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Article

The politics of picking: Selective vaccinators and population-level policy



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1. Introduction

A growing field of interdisciplinary scholarship explores parental refusal of childhood vaccines. While non-vaccination generates a problem for population health and governance, communities are now also mobilising to address vaccine refusal, and such community mobilisation formed the basis for this research project. This article explores how parents who broadly concur that vaccination is an individual and social good navigate the discourses and policy tools that seek to enforce it, whilst vaccinating selectively. This occurs within a 'local vaccination culture' (Streefland, Chowdhury, & Ramos-Jimenez, 1999) that is hesitant or critical of vaccination, but is itself surrounded by widespread societal, biomedical and government support for vaccination. The article thus considers whether and how those seeking vaccine compliance could implement systemic and policy changes change to address the parents' vaccination needs and wishes.

Vaccine hesitancy in high income countries is an increasingly well-researched phenomenon (Dube, Vivion, & MacDonald, 2015). In Australia, where this project was conducted, up to one-third of parents report concerns about the number of vaccines and distrust newer ones (Leask et al., 2012) but refusal rates remain at around 3.3 percent (Beard, Hull, Leask, Dey, & McIntyre, 2016). Hence, most parents who worry still vaccinate.

Scheduled childhood vaccines are available at no cost on the National Immunisation Plan (NIP), administered by nurses in clinics and GP surgeries. Data on individual children's vaccination records is recorded locally and collated nationally, and at the time of this study covered children up to the age of seven. In 2014, the Federal Government was financially incentivising parents to vaccinate according to the national schedule whilst enabling refusers to access the incentives after registering as Conscientious Objectors. (Conscientious Objection was abolished in 2016.) Vaccination coverage rates were at over 90 percent (National Health Performance Authority, 2014), with access rather than acceptance barriers accounting for over half of those not fully vaccinated (Beard et al., 2016). However, even this high coverage was still too low to provide immunity against some vaccine preventable diseases, with areas of low coverage at increased risk of outbreak (Omer et al., 2008).

Residents of Fremantle, a port city 18 km south-west of Western Australia's capital, Perth, might therefore have had reason to worry. Fremantle is known within Australia as an urban haven for alternative lifestyles. In 2012-13, only 85–89.9% of children here were fully immunized by 2 and 5 years old. As a Fremantle parent, I was embedded in homebirthing, breastfeeding and baby-wearing communities in which I frequently encountered parents who did not vaccinate. This mobilised me to transform from within my 'local vaccination culture' (Streefland et al., 1999). Consequently, this research project was embedded in the development of a pro-immunisation social marketing campaign which I conceptualised, designed, and directed for the Immunisation Alliance of Western Australia (IAWA). IAWA is Australia's first not-for-profit health promotion charity dedicated to advocating the importance of vaccination. Its volunteer membership includes academics, healthcare workers and parents.

'I Immunise' used role models representing parenting choices popular in Fremantle, such as home birthing, using cloth nappies (diapers), breastfeeding and baby-wearing, to start a community conversation around the benefits of vaccines and social responsibility (ref withheld). The campaign ran in January 2014, with the IAWA obtaining a grant from the Communicable Disease Control Directorate of the Health Department of Western Australia.

The campaign's centrality to the research inspired a community-based participatory research methodology that further developed through the participants' attempts to mobilize me and IAWA. Participants actively gave advice regarding a campaign that drew them towards immunisation advocacy. Simultaneously, they sought to build an advocacy platform for their child health desires. Through this emerged their coherent critique of 'the Establishment,' most notably its systemic (but largely unavoidable) failure to cater for the individuals who constitute mass populations.

2. Methods

The research underpinning 'I Immunise' had two distinct but connected purposes. The first was to guide then evaluate the campaign. The second was to explore how selective vaccinators understood themselves in relation to 'the system' that sought their timely vaccination, and how

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'the system' might respond to the parents' concerns. At the time there was little local or international data on this.

