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Running head: Internet-based vaccination decision aid

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ABSTRACT

Vaccination decisions, as in choosing whether or not to immunize one's small child against specific diseases, are both psychologically and computationally complex. The psychological complexities have been extensively studied, often in the context of shaping convincing or persuasive messages that will encourage parents to vaccinate their children. The computational complexity of the decision has been less noted. However, even if the parent has access to neutral, accurate, credible information on vaccination risks and benefits, he or she can easily be overwhelmed by the task of combining this information into a well-reasoned decision. We argue here that the Internet, in addition to its potential as an information source, could provide useful assistance to parents in integrating factual information with their own values and preferences – that is, in providing real decision aid as well as information aid. We sketch one approach for accomplishing this by means of a hierarchy of interactive decision aids ranging from simple advice to full-scale decision analysis.

TOWARDS INTERACTIVE, INTERNET-BASED DECISION AID FOR VACCINATION DECISIONS: BETTER INFORMATION ALONE IS NOT ENOUGH

Public policy in many countries encourages people to actively participate in decision making concerning their healthcare. In a vaccination context, some, perhaps most, individuals take on the responsibility of decision making in only the basic sense of deciding to accept the advice of a trusted source such as a family doctor or a government agency [1]. Others take advantage of this liberty to let “deep seated philosophical or religious objections to all vaccines” guide their choices and “[e]ven the best communication strategies are unlikely to change such people’s opinions” [2:729]. There remain a significant number of individuals who attempt to make thoughtful vaccination decisions for themselves and their dependents and for whom the right choice is not apparent given their values or their doctor’s recommendation, if any.

For such people, vaccination decisions can involve a difficult process of dealing with the risks and emotions involved [3;4]. Decision aids are designed to help people cope more effectively with situations in which they find it difficult to make the right choice. Decision aids typically include accurate and up-to-date treatment information and there is evidence for the effectiveness of decision aid interventions to facilitate patient decision making [3;4]. In the vaccination context, numerous authors have noted the importance of accurate, credible information concerning vaccine and disease risks in allowing decision makers to make sensible vaccination choices for themselves and their dependent children. Other authors have argued for the importance of providing information in forms not traditionally used in decision aids, such as narratives [5].

We suggest that, whatever its form, information alone is not sufficient. Even with access to complete and well-validated information about vaccine- and disease-related outcomes and probabilities, the decision maker needs a procedure or mechanism to translate the information into an action recommendation – that is, a way to use the information effectively to make a decision. Such procedures, though reasonably straightforward, are not trivial. As we will argue below it is easy to find oneself with masses of decision-relevant information, all of high quality and credibility, but with little sense of how it can be organized and structured so as to lead compellingly to a choice of actions. Help is clearly needed, and some useful steps to providing such help have been reported in the vaccine context [e.g. 6;7]. Below, we build on this work and suggest that these aids may be more effective when they not only supply information concerning the choice but also provide clear guidance and help as to how those elements should properly be brought together to select a course of action.

The problem, as we will show below, is that vaccination decisions can be complex, both psychologically and computationally. The psychological complexities have attracted some research attention. We will provide an overview in the next section. The structuring and integration issues have been less widely discussed; we will examine them briefly in the second section. The third section proposes a possible internet-based response to both classes of complexity. We propose a strategy by which the resources of the Internet might be harnessed to bridge the gap between over-simplified decision models and overwhelmed decision makers. The goal is to provide Internet-based, interactive decision support to a range of potential users.

SECTION 1: SOCIAL AND PSYCHOLOGICAL INFLUENCES ON VACCINATION DECISIONS.

The psychological difficulties of child-vaccination decisions are obvious for people who are neither straightforwardly following the advice of their doctor or have strong value-based preferences one way or the other. The decision involves the health of one's child, the possibility of serious negative outcomes following from either option, issues of future regret over actions taken or not, of altruism versus free-riding in one's own contribution to herd immunity, judgments about the credibility of different sources of information, perhaps a different sense of responsibility if one takes or shirks action, and more [e.g., 8;9;10].

