DOI: 10.1027/1016-9040/a000168

Category: Original Articles and Reviews

Submission date: October 11, 2012

Acceptance date: June 20, 2013

Running head: Health Decision Making in Respiratory Infectious Diseases

**Uncertain News – Trust and Preventive Practices in Respiratory Infectious Diseases** 

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#### **Abstract**

Trust influences a range of human behaviors including health decision making. Over the past 60 years a significant industry has sprung up to influence public opinion and mobilize grassroots challenges against evidence-based threats to vested interests. Simultaneously, media reports of scientific fraud, misrepresentation, constantly changing "evidence" for health, and "hyped" predictions of disasters that were ultimately less significant amplifies doubts about the reliability of scientific evidence and technology when hazards arise. This has contributed to the appearance of decay of trust in the veracity of scientific claims. Population responses during communicable disease epidemics illustrate these interacting processes that simultaneously create uncertainty and significant discomfort within communities. Research on the relative influences of formal versus informal information sources in driving protective behavior during recent influenza epidemics show how both the uptake of everyday preventive practices such as hand hygiene, and specific health interventions, such as vaccination are affected by these processes. We review recent work on influenza-related personal preventive practices, with a particular focus on the shifting roles and utility of formal and informal sources in decision making among the public, and consider the implications within the context of prevailing levels of trust, uncertainty, and doubt surrounding health care recommendations.

Keywords: health behavior, decision making, trust, epidemics, influenza

# **Background**

"The relationship between the scientific community and the general public has never been worse in living memory. The commercialization of research is largely responsible..." (Haerlin & Parr, 1999, 499).

Trust is defined as "assured reliance on the character, ability, strength, or truth of someone or something" (Merriam-Webster Dictionary, 2012). It is a critical component in social exchange. Trust undermined can profoundly affect existing relationships. Trust and perceived risk (the probability of undesirable consequences) are inversely related: low trust in something involves a higher risk that associated outcomes are unpredictable and loss of some kind more probable. Loss aversion and hence risk aversion is widespread (Tversky & Kahneman, 1974). Trust involves stable normative relations, where people must want to maintain a relationship (Six, 2005); in circumstances where one party is dependent on the relationship, such as in a health-care situation where patient is reliant on a provider, trust in the provider may be undermined by a more generally erosion of trust in the wider system, particularly in health care systems that use other than a named provider approach.

Public faith in science and scientists seems to be seriously challenged, paradoxically when it repeatedly evidences great success. In the past 25 years science and technology have brought major changes to peoples' lives of the same order of magnitude as did the utilization of previous scientific technological innovations: printing, steampowered transportation, electricity, telephony and television. You are probably reading this article on an electronic device, probably a portable one. Wireless computing technology has brought vast amounts of information into everyday reach; each of us has information dwarfing that of the Library of Alexandria in our pocket or bag.

The technological proof of science is so tangible to so many, and regarding technology, is mostly trusted because it works, usually, but regarding health, evolution and climate, why is trust in science apparently declining? Two main factors seem culpable.

The first is the growth throughout the late 20<sup>th</sup> century onwards in commissioning and use for public relations (PR) reasons of tailored scientific "evidence" calculated to generate uncertainty and doubt in the public eye. The tobacco industry's funding of

countervailing "science" intended to create doubt about smoking hazards served to delay effective tobacco control legislation for almost 30 years. So successful was this that the PR industry adopted similar tactics when their other clients felt threatened by negative scientific evidence regarding their products or activities. The PR industry now does "perception management" (PM), manipulating how people should see the world and their clients' roles therein. PR's penetration into politics means "Spin" is now an established political approach to information dissemination used in most western democracies (Doshi, 2005). Governments and industries rely on PM and the media play a largely-complaisant role in distributing this, with almost 60% of media content on any given day derived from PR-sourced press releases. More recently, national policies appear widely variant to their pre-election promises, for example, regarding the ongoing National Health Service privatization in the UK, further confirmation that policymakers say one thing and do another, usually geared to serving vested interests (Monbiot, 2012). More specific is the use of "policy-based evidence making" to justify often-ideologically derived policy:

"[Ministers] should certainly not seek selectively to pick pieces of evidence which support an already agreed policy, or even commission research in order to produce a justification for policy: so-called "policy-based evidence making" (see paragraphs 95–6)." (House of Commons Science and Technology Committee, 2006, Paragraph 89)

However, trust is a requirement for good governance and the lack of trust today is symptomatic of a widespread state of crisis in many western democracies as well as other states (Blind, 2007).