One-on-one interviews were chosen to explore the parents' views. Participants were recruited purposively through local newspapers, signs in the community, social media, and snowballing, with the sample size extending to saturation for the broader campaign development. Inclusion criteria were participants self-identifying as living an alternative lifestyle, having a child aged five or under, and either having refused a vaccine in the past, or keeping quiet socially about being fully vaccinated. The research was conducted under University of Western Australia Ethics permit RA/4/1/5890 and participants received a \$25 gift youcher. Participants gave informed consent following the sharing of an information sheet and completed a brief demographic questionnaire. A semi-structured interview guide covered how participants felt about immunising, concerns, motivating factors, information, perceived barriers in the community and relationship conflicts. Additional questions explored the 'I Immunise' campaign. Interviews were recorded and transcribed in full; I coded all the data using NVivo 10, developing themes iteratively. My analysis employed deductive social reasoning (Willis et al., 2007) and narrative analysis theory (Riessman, 2008). The IAWA obtained a \$20,000 unrestricted Vaxigrant from Sanofi Pasteur to conduct the research. The use of industry money was discussed frankly with participants, and did not appear to inhibit their contributions. The funder had no input into the development, conduct, or write up of the study.

I conducted face-to-face interviews with eleven parents during 2013 and early 2014. The aim was to interview all participants before and after the campaign, but one dropped out and others were recruited afterwards. These eleven parents covered both campaign target audiences – parents who refused some vaccines, and parents who fully vaccinated but stayed quiet about it. The six included in this paper (henceforth 'participants') were in the first category of selective vaccinators, and are described in Table 1. They constitute a notably small sample, but as there has been very little work published engaging with the pro-vaccination views of selective vaccinators, it is hoped that this research can provide a basis for others to build upon.

A community-based participatory research methodology I call 'mutual co-optation' developed during the interview process. The research had been initiated with a commitment to social change to benefit the community (increasing vaccination rates through persuasion rather than coercion), and was conducted with respect for free speech, social interaction and democracy (Anderson & O'Connor, 2013). As the participants encountered the 'I Immunise' campaign they were remarkably open, with useful advice on how it could best reach them. In this sense I co-opted them. However, the co-optation was not one-way. The research truly became a learning collaboration because of the unplanned role that participants claimed for themselves. The link between the interviews and the campaign invited selective vaccinators' nuanced perspectives as experts, inspiring the parents' co-optation of me. I became a conduit through which they could feed back to the system their heartfelt demands. I might be able to help the system to flex; thereby making the parents more inclined to vaccinate. The research participants thus sought an ally in the IAWA and in me; yet their desires accentuated the points of difference between us. The conversations that ensued highlighted the inflexibilities of a population level health policy

as it applies to individuals.

3. Theory

There is no measurement of Australian families on selective or delayed schedules. At the time of this research, many simply appeared in the Federal Government data as registered vaccine refusers, or 'Conscientious Objectors' (in local terminology). This category included people who might have delayed one vaccine as well as people who refused all of them, and as such could not differentiate between selective or delaying immunisers and complete refusers (Leask et al., 2012). However, US data shows that one in ten children there are on alternative or delayed vaccine schedules (Dempsey et al., 2011). Internationally, then, parents who refuse only some vaccines, or delay some or all of them, are a non-trivial cohort. Researchers locate such selective vaccinators a step away from vaccine refusers on the continuum from unquestioning acceptance to avowed refusal (Leask et al., 2012). Selective vaccinators demonstrate a *prima facie* acceptance of vaccination. However, in rejecting the timing or extent of the vaccination schedule, they reject population-level, one-size-fits-all interventions. While selective vaccinators can be read as the kind of 'activated health care consumers' that contemporary neoliberal discourses promote (Brown & Baker, 2012; Peretti-Watel, Larson, Ward, Schulz, & Verger, 2015; Reich, 2016b; Sobo, 2016), they experience pressure to come down on one side or the other.