A number of studies have examined factors affecting the uptake of specific vaccines in specific populations. For example Pearce et al [11] examined the decline in uptake of measles, mumps and rubella (MMR) vaccine in the United Kingdom in the wake of publication of a since-discredited scientific paper [12] that suggested that the vaccine posed significant and serious side-effects. Pearce et al found that, in addition to familiar socio-economic effects such as lower uptake rates in younger, single-parent, less-educated and less affluent families, there was also a reduction among older, more affluent and better-educated parents, many of whom made a conscious decision not to have their children immunized with MMR. Brown et al [13] included what they refer to as "attitude measures" (beliefs about MMR's advantages and drawbacks and the seriousness of the targeted diseases, and a variety of other measures) as well as demographic factors in a second study of MMR uptake in the United Kingdom.

Chapman and Coups [14] reviewed a total of 36 studies of predictors of influenza vaccine uptake by adults. Most of the studies focused on either high-risk populations (primarily the elderly) or healthcare workers. Chapman and Coups extended these samples to healthy adults. Most of the relationships identified in the studies seem unsurprising. Common findings include an increased likelihood of getting the vaccine among those who believe it to be effective, who think they would be likely to get the flu, who have a history of previous vaccinations, whose clinicians recommended that they vaccinate, and who receive reminder postcards. Such findings are of value in helping to design effective public health programs aimed at increasing vaccination rates, but do little to illuminate the individual's decision process.

In our own experimental research [8;15] we have tried to elucidate this process. In Connolly and Reb [8] we were concerned with studies [e.g. 16;17] that seemed to demonstrate that reluctance to vaccinate a child was, at least in part, the result of an effect called "omission bias", a judgment that harm to one's child resulting from taking action (vaccinating) is worse than equivalent harm to the child resulting from not taking action (declining to vaccinate). In a series of experiments we showed that the appearance of a bias towards inaction was a result of methodological weaknesses in the original studies and disappeared when these weaknesses were corrected. We also found that a sizable majority of U.S. respondents favored flu vaccination even in a hypothetical scenario where disease effects and vaccination side-effects were equally severe and equally likely. We did not, however, suggest that this was properly seen as a cognitive bias since there was no basis to establish what an unbiased decision would be. Most U.S. adults are inclined to vaccinate, a minority are not. Whether or not this is a bias, in the sense of departing from an agreed-upon normative standard, and whether or not it is a result of one choice involving action, the other not, are both matters of assertion rather than of evidence. Patt and Zeckhauser [18] and Tanner and Medin [19] reach similar conclusions. The parent's anticipated regret over poor vaccination and non-vaccination outcomes was, however, highly predictive of vaccination choices. (See Wroe and colleagues [20] for converging evidence in a real vaccination setting).

In Reb and Connolly [15] we attempted to disentangle the joint effects on anticipated regret for poor vaccination outcomes of three variables: whether or not a parent chose to vaccinate; whether or not that decision reflected the consensus decision of friends and family; and whether or not the decision was made in a thoughtful and careful way. This work is an outgrowth of Decision Justification Theory [21] which postulates that decisions are shaped by two distinct components of anticipated regret, one associated with the evaluation of unfortunate outcomes, the other with self-blame for taking a decision that is not justified. The central finding in Reb and Connolly [15] was that, although both action/inaction and normal/abnormal effects can be readily replicated in the vaccination context, both are eliminated when the decision processes is specified. Parents who follow a careful, thoughtful process (whether to vaccinate or not, and whether this conforms to social norms or not) regret unfortunate outcomes less than do those who reach the same outcome by careless, thoughtless decisions. The finding does not appear to be limited to US respondents only. A sample of Singaporean respondents showed very similar results. In other work [22;23] we have shown the converse effect: making salient the possibility of self-blame regret resulting from a poor decision process leads decision makers to invest more time and effort in making careful, justifiable decisions. Overall, these results suggests that, rather than being an obstacle to good vaccination decisions, emotion – in the form of anticipated regret – can facilitate good decision making by motivating people to make decisions more carefully.

The issue of decision justifiability is central to our concerns in this note. In the following section we examine the requirements that a high-quality, justifiable decision process must satisfy.