A second factor involves the string of high profile, but subsequently low impact events that have generated risk fatigue. Prominent amongst these were the Bovine Spongiform Encephalopathy (BSE) epidemic in the United Kingdom, which resulted in £15Bn of economic losses. The dire warnings in newspapers of tens of thousands developing New Variant Creutzfeld-Jakob ("mad-cow") disease was subsequently explained away as science "scaremongering." This was followed shortly after by more desperate media reports of Y2K bug predictions of wholesale computing failure, aircraft falling out of the skies and nuclear power station meltdowns, none of which happened. Again science "took the rap" for this inflated scenario. Straddling the Millenium, avian A/H5N1 influenza was sensationalized by the media as the next great

pandemic that would cull the human race. While A/H5N1 influenza remains worryingly problematic in many developing countries, for most people in developed western nations it dropped from the headlines in 2004 and has since ceased to be a problem. Disaster fatigue was setting in, with new scares every couple of years that were inevitably sensationalized by media organizations desperate for business. Several high-profile cases of scientific fraud were headlined around the same time, for example human cloning and genetics in Korea. However, it was in 2009 that the PR industry and disaster fatigue combined. The initial influenza A/H1N1 outbreak-related media panic failed to ignite the public's concern, and rapidly changed to ire when the WHO raised its alert to "pandemic" status even though millions had not died. In the media accusations began to fly about the World Health Organization's motives, financial interests of scientists in anti-influenza medication, of profiteering by vaccine manufacturers, and of conflicts of interest to obtain grant funding. In the same year the International Panel on Climate Change, and by implication the quality of science underpinning the report, were heavily targeted by industry-backed lobbyists at the Copenhagen Climate Change conference in December 2009, excerpting hacked emails from the Climate Research Unit at the University of East Anglia in the weeks before the conference "proving" claims of collusion and censorship. This episode combined media 'proof', not only of how scientists were "fixing" their data to ensure continued funding, and "censoring" dissenting opinion, or profiting from decarbonization strategies, with academic papers of dubious provenance echoing such views (cf. Fielding, 2011), commissioned by Think Tanks themselves funded by carbon industry groups (Fielding, 2011; Monbiot, 2012). The blogosphere was hot with scandal and denunciation of all the claims regarding anthropogenic global warming. So successful was this PM witch-hunt of climate science that opinion polls revealed large declines in population trust in the claims of climate and other scientists. Finally the evidence of science could be ignored in favour of the evidence of sponsored media opinion, dogma and ideology. It is within this context of manufactured doubt that the present paper is developed.

"Some scholars make a distinction between the concepts of "confidence" and "trust," associating the former with a passive emotion accorded to the overall sociopolitical system, and conceptualizing the latter as a group of more dynamic beliefs and commitments accorded to people." (Blind, 2007).

Blind's distinctions between and definitions of confidence and trust will be used here. Credibility, in the eyes of the public, emerges when policies (and politicians) perform in the intended manner, which contributes towards building trust; hence it follows that the production of policies which repeatedly lack credibility will result in a loss of trust (Blind 2007). This is compounded by perceived political and institutional corruption in the western sense of selective patronage towards political donors, often corporate beneficiaries, and of perceived conflicts of interest by decision-makers, an issue of particular topicality in the recent A/H1N1 influenza pandemic. Blind concludes: "Decline in trust is happening across countries with diverse institutional structures, historical legacies and cultural underpinnings...the possible explanations for, as well as the potential solutions to the decline of trust in government, might very well be grounded in the new requirements imposed by globalization (Dalton 2005)." (p.14). The decline in trust in science may in fact be apparent, with the real decline occurring in the institutions needed to communicate, namely the alliance of corporate PR and media deliberately seeding doubt about undesired scientific evidence.