In Australia, aided by the explicit campaigning conducted by some media sources (Harvey, 2015), binary constructions of vaccination attitudes prevalent in the community pit 'anti-vaxers' against the scientific establishment. Government policies reinforce this by treating selective vaccinators the same as complete refusers. Thus, existing treatments of vaccine refusers construct a liminal space in which selective vaccinators are trapped. Neither 'side' claims, represents, understands or respects them; consequently, selective vaccinators lack a voice and a place in policy. Those in this study sought to change that.

4. Results

Influential publications in vaccination social science utilise a continuum to explain parental vaccination attitudes and behaviours (Larson, Jarrett, Eckersberger, Smith, & Paterson, 2014; Leask et al., 2012), yet a key finding of this study was that participants did not experience this in societal discourse or engagement with the medical profession. Alienated from the two visible camps – pro and anti-vaccination – the parents worked hard to create a legitimate social category of selective vaccinators. The features of this category elaborated in Section 4.1 include what I call basic hesitancy (concern about some or all vaccines), belief in the benefits of vaccination, critical thinking, struggles with information and decision-making, and frustration with medical practitioners, 'the debate,' social interactions and 'the system.' Section 4.2 elaborates their wishes.

4.1. Selective vaccinators: trapped between sides

Echoing existing research, the parents worried about the number of vaccines in the schedule, giving numerous vaccines at once, the age at

Table 1
Participants included in this article (pseudonyms).

Name	Age	Gender	Education	Age of youngest child	Vaccination behaviours
Rob	36	M	University	5 years	Delayed some
Amanda	25	F	University	22 months	Refused one
Clara	36	F	University	2 years	Delayed all, accepted one.
Meg	44	F	University	2 years	Separated and delayed some
Tabitha	33	F	University	9 months	Separated and delayed some
Denae	30	F	Vocational	7 weeks	Refused one; next scheduled vaccinations booked.

which vaccination commenced and the necessity of all of vaccines. Vaccination commences in Australia with hepatitis B at birth, which parents in this study considered a disease of the underprivileged and hence not suitable for their own children. However, despite the parents distrusting vaccine manufacturers and the government (Attwell et al., 2017) they displayed clear support for vaccination. '...[I]mmunisation on the whole is really important and that it's done a lot of good for society,' said Tabitha (33). 'But I do feel a bit fearful about the effect on the individual...' Tabitha displayed the tension between accepting a one-size-fits-all vaccination schedule, and the particular needs and concerns of the self.

Another feature of the parents was critical thinking. 'I feel concerned about the ignorance around the issue ... All the traditional sense of: you don't need to inform yourself about it, just immunize' (Clara, 36). Simply following the recommendations of others would be insufficient; instead, the onus was on self-education. Yet for the participants, questioning did not lead to satisfactory answers.

I also wonder about the data, I don't fully understand it. Perhaps infectious diseases really were reduced because of hygiene and not because of vaccines. And the fact that we don't fully understand the immune system, why it works and how it works and that kind of thing ... (Amanda, 25).

The parents were all university educated except Denae (30), and their engagement with information incorporated research skills. Education may also have informed their confidence to critique information. Denae, the outlier, referred to herself as a 'pleb' and peppered her responses with qualifiers about her lack of knowledge. However, crucially, this did not make her warier about vaccination than someone like Clara, whose skills opened up never-ending avenues of contradictory information.

All the parents were trapped by distrust in the information they encountered, lacking the certainty of either vaccine advocates or refusers. This affected decision-making, which they recounted as being long and fraught.

I could be swayed. I am on the fence. But the more I speak to people who are pro-vaccination, the more I am on the other side. It sounds like people can't be honest about the risks on both sides. On the other hand, I'm not going to get those answers from the anti-vaxers either, because they're so biased... (Denae, 30).

The participants' critical thinking was particularly noteworthy when it came to anti-vax health practitioners, whose advice sometimes generated outright hostility. Tabitha described her first visit to a GP known to be supportive of alternative lifestyles. Tabitha was experiencing trauma after her planned homebirth ended in emergency caesarean. The doctor disclosed, uninvited, that she had birthed alone in a rainforest, then proceeded to tell Tabitha that she had not vaccinated her own children.