SECTION 2: THE COMPUTATIONAL COMPLEXITY OF THE VACCINATION DECISION

Closely examined, even quite simple decisions make substantial, often overwhelming, cognitive demands on the decision maker. Consider, for example, a parent's decision to vaccinate or not vaccinate a child. A highly simplified view of a hypothetical vaccination decision (see Figure 1) might portray it as a one-time binary choice under uncertainty: Vaccinate, or Do Not Vaccinate. The "Vaccinate" option leads, with some probability p1, to an unfortunate outcome O1, in which the child suffers significant side-effects of the vaccination as well as enjoying its protective benefits, and, with probability (1-p1), to a much better outcome, O2, in which she enjoys immunity from the threatening disease without the side-effects. The other alternative, "Do Not Vaccinate", leads, with some probability p2, to the child suffering the disease (Outcome O3), and with probability (1-p2) to her escaping the disease without vaccination (Outcome O4).

[Figure 1 about here]

This sketch is, of course, too simplified to represent actual vaccination decisions in a realistic way. It does, however, serve to illustrate the structural challenges the decision maker faces. First, he or she must assess two conditional probabilities: p1, the probability that the child will suffer side-effects if vaccinated, and p2, the probability that the child will contract the disease if not vaccinated. Even if good population-level estimates are available for each, the parent may plausibly judge that these estimates do not apply to this particular child and context, or that they are intentionally distorted in the interests of pharmacological companies' sales or government policy [24]. Supposing that at least a substantial part of the probability-related information is now acquired via the Internet, the decision maker must filter the inevitable variety of alternative sources for higher or lower credibility and straightforward mendacity and cracked-pottedness.

Second the parent must assess the overall value or "utility" of each of the four outcomes, O1 – O4. This requires a parent to assess, for example, the disutility of the child getting a disease such as measles. As most parents have little experience with such diseases, this is a non-trivial endeavor. Indeed, one of the paradoxes of the success of vaccination is that people may underestimate the seriousness of the diseases vaccinations protect against [24]. Additionally, each outcome may include a number of different dimensions or attributes that a parent might care about. One individual evaluating O1 might include issues of cost, inconvenience, anticipation of heightened regret for having directly caused the child's distress, and a desire to contribute to maintaining community immunity as well as the obvious components of immunity and side effects. Another might consider an entirely different set of issues in evaluating the same outcome. Combining these considerations into meaningful overall scores reflecting the relative (un)desirability of each outcome to a specific individual is a non-trivial undertaking (see for example Clemen [25:586ff]).

With probability estimates and outcome evaluations in hand, the decision maker must finally combine these into two overall scores, one reflecting the blend of probabilities and outcome evaluations expected to result from the selection of the "Vaccinate" option, the other reflecting the blend resulting from non-vaccination option. Conventionally the recommended combination rule is that of "expected value", in which outcome values are discounted by the probability of the outcome resulting from each action. That is, the "score" for the "Vaccinate" option is:

p1 x (Value of Outcome 1) + (1-p1) x (Value of Outcome 2) ……..………..(1)

and the "score" for the "Do Not Vaccinate" option is:

p2 x (Value of Outcome 3) + (1-p2) x (Value of Outcome 4) ………………(2)

The conventional decision rule is to select the option with the higher score. (Other defensible rules have been proposed [26] but would not change our central argument here). Computational aids would be useful even for this simplified model, and would probably be essential if the model were extended to include other choice options such as multi-stage vaccinations or more complex outcomes such a vaccine failures. Even the highly simplified model of the vaccination decision shown in Figure 1 confronts the decision maker with significant cognitive/computational difficulties. Enriching the model to more closely represent real-world complexities can only add to these challenges.

It seems clear, then, that the model of vaccination choice represented in Figure 1 is (a) much too simple to reflect the complexities of real vaccination choices, and (b) much too complex to provide a realistic model of real human decision-makers. Selfreport accounts of the factors parents actually consider in making vaccination decisions for their children [e.g. 8;20;24] typically suggest that only a modest subset of the potentially relevant factors are considered, and those only in rudimentary ways. It is not unusual to find single-factor accounts such as "I thought about how terrible I would feel if I vaccinated and my child suffered serious side effects, and I therefore decided against vaccination". Such an account, though perfectly understandable, is defective in that it considers only one part of the Outcome O1, no part of any of the remaining three outcomes, and neither of the probabilities involved. It is, in short, a "shallow but nice-sounding rationale" [27], characteristic of a set of decision biases known as Reason-Based Choice Effects [28;29]. Inattention to probability information is a special concern in vaccination decisions, especially in light of the extensive research on what is known as "probability neglect", the tendency to underweight or ignore very large differences in likelihoods of different decision outcomes [e.g. 30;31;32]. Ball, Evans and Bostrom [33] note several other challenges for unaided decision makers in processing risk-related vaccine information.