# **Emerging respiratory diseases in Hong Kong**

The context for our ongoing work on human responses to and behavior regarding associated risks of acute respiratory diseases in Hong Kong arose from experiences providing a somewhat different historical context to that of Western Europe. In 1997 A/H5N1 influenza infected 18 people, 6 of whom died (Mounts et. al., 1999), despite Hong Kong's world-class medical care. The outbreak was ended by the culling of all poultry in the territory, a drastic step at the time, but the first of many. Then, in 2003, Severe Acute Respiratory Syndrome (SARS) erupted, with 1,760 infections and 299 related deaths, (8,422 cases and 916 deaths worldwide), including many health workers, and Hong Kong came close to panic before the epidemic subsided.

Government information available in Hong Kong during SARS was placatory until a group of independent bloggers utilized a website documenting the number of SARS cases from each estate in Hong Kong (<a href="http://www.sosick.org/timeline.html#english">http://www.sosick.org/timeline.html#english</a>). This was a crucial move in forcing the government's hand in releasing information about the pattern of the epidemic. Subsequently the then Secretary for Health resigned over the episode. The negative impact on public confidence in government information during epidemics and in response a Centre for Health Protection was established in late 2003 to perform the same role as the European Centre for Disease Prevention & Control (ECDPC). That Centre has since worked hard and largely rebuilt trust within the community by providing timely and transparent information.

# Exploring risk in the context of communicable disease

The HIV/AIDS epidemic in the late 20<sup>th</sup> C prompted a lot of work on understanding how and why people exposed themselves to risk through personal behavior, some of which was done in Hong Kong in relation to sexually-transmitted disease (e.g. Abdullah, Fielding & Hedley, 1998; Abdullah, Hedley & Fielding, 2000; Abdullah, Fielding & Hedley, 2001; Abdullah, Fielding, Hedley, Ebrahim, & Luk, 2002; Abdullah, Fielding & Hedley, 2002; Abdullah, Ebrahim, Fielding & Morisky, 2004). HIV/AIDS prompted interest in respiratory disease from a behavioral perspective mostly limited to studies of general protective behavior, and some vaccination uptake studies.

Hong Kong has been an epicentre of influenza virology research since the mid-1970s. Prior to 2003 almost no research had reported population behavior during respiratory epidemics. As part of the work during SARS to build an epidemic curve, (a frequency histogram of the daily number of new cases) in the absence of clear data we undertook a population-wide telephone survey of the Hong Kong general public. This was the first study attempting to measure respiratory epidemic anxiety on a population level (Leung, Lam, Ho, Ho, Chan, Wong et al, 2003; Leung, Ho, Chan, Bacon-Shone, Hedley, Lam et al, 2005). The results were quite sobering: Of 1115 randomly sampled Hong Kong Chinese adults, 30% felt they were very (1.2%) or somewhat (28.9%) likely at risk of contracting SARS (perceived vulnerability) but only 25% felt they would likely survive if they did so (perceived severity), while 40-55% were unsure of the modes of transmission (and thus how to protect themselves).

Consecutive cross-sectional and cohort surveys throughout the whole SARS epidemic period were conducted, showing a declining trend of population anxiety from the initial SARS epidemic peak to the post-epidemic period (Leung, et al., 2005). This study revealed population anxiety in response to SARS in the initial epidemic phase indicated by the moderately high mean item score of 2.48/4.0 on the State-Trait Anxiety Scale (STAI) (Speilberger, Gorsuch, Lushene, Vagg & Jacobs, 1983). Population anxiety was found to be closely related to daily numbers of reported SARS cases but had no association with the case-fatality ratio reported by the government. This suggests that strong initial emotional response was prompted by the uncertainty during the initial phase of SARS epidemic rather than the government information regarding the severity of the disease. Public distrust in the government may have further amplified this uncertainty at the beginning of the epidemic, which was an important factor that accounted for the failure of government information to calm down public anxiety. The quick decline of population anxiety after the initial epidemic phase may have been due to increasing public trust in the government's competence over controlling the threat, the decreasing uncertainty about the threat as evidence accumulated or an demonstration of risk fatigue. The study also revealed an apparent dose-response relationship between population anxiety and adoption of protection, but no significant associations between perceived likelihood of contracting SARS or survival if infected with adoption of protective behaviors, an important phenomenon needing further exploration.