I was already sort of pissed off, and then she said this, in the nastiest way, and the way she said it was so dismissive. It was like... In an 'off-the-record-but-this-is-what-I-tell-people,' and I just felt like it was irresponsible, more than anything. ... It felt like she was giving the right to just go, ... 'Well, she doesn't do it, so I won't do it, because she knows what she's talking about.' ... That made me really angry. No, it didn't sway my decision at all. It really just made me want to punch her in the face. Of course, I just paid up and left. (Tabitha, 33).

While such experiences had the capacity to unleash participants' support for vaccination as a social good, encounters with vaccine-promoting medical practitioners had the opposite effect. Clara (36) described a community nurse who 'treated me like I was completely stupid,' and a GP who told her that the pertussis vaccine was 'completely safe' and said, if anything, she should be worried about the tetanus vaccine. Denae's vaccination nurse encouraged her to imagine a

 $child\ afflicted\ with\ whooping\ cough,\ which\ made\ her\ feel\ manipulated.$

The middle space the selective vaccinators occupied was also notable in community discourse. Clara 'felt really caught in between a real push for immunisation and the anti.'

... I felt judgement, definitely. From people who believe you need immunize immediately, and feel that you're putting their children's health at risk ... And then also on the other side; it's more like if you immunize you are compromising your child's health. (Clara, 36).

Vaccination as a social good, then, could be weaponized against those who did not vaccinate. Meanwhile Amanda described feeling obliged to offer her peers a 'politically correct' explanation for vaccinating her son.

I felt like I had to say to friends that, yeah, we're going overseas and that for us, it didn't feel safe [not to vaccinate]... Even though my true narrative is a moral reason, you don't want to bring it up, because you're kind of accusing a person of not caring about other people. (Amanda, 25).

In the Fremantle milieu, concern about damaging a child sometimes outweighed the responsibility to contribute to community immunity. This trapped selective vaccinators, especially if they were critical of how their peers had weighed up these factors.

Trappedness also manifested with regard to interactions with government policies. Rob described a system that treated him the same as parents who missed all vaccinations. "The way you are treated if you are not up to date is: really rudely." He went on to explain that Centrelink, the agency administering government benefits,

send you letters saying that you are going to be cut off, and you have to put forms in the day-care, the Conscientious Objector forms. It's kind of interesting because we are pro-immunisation, but we felt like, you know, they could wait a year, especially little one, who was always really small. (Rob, 36).

Rob did not identify with the people who refused all vaccines, yet government paperwork inserted him into the 'non-vaccinator' binary. Rob's narrative also highlights the tension between belief in vaccination as a social good, and a sense that it was not appropriate in its standard form for one's own child. Rob elaborated this more explicitly when discussing vaccine ingredients.

...From what it looks like, [vaccine manufacturers] did research to see if it was safe to add all those things in, and they decided it was safe because of the very small number of people that have bad reactions. I do think it didn't seem as safe to us as it did for them. It's like treating people as populace and saying losing a couple is all right. (Rob, 36).

Several parents expressed a fear that somehow their child might end up being the unlucky one in a system designed for mass benefit, but with extremely occasional catastrophic results for individuals. Clara and Tabitha's children had health problems, which alerted them to the existence of statistical lottery whereby one could, indeed, be the one-in-however-many-million to be vaccine-injured.

4.2. What we want from 'the system'

The selective vaccinators advocated for systemic change. They demanded a neutral source of facts; ability to separate vaccines; and greater publicity for alternative schedules.

4.2.1. Neutral facts

For the participants, the problem with the middle ground was that nobody was servicing it with information that did not try to persuade.

I am wanting open and welcoming and rational discussion with all the facts laid out before me, both positive and negative. So I can take them away and make my own my own decision, not what you wanted me to make. (Meg, 44).

The parents were looking for more representations of what they saw as the cons of immunisation. They felt that the pro side eschewed engagement with these, or hid information.