The vaccination decision, as we have sketched it, presents the decision maker with a complex high-stakes decision which he or she is strongly motivated to make in a defensible, careful way but without the means to do so. It seems likely that this difficult situation leaves the decision maker vulnerable to over-simplifications and short-cuts, such as the single-reason decision rationales sketched above. The decline in MMR vaccination rates in the UK following publication of the now-discredited *Lancet* paper in 1998 [12] may well be an example. Overwhelmed with complex, worrying information and lacking any help in assessing and integrating it, some caregivers appear to have focused on a single justificatory rationale, such as “Vaccination has some chance of leading to serious side-effects for children” and chosen non-vaccination, with tragic public health consequences.

Much of the information used in making vaccination decisions comes from the Internet, a source that is itself evolving rapidly. The broad term “Web 2.0” is used to characterize this evolution. It refers, among other things, to the fact that the Internet has moved beyond simple distribution of pre-codified information to interactive, social-media sharing of information among users. In the vaccination context these developments imply that, in addition to official and expert data provided by physicians and government agencies, much of the information available to an individual trying to make a careful vaccination decision will come from anecdotes and personal narratives of other lay people [5;34]. We view such narratives as potentially a two-edged sword. On the one hand the rich, vivid nature of the reports is likely to make them more persuasive to naïve readers than pallid statistical summaries of research studies. They are more likely to affect readers’ actual behavior and enhance their ability to imagine specific vaccination outcomes realistically and vividly. On the other hand there is considerable evidence that such specific case-based information tends to attract undue weight in a decision maker’s mind. Research on “base-rate neglect” [35;36], for example, has repeatedly demonstrated large errors in probability judgments when statistical evidence points in one direction (e.g. that a given car model is highly reliable) while a single vivid anecdote points the other (e.g. a stranger’s detailed story about how unreliable his particular car has been). A personal narrative of one child’s struggle with a particular disease or vaccine side-effect may help a reader understand how dreadful this outcome really was, but casts little light on the probability of it occurring. One of the many challenges facing a decision-aid designer will be to help the user to balance statistical and narrative information in assessing the probabilities and values that decision models require.

To summarize, our argument to this point has been:

a. That at least a significant subset of parents and caregivers seek to make vaccination decisions for their children in a careful, well-informed way (not necessarily limited to narrowly personal cost/benefit considerations) that will allow them to justify their choices to themselves and others.

b. That the cognitive demands of carrying out even a simplified rational choice analysis is beyond the capacity of unaided decision makers, leaving them vulnerable to a variety of decision heuristics and errors in assessing and using risk-related information.

There thus appears to be real potential for developing appropriate decision aids for this group. In the final section of this note we sketch one possible approach to providing such assistance in the form of Internet-based decision aids.

SECTION 3: A PROPOSED HIERARCHY OF INTERACTIVE DECISION AIDS FOR VACCINATION DECISIONS

Designers of decision aids have proposed that decision aids adopt certain “best practices” such as the CREDIBLE criteria (Competent developers and development; Recent; Evidence based; Devoid of conflicts of Interest; BaLanced presentation of options, benefits, harms; Efficacious) as defined by the Cochrane Review of Decision Aids [4;6]. At the same time, it seems unlikely that a “one size fits all” decision aid be effective for the wide range of possible users, vaccination options and availability of information. Our proposal is for a series of aids of increasing complexity and sophistication, allowing the user to explore to a level that meets his or her needs. ~~For example:~~We suggest 3 levels below.

