed changes to ART public funding were sourced as shown in Table 1. Searches and culling were carried out by one researcher (SH) based on criteria developed by all authors.

Data Analysis

No relevant peer-reviewed literature and only one grey literature discussion paper were identified, the latter being an examination of the dominant discourses in Australian ART policy. (5) Data for analysis included 65 media articles with 39 associated discussion forums, relevant postings from 13 blogs and three Facebook pages. Collected data were analysed by SH and JS using thematic analysis as summarised by Liamputtong and Ezzy. (6) Detailed description of coding can be found online (link). Direct quotations taken from the data are shown in italics in the findings.

FINDINGS

The media articles focussed on the significance of parenthood and the potential impact of policy change on the ability to achieve parenthood but also gave considerable space to the political context, the nature of the potential policy changes and the opinions of politicians and lobbyists with respect to such changes. Community views, expressed in discussion forums and blogs, reflected a much broader slate of opinion topics. Abortion, adoption, overpopulation, scarce resources, equity, comparison with alternate funding choices and the expectations and rights of taxpayers were discussed. Participants framed the issue in particular ways to support their case: for example, supporters of public funding for ART framed infertility as a *medical condition* whereas non-supporters, in contrast, framed it as a *lifestyle choice* which was *non-essential*.

Value of parenthood

A subset of twelve media articles, drawn primarily from tabloid newspapers, focused on the high value placed on parenthood in Australian society. These employed emotive photos and language including a widely quoted response from one Federal Senator that restrictions on public funding for ART would be *pricing people out of parenthood* (7; 8) and from another that it amounted to a *tax on mothers*. (8) Personal stories of experience with ART formed the basis for a number of articles (e.g. (9-11)), including one from a Federal Member of Parliament. (12) Such articles described babies as *miracles* (12-14) and suggested that attempts to place a value on a baby were inappropriate. Others reported the anger of families who saw the cuts as unjust (10; 14) and described the *torment* experienced by families undergoing ART. (12; 14)

Similarly the community response, particularly in blogs and forums devoted to ART advocacy, focused on the value of parenthood and the strong emotion bound up in the desire for children. Participants used emotive language to describe the revelation of infertility as *heartbreaking* and the children born of ART as *precious miracles who are deeply loved and cherished*. Many participants indicated that reducing public funding would price ART services beyond reach. Media discussion forum participants were less sympathetic and painted the desire for children as an *irrational desire to breed* and parenthood as only one of the options that life might provide.

Allegations of profiteering by doctors

Broad coverage was given to the Government's primary argument, that burgeoning ART costs ensued from doctors' profiteering (15; 16). However, even more space was devoted to strong responses from clinician lobbyists and a patient lobby group including denial that costs were as high as reported (17) or alternatively that costs *were in line with general medical inflation* (18; 19), proceeded from improved costlier methods (18), constituted 'catch-up' for previous inadequate funding (15) or represented costs of large staff loads. (19)

Most responses in discussion forums and blogs were critical of doctors. Patients complained of large price hikes in private ART services and variability in out-of-pocket expenses. Respondents called for redirection of investment away from private clinics and towards the public sector. One respondent questioned the integrity of some ART physicians:

...baby making is big business and there are some people out there selling false promises. ['Rev', Money Mum Blog] (20)

Some ART users considered that the policy changes would target patients and instead should target doctors *rotting* the system. One respondent summarised these views:

If the unreasonable [sic] increase in specialists [sic] fees are truly to blame for these budget cutbacks, why don't you actually implement one of your election promises - reform medical system. ['Katherine', Discussion forum: Daily Telegraph] (21)

Managing public money and policy choices

Many media articles reported the Government line, namely that restricting public funding to ART was responsible budgeting. Some emphasised the issue of burgeoning cost but many also covered the medical lobby backlash. (e.g.22; 23) However, greater media emphasis fell on the financial pressure threatening individual patients than on that faced by National budgets.

In contrast, respondents on discussion forums and those blogs not dedicated

to supporting ART public funding, recognised the problems associated with managing a budget for a system where demands are theoretically unlimited. Some respondents questioned the use of funds for ART when rural areas and marginalised groups lacked access to good health care, while others saw it as part of a larger area where disinvestment was needed.