I trust what is said on the forms of the immunisation from the government, but I'd also say this is not everything. ... I do think that some things are not stated, and there's a whole lot of conjecture in the community... (Amanda, 25).

Nowhere was the desire for balanced information better captured than by Denae:

Where are the people who are more objective about the whole thing, not for or against, that just sit right the middle and just be a fact machine for me? I don't want your opinion on it. I want hard evidence. I don't need you to try and sway me, I can do that myself. (Denae, 30).

Denae explicitly sought 'some statistics that have been collected by fence-sitters themselves'.

4.2.2. Separating vaccines

A recurring complaint was that participants were not able to separate vaccines. In Australia, single vaccines against measles, mumps and rubella are not licensed; only the combined vaccine is available. This was a source of frustration for Meg.

Why can't these people have the option of paying more and getting them separately...? You know, whether you go by car, bike or train from point A to point B, it doesn't matter. ... Some people are terrified of flying, you know, some think trains are long and boring ... Just know you are going to lose some people. And you are going to lose them badly. (Meg, 44).

Tabitha was even warier of the combined vaccines delivered in early infancy.

About four [vaccines] is the minimum you can get in that first round, so if you want to have whooping cough, the other three come with it, and I know it's different in other countries ... I feel that it's an unfortunate situation that we are forced to do four, instead of just the one that we want. (Tabitha, 33).

Denae explicitly used the framing of *help us to help you to help us.* 'Convince the pharmaceutical companies to separate the vaccines,' she demanded.

If you guys would still be happy to be pro-vaccine for some [vaccines] rather than none, have them make them separate. I don't feel the need to have my eight week old or two-month-old or six-month-old vaccinated against hepatitis B, not in the country that we live in. (Denae, 30).

Denae presented combined vaccines as 'trying to make the decision for you.'

... They are trying to sway you. If they have you on the fence and they could tip you over for one of them, then they can tip you over for all of them. And I'd rather tip towards none of them, and be missing out...I feel like they are scaring me by giving them all at once. (Denae, 30).

4.2.3. Advocacy of different pathways

Parents thought information on how to separate vaccines belonged in the public domain, particularly given that it might be a choice between doing it differently and 'missing out.' On this basis, Meg thought that the 'I Immunise' campaign should include parents who had not followed the schedule. 'I think that we just need to be catered for somehow... [Otherwise] you get me close and I ... go, 'This is bullshit.' (Meg, 44). Tabitha wanted 'a booklet with resources that might be interesting for people who are sceptics of immunisation.' (Tabitha, 33).

5. Discussion

Participants in this study faced some key issues as individuals navigating a system designed for mass populations. The concern parents felt for their own child has arisen in other studies (Hobson-West, 2003), including parents constructing 'vulnerable children' particularly unsuitable for vaccination (Poltorak, Leach, Fairhead, & Cassell, 2005; Reich, 2016a; Rogers & Pilgrim, 1995), Leach (2007) characterizes the 'personalized ethics and a liberal politics of choice' underscoring this reasoning. She suggests this is responsible for the discrepancy between what policy-makers want (vaccination) and some parents' feelings about vaccinating their own children. There is a scalar issue whereby the incontestable at one level (vaccinations are good for populations) appears problematic at the individual level. Contemporary societal discourses around choice and personal responsibility do not merely generate entitlement to question or reject health interventions, but perhaps even an obligation to do so (Reich, 2016a; Sobo, Huhn, Sannwald, & Thurman, 2016), evident in Clara's dismissal of parents who would unthinkingly immunize. Such questioning occurs with minimal reflexivity regarding the impact of one's decision on different social classes, or the populace as a whole (Reich, 2016a).

It became evident that as the parents sought to navigate this and other issues, they sought an advocacy organisation for people in their position. Denae appealed for vaccine information from fence sitters, but was fence-sitting a position that could be sustained over a period of time; an interest group that could self-organize and cater to its members? In its absence, participants appealed to the IAWA. Yet IAWA, like other organisations working in the public health space, would find it very problematic to pursue these agendas, and the capacity for vaccine advocates to enter the space the participants sought and be considered trustworthy was unclear.