It is difficult to examine the associations between perceived risk of/from the disease/threat and adoption of protective practices using longitudinal data in the context of communicable disease outbreaks/epidemics because both perceptions of risk and protective behaviors could change in a parallel with the change of the epidemic situation. Therefore, most relevant surveys (Bish & Michie, 2010), like Leung et al (2003), were cross-sectional and hence disentangling causality was problematic. A slightly better option is to conduct a series of consecutive cross-sectional surveys paired with cohort surveys, like Leung et al (2005). Epidemics of emerging respiratory infectious diseases constitutes highly uncertain situations that are dynamic and with high personal threat, particularly in the initial phase of the epidemic. It is a difficult job for a health authority to communicate this uncertainty, and thereby maintaining a trust relationship between the authority and the public is a core issue (Calman, 2002). To bet-

ter understand these influences of trust and communication of uncertainty on public adoption of protective behaviors against communicable diseases, we review studies exploring these issues in more depth.

Personal protective practices (PPPs): PPPs regarding influenzas include strategies and activities specifically carried out for the prevention of influenza. Some of these are highly specific, such as avoiding crowded places or public transport during influenza epidemics, and others less so, such as the wearing of face masks for upper respiratory tract infections, hand-washing, and food and household hygiene, all general habitual behaviors. In a later review of 26 papers that addressed PPPs against SARS, A/H5N1, A/H1N1 (Bish & Michie, 2010), perceived susceptibility and perceived severity of disease were evidenced to predict PPP behavior. However, these associations mostly become insignificant after controlling for anxiety level (Leung et al.2005), possibly because anxiety mediated the associations of perceived susceptibility and perceived severity with adoption of PPP.

For newly emerging infectious diseases, perceptions of risk mainly results from risk communication, either through government-agency channels such as TV, radio, newspaper and official websites (Formal) or through informal interpersonal communication such as listening to what other people (e.g., family, friends, neighbours, colleagues, or general others) say and observe what they do (Informal). Trust is important for successful persuasive communication (Reynolds & Quinn Crouse, 2008), indicating utilization of information. Several studies have explored the associations between trust in different types of information (e.g., Formal or Informal) and perception of risk and subsequently PPPs.

In Quah & Hin-Peng's (2004) study, perceived openness of government communication, an essential component of trust (Reynolds & Quinn Crouse, 2008), was associated with adoption of PPPs against SARS among 1,201 healthy adults in Singapore. Tang & Wang (2005) also reported a positive association between having confidence in local health authorities and adoption of PPPs against SARS among 354 Chinese aged 60 or above in Hong Kong.

Later studies tended to focus on prevention of A/H1N1. Rubin, Amlot, Page and Wesley's (2009) study conducted in the initial stage of A/H1N1 among 997 British adults provided more insights about the relationships of adoption of different PPPs against

A/H1N1 with trust, communication, uncertainty and public anxiety. The study found that trust in the authority was positively associated with adoption of general hygiene practices (i.e., washing hands) that were recommended by the UK government but was not significantly associated with social distancing behaviors (i.e., avoiding public transport) that were not recommended by the government. Moreover, the study found that respondents perceiving A/H1N1-related information as "good" reported adopting more hygiene practices, while respondents who perceived that this information was exaggerated were likely to report adoption of fewer hygiene practices. However, perceived quality of information did not seem to affect social distancing behaviors. In this study, information mainly referred to Formal information from governmentagency sources. Perceived uncertainty was not associated with adoption of any types of PPPs. This may reflect adjustment for anxiety in the model because anxiety is likely to be higher under conditions of perceived uncertainty. Another reason could be due to the poor measure of uncertainty in the study which consisted of only one item "I do not understand what is happening with this swine flu outbreak". In Rubin et al's (2009) study, anxiety level was measured with a scale similar to that used in Leung et al's studies (2003; 2005), and which was positively associated with adoption of both hygiene practices and social distancing behaviors. The association between anxiety and social distancing behaviors seemed stronger. Anxiety level was lower among respondents who received a government leaflet about A/H1N1, suggesting Formal government information is effective in reducing public anxiety, possibly because the British public had a high level of trust in the UK National Health system. This is in contrast to what happened during the initial stages of the SARS outbreak in Hong Kong. Overall, Rubin et al's (2009) study reveals different influences on adoption of different PPPs. While adoption of government-recommended hygiene practices appears to have been influenced by trust in Formal government information, adoption of social distancing behaviors was independent of Formal government information but strongly influenced by level of anxiety which in turn may be related to the uncertainty of the epidemic situation. Moreover, the study also suggests that trust may be an important element that determines whether government information could be effective in reducing public anxiety or not.