So first taxpayers (and yes taxpayers include people who don't WANT children) have to help subsidise the IVF, then we have to subsidise the baby bonus, and then if it's a working mother the up to 26 weeks paid leave! Give me a break. [‘Kelly of Brisbane’, Discussion forum: Courier Mail] (9)

Many, however, questioned why ART funding should be targeted when these other benefits for fertile couples would continue. (24; 25)

Prognostic factors

We were interested in how relevant prognostic factors that could be the basis of disinvestment, such as maternal age and number of cycles, were discussed. The 2009 change was not focussed on prognostic factors thus this aspect attracted little attention in the news or social media although the perceived need to fund several cycles in order to maximise success was discussed. (11; 14) Any focus on prognostic factors was challenged, particularly on ART support blogs and Facebook pages, on the basis that many couples and individuals accessing ART were of normal weight and young or, if older, had already effectively paid for ART in their taxes.

A human right or a lifestyle choice

Some supporters of public funding for ART framed the issue as a basic right:

We have every right to have children. We didn't ask to have fertility issues. This is the hand we have been dealt and they should admire our strength and determination to strive for our dream. [‘Tanya Spreitzer’, Discussion forum: Sunday Mail] (26)

The principal patient lobby group gained wide coverage for its opposition to the proposed policy changes by focussing on the issue of equity. (8; 11; 14; 22) This stance reflected the sentiment of a Senator: the proposed changes would *make IVF affordable only for the wealthy* and were inequitable in targeting a *common medical condition* for funding restriction. (27) No articles discussed the inequitable exclusion of those unable to afford up-front payments or out-of-pocket expenses. This issue was raised in a small number of community postings which suggested that it was doubly *unfair* because consumers had to deal with both the pain of infertility and the financial cost of ART. (28)

The framing of the issue as a right was challenged by many respondents who portrayed the use of ART services variously as a *lifestyle choice*, *selfish*

desire' or luxury good.

You have a basic maternity right - the right to get pregnant & be maternal. It doesn't provide a 'right' to have us pay for it. Your kid, your cost. [PGS, Discussion forum: Daily Telegraph (29)

Some respondents suggested that resources were limited in a context of competing needs but others were more concerned about the impact on society from what they saw as an unnatural experiment. Some forum participants singled out IVF users for vilification, accusing them of not only contributing to their own failure to reproduce but also being selfish.

How about the link between infertility and obesity? Try losing weight, you'll save money on cheesecakes and treatment. [Brett, Discussion forum: Sunday Mail] (26)

IVF is for selfish people. It's not a desire for children per se - more of the biological imperialist attitude of MINE! [REDstar, Blog response: The Punch] (27)

It is not surprising that many ART consumers chose to only participate in sympathetic forums and that, in response to this unsympathetic framing of the debate, supporters of public funding for IVF positioned themselves as worthy taxpaying citizens 'deserving' of funding.

I have paid tax since I was 14yrs and 9mths of age. Why shouldn't I claim on the one thing I have needed assistance for in my life? [Vicki Clare-Geluk, Facebook] (30)

DISCUSSION

There are few standardised methods for examining the social aspects of a health technology, particularly in the context of disinvestment. A variety of techniques have been used to collect public preferences, including consumer representation, conjoint analysis, surveys, interviews, focus groups and citizen juries (31). Only some engage with and elucidate broader socio-political contexts. We have previously demonstrated that information about social aspects of a new technology may be collected from on-line social media. (4) In our current research, we extend this method to examine the socio-political aspects of disinvestment from an existing technology using an analysis of on-line news media, discussion forums and blogs.

In 2009, with little reference to the broader socio-political landscape, Australian news media narrowly framed proposals for disinvestment from ART public funding as: (i) the emotive narrative of individual infertility distress and (ii) the political nexus of interests. Similar findings were reported in a media analysis examining the introduction of the drug Herceptin. (32) Canadian and

UK coverage of the story used primarily “individualistic general story frames” with positive framing of the benefits of the drug and little consideration of societal impact particularly in terms of differential effectiveness, capacity to benefit and opportunity cost.