Both these issues – individuals navigating 'mass' systems and accessing advocacy and information within them – played out around the fraught issue of combined vaccines. Denae's feelings of manipulation here demonstrate the contingency of consent. Combined vaccines reduce the number of injections required and increase timeliness, improving coverage (Kalies et al., 2006). They could be conceptualized as a 'nudge' – an alteration to the choice architecture to shape behaviour (Thaler & Sunstein, 2008). Cost and timeliness are salient at a population level. Combined vaccines suit individuals who are not worried, happy to have less injections, or are unconcerned about accepting additional vaccinations along with those might particularly value. But for the participants, the nudge failed. Denae 'tipped towards none,' but this did *not* result in the minimal negative consequences for avoidance, characteristic of nudges as public policy. Rather, her child might 'miss out' on being vaccinated.

The answer, of course, would be to provide parents with alternative vaccine schedules, including separate vaccines, and to make information about these clearly available, as participants sought. However, the unintended consequences of this could include undermining the schedule. Gofen and Needham (2015, p.278-279) found that while personalising vaccination increased compliance, there was a risk to 'the broader argument that vaccination can be safely administered as a standardized intervention,' and 'crowd[ing] out' a sense of 'public duty.' This could ultimately result in the replacement of a 'relatively low cost standardized public health intervention...' with 'personalized interventions that are much more costly and fragile.' The US study exploring alternative schedules by Dempsey et al. (2011) adds support to the idea that public validation might threaten official schedules. Twenty-two percent of parents they surveyed who were following the standard schedule nevertheless disagreed that it was the best, and 20% of them thought delaying was safer. What might such parents do if the state promoted alternative schedules? And would this raise doubt in parents who currently have confidence?

IAWA grappled with such issues, and concluded that we could not feature parents following alternative schedules in the campaign. We had to accept 'losing' someone like Meg. We, too, suppressed the nuance of the middle position, framing our participants as an audience from whom we were seeking full compliance. Such demands for diversity face public health agencies across the world as they strategize how to engage with hesitant parents. Health professionals experience this dilemma face to face. Empowering parents to follow an alternative schedule (rather than eschewing vaccination) would be a win for all. However, it could threaten the regular schedule, with its rigorous testing and delivery times calculated to maximize immunity and maintain affordability. Catering for selective vaccinators could cue people to reject vaccines, or make vaccines less effective or available.

While this study sheds light on a cohort of parents that could be akin to those in other developed countries (ref withheld), the results must be interpreted in the light of a small sample in a single city. The selective vaccinators were a small cohort. Other limitations relate to the context of the research. My epistemological positioning shaped and influenced the research, likely affecting the sample and the findings. Potential participants may have been alienated from engaging with a campaign that sought to change their behaviours, or distrusted the funding source. While my positioning may have inhibited what interviewees would reveal, my standpoint – and for some, the fact that we knew each other – appeared to mobilise many of them to speak frankly and freely.

6. Conclusion

The selective vaccinators in this study sought to carve out a legitimate identity for themselves as they depicted a binary of vaccination into which they did not fit. Participants sought to challenge their positioning by co-opting the interview process. In doing so, they revealed 'the system's' lack of capacity to adequately engage with them. Delivering cues to hesitant parents would risk generating greater hesitancy amongst *all* parents. Yet the parents in this study are not currently catered for. This poses a significant dilemma for designers of vaccination programmes and health professionals. Further research and pilot interventions might determine whether (and which, if any) coded cues could be made available to hesitant parents without increasing hesitancy generally. However, even if such cues proved effective, they could still not fully resolve the tension between individual and population-level health interventions that this study illuminates.

Ethical statement

This work has not been published nor is under consideration for publication elsewhere. Appropriate attribution and citation is given for any material reproduced from any other source including the authors' prior publications. The material in the manuscript has been acquired according to modern ethical standards and has been approved by the legally appropriate ethical committee. All material conflicts of interest have been declared including the funding source.

Declaration of interest

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