While the above studies mainly focused on the influence of information from Formal sources, Liao et al's (Liao, Cowling, Lam, Ng & Fielding, 2010; Liao, Cowling, Lam

& Fielding, 2011a) studies further examined the influences of trust in different types (Formal and Informal) of information on PPP related to A/H5N1 and A/H1N1 influenza using structural equation modelling. In the first paper (Liao, et al 2010), a hypothetical model involving degree of trust in Formal and Informal information influences on behavior was tested based on a cross-sectional study of 1,001 Hong Kong Chinese adults interviewed by telephone. The study revealed that trust in Formal information was associated with greater understanding of A/H1N1 influenza cause and higher self-efficacy for preventing influenza, both of which were significantly associated with better self-reported hand hygiene scores. In contrast, trust in Informal information was positively associated with influenza worry which in turn was significantly associated with greater social distancing behavior (Liao, et al, 2010). Interestingly, the study found that trust in Formal information was independent of perceived susceptibility and disease worry and thereby almost independent of social distancing behaviors while trust in Informal information was independent of disease knowledge and perceived self-efficacy and thereby almost independent of adoption of hygiene behaviors. These findings when considering together with Rubin et al's (2009) findings suggests that when the situation is highly uncertain (particularly so in the early epidemic stage), the public may be more likely to rely on Informal sources to obtain relevant information which may subsequently heighten their anxiety or disease worry in the public and thereby lead to more social distancing, a more extreme attempt at protection against respiratory diseases. Previous studies conducted during the SARS epidemic also suggest that Informal information such as observing what other people around do might easily arouse negative emotional responses to the epidemic and thereby cause more extreme protective behaviors (e.g. social distancing or wearing face masks) (Syed, Sopwith, Regan & Bellis, 2003; Slaughter, Keselman, Kushniruk & Patel, 2005).

Applying the model to data gathered during A/H5N1 influenza activity (Liao, et al, 2011a) showed the robustness of these findings and further clarified differences attributable to disease type. Trust in formal information was positively associated with influenza worry about A/H5N1, but this was not the case for worry about A/H1N1. Influenza worry was influenced by trust in Informal information in both datasets but was only positively associated with personal hygiene practices in the A/H5N1 data. This suggests that only disease worry derived from Formal information would lead to

adoption of government-recommended hygiene practices. In other words, trust in Informal information appears not to influence government-recommended protective practice uptake. More trust in Formal information was associated with better self-reported knowledge only in the A/H1N1 data but was consistently associated with higher perceived effectiveness of hygiene in prevention in both A/H1N1 and A/H5N1 datasets and subsequently, both higher self-reported knowledge and perceived effectiveness of hygiene were consistently associated with more hygiene practices (Liao, et al 2011a). These findings suggest that although more trust in Formal information may not necessarily lead to promotion of knowledge, probably due to differences in epidemic situations, it could consistently promote efficacy beliefs which increase the probability that government-recommended protective practices are adopted. In both datasets, perceived influenza susceptibility was positively associated with disease worry, again indicating a mediation effect of emotion (worry or anxiety) on the relationship between perceived susceptibility and adoption of protective behaviors.

Furthermore, these two studies (Liao, et al 2010; Liao, et al 2011a) suggested that perceived effectiveness of interventions and self-efficacy exert significant variance on influenza PPPs, both of which were associated with trust in Formal information, partially mediated by knowledge of influenza cause only in A/H1N1 influenza data. This may reflect differences in the characteristics of the two diseases. It was notable that reported levels of trust in formal information was marginally higher in the A/H1N1 data than in the earlier A/H5N1 data, perhaps reflecting a historical recovery of trust in official information from the low that occurred during SARS.