By contrast, in our study, discussion on forums and blogs in response to media articles about disinvestment from ART funding, although incorporating both of these frameworks, was more complex, placing the issue within the context of limited resources and alternative policy funding choices. Interestingly the argument used by the Government to support disinvestment was not explicitly framed as the usual relative cost-effectiveness argument but rather one of controlling greed (of providers). This shifted responsibility for the cuts away from Government and highlighted the notion of opportunity cost, where less profit need not impact services, but permit redeployment of scarce resources. This resonated with on-line respondents who recognised the impact of commercial interests and questioned the primarily uncritical portrayal of ART providers in the media. Interestingly there is no clear unified message of community support for ART public funding on blogs and discussion forums despite research which suggests that public opinion strongly favours such measures. (33) This may be because the majority non-partisan community voice is not well represented within these forums. In addition, the voices of the consumer majority, those who had undergone ART but not gone home with a baby, were largely silent. The major voices represented in the forums and blogs were polarised: disenchanted taxpayers and defensive IVF consumers.

Web 2.0 sites differ from traditional media commentary, such as letters to the editor or talkback radio, in that posts may be unfiltered and are often anonymous. This permits the collection of views which may be popular in the community but not generally collectable through standard research methods because self-selected participants may moderate their views in interaction with others. A limitation of the research is the lack of participant demographic data and the potential for commercial interference in influencing the debate through fabricated posts and promotion of consumer protest.

A clearer understanding of the socio-political context for disinvestment from ART in Australia emerges from the interaction of media and public. This interaction is itself underpinned by the relationship between politics and scientific evidence. Lehoux and Blume (34) building on the work of Cozzens and Woodhouse (35) classify three types of such interactions: political shaping of knowledge, social distribution of authority between experts and lay participants and, business steering of knowledge. With respect to the political shaping of knowledge it is apparent that the nature of knowledge collected in a standard HTA is different to that synthesised from news articles and social

media. 'Evidence' in the form of efficacy, safety and cost-effectiveness is relatively unimportant if ART is framed as a *right* or ART patients as *selfish*. Similarly the dominant role of clinician as expert in this disinvestment agenda may be problematic due to conflict of interest. In particular, disinvestment from ART public funding impacts on the livelihoods of ART clinicians and the viability of private ART clinics. Some public participants in the discussion forums recognised this conflict and challenged ART clinicians' standing as experts in this debate. This connects to the importance of industry steering of knowledge: framing infertility as a *medical condition*, as ART clinicians did (and beyond this, ART consumers), places funding for ART into the protected realm of doctor-patient decision-making.

Our objective was to examine whether analysis of commercial media output, blogs and discussion forums provided a useful view of sociopolitical aspects of a technology and in particular, community beliefs and values with respect to disinvestment from publicly funded technology. This research suggests that in the case of a disinvestment decision, where there are strongly held beliefs and values, the news media, personal blogs, discussion forums and other Web2.0 media will be dominated by polarised debate. Understanding this debate is essential if we are to understand the social and political aspects of ART and other contentious technologies. Our study provides a window into the nature and extent of the debate but additional measures of community and stakeholder engagement are essential for a full understanding.

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Research dimension	Media coverage		Community perspectives: peer reviewed and grey literature			Community perspectives: response data	
			Peer reviewed literature		Grey literature	Weblogs	Forums
Databases	Dow Jones Factiva	Google Alert ¹	Scopus MEDLINE	Australian Indigenous Health Bibliography	Google Scholar	Google blog search Google advanced search ² Blog roll ³ Facebook	Not applicable
Search terms	Combinations of terms full list online e.g. IVF Infertility medicare funding 'safety net')	'IVF'	Combinations of terms - full list online e.g. infertility, in-vitro fertil*, IVF, ICSI, consumer satisfaction, perspective*, opinion*, qualitative research, focus group*, interview*, Medicare, health policy.	infertile infertility IVF	Combinations of terms - full list online Additional terms: 1. "Tony Abbott" 2. "2005 policy" 3. "safety net" 4. "public reaction" 5. "Medicare rebate"	Infertile Infertility IVF	Not applicable
Search date	January 2010	Continuous (2009)	January 2010			January 2010	
Inclusion criteria	- Drawn from Australian publication or broadcast - English language - Content included reference to 2009 changes to EMSN as it related to ART public funding		- Research conducted in Australian institutions relevant to ART public subsidy policy changes of 2005 or 2009 - For searches undertaken for grey literature in Google Scholar, first 100 results only			- Personal Blogs - Australian blogger - Posts responding to a media article	- Community responses appended to relevant media article as captured in 'media coverage' search
Exclusion criteria	- Duplicate publications (syndicated material) - Articles not meeting inclusion criteria		- Views expressed by commercial organisations or their representatives			- Commercial Blogs - Those where nationality of blogger was unclear	- Any response not appended to a captured media article
Date limits	January – December 2009		January 2004-December 2009			January – December 2009	