Liao et al.'s (2010; 2011a) data suggest that it is paramount that the public understand the effectiveness of PPPs in influenza prevention and are helped to be proficient in the appropriate practice of these. However, the provision of more information about causality is unlikely to improve PPP implementation or maintenance.

These and other studies suggested that risk habituation, where over time persistence of a threat leads to a lowering of risk perceived as inherent in that threat (Fielding, Lam, Ho, Lam, Hedley & Leung, 2005; Liao, Cowling, Lam & Fielding, 2011b) may result in a dilution or slackening of preventive effort (Liao, Lam, Dang, Jiang, Udomprasertgul, & Fielding, 2009; Liao, et al, 2011b).

Vaccination uptake: Vaccination is an important preventive strategy that has been well studied in RIDs. Considerable controversy periodically emerges surrounding vaccinations and the degree to which, in particular, parents feel they can trust child-hood vaccinations. This has lead to many parents withholding their children from beneficial childhood vaccinations for damaging diseases such as measles, rubella and pertussis. This is partially attributable to disproven inaccurate claims of their links to autism (Godlee, Smith & Marcovitch, 2011) receiving widespread publicity during the 1990s.

The existing literature on trust as an influence on willingness to undergo vaccination against influenza is more substantive than that on other PPPs. While little harm is usually envisaged from washing hands, wearing a mask or not visiting a shopping mall, vaccinations are not entirely risk-free. Two main areas of vaccination risk studies are apparent: self-vaccination against epidemic/pandemic strains and parental decision making for vaccination of children against epidemic strains of, usually, influenza.

For either study domain, it is apparent that seasonal vaccination is generally associated with less controversy than was the pandemic A/H1N1 vaccine of 2009-2010 (Kraut, Graff, & McLean, 2011; Tanguy, Boyeau, Pean, Marijon, Delhumeau & Fanello, 2011). Distrust in the safety of A/H1N1 vaccine was a major reason accounting for the generally low uptake of the pandemic A/H1N1 vaccine (e.g. CDC, 2010; Bish, Yardley, Nicoll & Michie, 2011; Brien, Kwong & Buckeridge, 2012). In a sample of pregnant Canadian women, the potential risks of the vaccine were prominent features influencing decision making for vaccination (Kowel, Jardine & Bubela, 2012). Bults, Beaujean, Richardus, ven Steenberger & Voerten (2009) interviewed 1,227 Dutch parents immediately after they had taken their children for their second A/H1N1 vaccine dose, and six months later they interviewed another 1,900 decliners of vaccination about factors influencing their vaccination decision making. Fear of vaccine side effects/harms was the most common reason (51%), followed by "a bad feeling about it" (46%) and beliefs the vaccine had been inadequately tested (39%) among reasons cited for declining vaccination for their children. Over 35% reported "no trust in the efficacy of the vaccine", 34% "contradictory messages from the media" and 16% "no trust in the government", a remarkably high proportion. Only 5.5% reported accepting the vaccination because "the government recommended it".

Low levels of trust in the vaccine are partly attributable to the perceived conflict of interests underlying the decision making behind its release (see Vlassov, 2011 for an illustration). Both were controversial, with considerable debate and criticism subsequently levelled at the World Health Organization for declaring a pandemic which fortunately did not meet the early anticipation of 5-10% mortality rates, which were popularly but incorrectly perceived as being insignificant (e.g. Epstein, 2011). Recent estimates identify ~200,000 (range 105,700—395,600) respiratory and 83,000 (46,000—179,900) cardiovascular deaths due to A/H1N1 in the first year of the pandemic, 80% of which were in people aged under 65 years of age, 51% being in south East Asia and in Africa (Dawood, Luliano, Reed, Meltzer, Shay, Cheng, et al, 2012). Calls for the vaccination of children who were at higher risk of A/H1N1 infection, and adults with pre-existing medical conditions (e.g. Sachedina & Donaldson, 2010) conflicted with popular media commentary and scientific opinion. For example, Wiwanitkit (2012) states "Black et al. noted that "if a cohort of 10 million individuals was vaccinated in the UK, 21.5 cases of Guillain-Barré syndrome and 5.75 cases of sudden death would be expected to occur within 6 weeks of vaccination as coincident background cases." This reflects the possible rate of 2.15 per million of Guillain-Barré syndrome (GBS) and further death rate of 0.58 per million death due to new pandemic Influenza A: H1N1 2009 vaccination." The author then points out that while these figures might be acceptable in locations with high A/H1N1 mortality, they would not be in most European countries.