Table 1: Search criteria

NOTES: * truncation character; ¹ Google Alerts are email updates of the latest relevant Google results based on own choice of topic" ² within domains of blogspot.com and blogger.com; ³ List of blogs relating to infertility, pregnancy and adoption, <http://www.stirrup-queens.com>

Methods:

Published documents detailing media and community response to the 2009 proposed changes to public funding for vitro fertilisation (IVF) and intracytoplasmic sperm injection (ICSI) were sourced. Searches were carried out by one researcher (SH) based on criteria developed by all authors.

Media coverage: Print and on-line media coverage of proposed changes to public funding, restricted to Australian region and English language, were sourced for 2009 through the Dow Jones Factiva database (<http://global.factiva.com/>) which can only be searched using free text. Keywords are shown in Table 1. Media articles were also identified from a 2009 Google alert¹. Articles for further analysis were selected on the basis of criteria shown in Box 1. In total 363 media articles were identified. Duplicates of syndicated material and papers which did not fit the criteria were eliminated leaving sixty-five articles for analysis. A summary breakdown of the nature of the articles is shown in Table 3.

Table 1 - Factiva searches

Search	Title-Abs-Key	Number*
#1	(IVF OR infertility) AND medicare	102
#2	(IVF OR infertil*) AND funding	30
#3	(medicare AND "safety net")	123
#4	(ivf or infertile*) AND (medicare OR "safety net")	108

*Includes duplicate articles and Australian Associated Press releases

Box1: Criteria used to select material for analysis**media articles**

- Drawn from an Australian publication or broadcast
- Content included reference to the 2009 proposed changes to Medicare Safety Net as it related to public funding for ART

peer reviewed or grey literature

- Authored within an Australian institution
- Content included reference to proposed changes to Medicare safety net as it related to public funding for ART
- English language

TABLE 3 – MEDIA ARTICLE SUMMARY

PUBLISHER	News Ltd	Fairfax	Herald & Weekly Times	Australian Associated Press (AAP)	Australian Broadcasting Corporation (ABC)	other

¹ Google alert – “are email updates of the latest relevant Google results (web, news, etc.) based on your choice of query or topic.” <http://www.google.com/alerts>

no. articles	23	24	2	2	4	4
LENGTH (words)	Equal to, less than 200	Equal to, less than 500	Equal to, less than 800	Equal to, less than 1100	1101 or more	
no. articles	7	31	18	2	1	
POINT-OF-VIEW	Unsupportive of policy change	neutral	Supportive of policy change			
no. articles	35	17	7			
SYNDICATION	not syndicated	1 time	2 times	3 times	3 times +	NA
no. articles	32	11	9	3	3	1

Community perspectives:

Peer reviewed and grey literature

The peer reviewed literature was searched through the Scopus and Medline bibliographic databases to identify studies providing community views on proposed public funding policy changes (see Table 2 for a list of search terms). The years prior to 2009 were included - to capture discussions relating to proposed policy changes in 2005 and in the lead up to the policy change in late 2009. Views on the proposed policy changes, expressed by commercial organisations or representatives of commercial organisations, were excluded. Use of Scopus permitted the search to be limited to research conducted at Australian institutions only. The Australian Indigenous HealthBibliography², was searched using the search terms, infertile, infertility and IVF, to capture any publications (peer reviewed and grey literature) relating to the potential impact of the proposed policy changes for the Indigenous Australian community. No articles were identified.

Titles and abstracts were examined to determine relevance and if unclear the full article was retrieved and read. Only one piece of relevant literature discussing community perspectives with respect to public funding of IVF in Australia was identified from any of the searches. (1)

Table 2: Search terms for peer reviewed literature

NB: If not otherwise indicated, search terms were searched as free text

Category	Search terms
Disease condition descriptors	<ul style="list-style-type: none"> • Infertility[MeSH] OR infertil* • IVF OR in-vitro fertil* • ICSI OR (*sperm inject*)

² *Comprehensive bibliographic database produced by the Australian Indigenous HealthInfoNet, Kurongkurl Katitjin: Centre for Indigenous Australian Education and Research.*

What are we trying to canvass	<ul style="list-style-type: none"> • Consumer satisfaction ([MeSH] OR text word) • Consumer participation ([MeSH] OR text word) • Patient participation ([MeSH] OR text word) • Attitude* • Perspective* • Opinion* • View*
Methods	<ul style="list-style-type: none"> • Qualitative research ([MeSH] OR text word) • Focus groups [MeSH] OR focus group* • Interviews[Publication type][MeSH] OR interview* • Internet
Policy	<ul style="list-style-type: none"> • Medicare • Health policy • Cost • Funding

The Australian grey literature was searched using Google Scholar with combinations of search terms described in Table 1 and additional search terms: “Tony Abbott” (the Federal Health Minister who proposed policy changes in 2005), “2005 policy”, “safety net”, “public reaction” and “medicare rebate”. Due to the large number of hits, examination of results was restricted to the first 100 results from each of sixteen searches. Only one discussion paper was identified examining dominant discourses in Australian ART policy.

Community response data

Community responses to the proposed policy changes were identified in discussion forums appended to - or blogs and public on-line forums which responded to - a relevant media article. Data were imported into NVivo 8 (QSR International) for analysis and coding.

Weblogs or blogs (on-line journals documenting views and experiences of a single or small number of authors) were searched using Google blog search, Google advanced search (run within domains of blogspot.com, blogger.com) and within ‘Stirrup Queen – Infertility blog roll’³ and the search terms ‘infertile’, ‘infertility’ and ‘IVF’. Many blogs are public documents which permit and invite comment from readers although blog owner(s) may remove offensive postings. Our searches were restricted to personal blogs from an Australian blogger in 2009 which contained discussion in response to a relevant media article. If there was difficulty ascertaining the blogger’s nationality or whether the blog represented commercial interests, it was excluded.

Australian media websites, associated with newspapers and television stations, post media articles to be viewed online. Some have attached

³List of blogs relating to infertility, pregnancy and adoption. <http://www.stirrup-queens.com/2006/06/whole-lot-of-blogging-brought-to-you/>

discussion forums. Moderation by the media source may mean that some of these comments do not appear or are removed after a period of time.

The social media tool, Facebook, was searched for relevant public pages using the search terms 'IVF', 'infertile' and 'infertility'.

Data Analysis

Data included 65 media print and on-line articles and thirty-nine associated community comments and relevant postings from 13 blogs and 3 Facebook pages. The collected data were analysed within a conceptual framework incorporating social constructionism and discourse analysis with associated thematic analysis as summarised by Liamputtong and Ezzy. (2)

Coding of data

SH and JS independently carried out initial open coding and the codes discussed and differences discussed and resolved. In open coding, some codes arose from the 2005 attempt to change the criteria for funding and from our framework of health technology assessment, namely the prognostic factors described by the codes, 'maternal age' and 'number of cycles', and others emerged from the material itself such as 'profiteering' which related to the framing of the proposed policy change as a bulwark against clinic profiteering. After extensive open coding, a more in-depth analysis of the relationships between the codes was performed by JS and SH with associated division and collapsing of codes and their organisation into relationship trees. For example, the codes '2005 policy', 'lobbying', 'Opposition' and 'backflips' were grouped under the code 'political resistance' since they all related to rhetoric in the political arena which aimed to undermine the case for policy change. Comparison between the coding for media and coding for community comments also occurred at this stage. This was followed by selective coding where we looked for overarching themes and built relationship diagrams. One such overarching theme was 'value of a baby' which found resonance both in the media and community responses.

References:

1. Doherty B. Destruction, creation and immortality: Discourse, public policy and nascent human life. Australasian Political Studies Association (APSA) Annual Conference. Monash University, Melbourne; 24th-26th September 2007.
2. Liamputtong P. & Ezzy D. Qualitative Research Method. 2nd ed, 1999.