The risks associated with this controversial vaccine remain very low, but people are notoriously poor judges of risk (Branstrom et al, 2006), being vulnerable to, among other influences, availability bias, where ease of recall of examples distorts risk probabilities upwards (Slovic, 2000). These effects are likely compounded by mistrust both of the vaccine manufacturers (Black & Rappuoli, 2010) in a world where profit motive is increasingly prioritized, and governments increasingly seen as victims of regulatory capture by business interests. Many empirical studies have reported a relationship between trust in the health authorities/government/healthcare workers and acceptance of A/H1N1 vaccination. For example, a US study among 337 African-American and Caribbean community members in New York City found level of trust in the vaccine, the medical profession and the government strongly influenced decisions to be vaccinated (Noyes et al, 2006). Another study conducted in Turkey also

reported a positive association between trust in the health authority and parents' decision to vaccinate their children against A/H1N1 (Torun, Torun & Catak, 2010).

However, a qualitative study conducted among nurses reveals general mistrust with health authorities after the A/H1N1 pandemic (Baron-Epel, Bord, Madjar, Habib & Rishpon, 2012). Respondents generally perceived that the health information from health authorities was inadequate and not useful for them to make a decision about vaccination, indicating a relationship between trust (towards the institutions) and perceptions of the information quality which may subsequently influence the utilization of the information for decision making. Obtaining information from Formal sources such as government, WHO, CDC and healthcare workers was found to increase vaccination uptake against A/H1N1 (Brien, Kwong & Buckeridge, 2012). In comparison, consultating mainstream websites (unofficial websites) was associated with less likelihood of vaccination against A/H1N1 among pregnant women (Fabry, Gagneur & Pasquier, 2011). This seems to agree with the findings about the associations between trust in Formal/Informal information and adoption of government recommended PPPs discussed above. In a longitudinal study, baseline trust in Formal (medical organization) information positively predicted follow-up vaccination against A/H1N1 (Gilles, et al., 2011). The study further suggests that trust in Formal information increases efficacy beliefs in government recommended measures for preventing A/H1N1 including hand hygiene and A/H1N1 vaccination which may subsequently lead to more uptake of these preventions, consistent with Liao et al's (2010; 2011a) findings.

Also consistent with what Liao et al (2010, 2011a) reported is that vaccine decliners who felt more doubt about their vaccination decision sought information from their informal social networks more than did vaccine accepters (Bults, et al, 2011). A separate study on vaccination attitude found that although skepticism about the A/H1N1 vaccine was widespread, respondents tended to change their attitudes towards the vaccine once a single person they knew contracted the illness (Taha, Matheson & Anisman, 2013). This suggests that when uncertainty is widespread, Informal information and threat imminence can strongly influence beliefs and behaviors.

Here we again see the influence of multiple layers of trust/mistrust re-emerging in a completely different cultural context, to influence vaccination behavior. Trust deficits

involved doubting the honesty of government motives, manufacturers' responsibility, manufacturers' honesty and on a different level, conflicting information generating uncertainty, coupled with what appears to be anticipation of negative affect. Under conditions of uncertainty, decisions appear to be made on the basis of observing general patterns of behavior and by following previous patterns of behavior that presumably have proved uncontroversial in the past. Consistent with widespread evidence that past behavior is the best predictor of future behavior, so vaccination history for seasonal influenza was a consistent and strong predictor of vaccination uptake during the A/H1N1 pandemic phase (Gidengil, Parker and Zikmund-Fisher, 2012).

### **Synthesis**

Trust in formal information sources appears to be an important influence on people's decisions to adopt vaccination and government-recommended PPPs. However, under conditions of uncertainty it seems that people may be more likely to base their decision making more on the perceived actions and behavior of their peer group, taking their cue from what other people are doing. Informal information, perhaps functioning as a proxy of social norms, is particular influential for behavioral change when uncertainty is widespread and anxiety level is high among the public.

Trust may play a central role in determining affective responses, and trust, of course, is an implicitly social process. In deciding which course of action to follow, a person has a choice between "expert" and "lay" opinion. However, the absence of consensus and the greater spectrum of opinion that exists courtesy of the Internet, makes an informed explicit choice increasingly difficult, as opinion exists on every perspective, much of it claiming to be "informed", and controversy, real or contrived, rages on most topics as a result. This serves to amplify uncertainty. In contrast, observing others in your daily life, peers, friends and acquaintances, who at least to some extent, can be relied upon to behave in a mostly self-interested, and therefore "honest" manner is an important information source. Hence, accessing Informal information sources and social norms may be one way of capturing this social information. In these circumstances, what Slovic, Finucane, Peters & MacGregor (2002) termed the "affective heuristic" takes on particular salience.

Anxiety can interfere with the ability to process and understand information. Also, the anticipation of negative affect, which in modelling future potential loss-related affect states likely involves activation of the same signalling pathways involved in negative affect such as anxiety (Zajonc, 1980; 1984), for example the amygdala can make it more difficult to understand related information (Kash, Holland, Halper & Miller, 1992). In turn this could amplify uncertainty and increase perceived risk. The desire to avoid or minimize anticipated negative affective states then should drive the intention to seek or avoid vaccination. Alternatively, others have argued "...negative affect seems to trigger a more effortful, analytic and vigilant processing style (Clark & Isen, 1982; Isen, 1984; 1987)." (van der Pligt, 2002), then, if so, it may be that additional processing results in higher perceived risk estimates. Requiring respondents to take a slightly longer time perspective makes the post-behavior feelings more salient, which also influences behavioral intentions and self-reported behavior, but a longer-term perspective also runs the risk of evoking discounting of outcomes that may be construed to be far in the future (van der Pligt, 2002).

Van der Pligt's (2002) wide-ranging and comprehensive review argues that primary risk assessment processes automatically trigger social comparisons concluding that optimistic bias occurs not because people under-estimate their own risk, but because they over-estimate the risk to others (van der Pligt, 2002). Reliance on social comparisons uncritically would be foolish. Instead, it is intuitively appealing to invoke some quality control mechanism by which the validity and reliability (or their equivalent) of one's estimates of risks to and activities of others are judged. Trust would seem to be a mechanism that fits such a purpose.

A second issue is alluded to in van der Pligt's (2002) review, namely that what might be a concern for governments and population scientists is often not a concern for members of the community. It is notable that during the 2009 A/H1N1 pandemic influenza event most studies examining vaccination uptake found very low levels of vaccine uptake, even among health professionals with high levels of expert knowledge, and a major reason given for not being vaccinated was the poor risk-benefit ratio, where the disease was simply not seen as particularly risky (e.g. Liao et al, 2011c), hence the imputed benefits of vaccination were lower relative to the highly accessible information about harms arising from repeated media reporting of (mostly apparent rather than real) vaccine-related side-effects (but also see Wiwanitkit (2012)

above). The different frames of reference between the public health community and the population, the easily accessible but often complex and contradictory information about the nature of the disease and the conflict between reassurances about vaccine safety and benefit and media reports of associated "harms" quite possibly lead to the perception of distortion in Formal information sources, particularly against a backdrop of issues outlined in the opening sections of this paper. This would lower trust in Formal information and force greater reliance on Informal sources, most likely in those least able to independently judge the veracity of competing formal information for themselves; the less well educated and the younger (less experienced at disease-risk judgements).

### **Conclusions**

There is a growing body of work on information sources used during RIDs and how these associate with decision making about adoption of PPPs and vaccination. However, the role of trust has barely begun to be investigated in this area beyond more superficial descriptions. Trust itself is generally not deconstructed with the result that trying to make sense of a wide spectrum of information on risk-taking, decision making and cognitive-emotional processing under conditions of uncertainty reveals the limitations of our understanding about this area. Nonetheless, there is a deepening focus on the processes associated with uncertainty, trust, and decision making confidence seen in the literature regarding RIDs that is beginning to illuminate this fascinating area of health psychology. Of particular relevance is the fact that we have almost certainly not seen the end of significant RIDs and as population densities increase in an era of ideologically-driven cuts to social and heath programmes, these are likely to be important threats to population health in the coming years in ways we have not yet anticipated.

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