Level 1: Simple R~~r~~ecommendation~~:~~

The user essentially consults a trusted source for direct advice on a vaccination decision. The Centers for Disease Control and Prevention (CDC), for example, offers a straightforward advice-giving page entitled "What vaccines do *you* need?" [37]. The user completes a very brief questionnaire (gender, age, where you live, travel plans, and health status) and receives a list of vaccinations that the CDC Advisory Committee on Immunization Practices recommends (with advice to discuss these recommendations further with your health care provider). For users who feel that CDC advice, supported by a trusted physician, is adequate to justify a vaccination decision, simple recommendation of this sort may be all that is required.

Level 2: Supported R~~r~~ecommendation~~:~~

Underlying the Level 1 recommendations will presumably be a range of supporting materials, ranging from narrative accounts of ACIP deliberations to full-scale decision modeling of the sort simplistically sketched in Section 2, above. We visualize these supports in layers, with drop-down menus of the "tell me more" sort. For example, an assertion that a particular ~~vaccine~~ disease was associated with a certain percentage of minor, moderate, and severe ~~side-~~effects might allow the user to probe further into the supporting studies on demand as well as a more detailed description of these effects using different media (photos, narratives etc.). Expert judgments of the value of different outcomes in a decision model could similarly be available for further exploration by the user if desired. The aim would be to build credibility by having supportive evidence and argument available for each of the key assertions leading to the recommendations offered. The decision model, if any, used by the expert panel would be available for inspection, as would the (ranges of) values they assigned to its probabilities and outcome preferences and the decision rule(s) they used.

Level 3(a): Interactive P~~p~~ersonal D~~d~~ecision M~~m~~odel~~:~~

Evolving from the experts' decision model, the decision tree developed at this level would be specified by the user, both in its structure and in its numerical values and computations. If, for example, a parent~~user~~ felt that her or his child would be much less exposed to a particular flu than the population value, the parent~~he~~ could insert this modification into the model and trace its consequences for the preferred cause of action. Similarly if a particular religious position led a person~~him~~ to value one outcome very differently than did the expert panel, he or she could make the appropriate adjustment to the model and explore its impact, if any, on the recommendation. Standard procedures have been developed by decision analysts for eliciting both probability and value estimates, and these could be offered in interactive form as the user (now more appropriately, the "client") wished. The decision aid could display not only the consequences of the particular decision to vaccinate or not, but also the projected consequences if everyone were to decide in this way. Further, a variety of information could be provided in different formats (visual, narrative experience reports of affected parents, etc.) to help the user translate verbal outcomes ("measles") into personal values ("what is the disutility of my child getting a serious case of measles?") [5;24].

It might be expected that few users would avail themselves of the opportunity to build a personalized decision model in this way (though recall that many of the MMR non-vaccinators identified in Pearce et al [11] were affluent and well educated and thus more likely to have both the time and intellectual skills to develop their own decision models). Interactive models approaching this level of complexity are widely offered by financial services firms to help people in planning their financial arrangements for retirement, taking into consideration risk attitudes, planned retirement age, desire to leave bequests, and more,.W~~. W~~e are not aware of research systematically evaluating the value of these models.

A second approach to the same objective might be useful:

Level 3(b): Assisted P~~p~~ersonal D~~d~~ecision M~~m~~odel~~:~~

Wroe et al. [7] used the setting of an antenatal education class to examine the effectiveness of an intervention strategy that included a printed booklet detailing the risks and benefits of immunizations and the possibility of omission bias; a "focusing questionnaire" that encouraged participants to consider and focus on significant decision-relevant issues; and suggestions of good ways of thinking about the immunization decision (for example, emphasizing that both immunizing and declining to immunize represent active decisions). Compared to a control group that received a blander, neutral brochure presenting only factual information about immunization [38], the experimental group showed a number of changes, including, crucially, an increased probability of intending to immunize their children (and, on follow-up, of actually doing so).

Our proposal, building from the Wroe et al [7] model, would be to involve the parents and the "lead maternal caregivers", or LMCs (midwives, general practitioners and obstetricians) in jointly developing personalized decision models for each individual. With appropriate training the LMCs could help with the model-building procedures; and the experience of joint patient/care-giver interaction around an important medical decision should be supportive of patient/provider interaction [39]. In this setting the personalized decision model might be more feasible, and more informative, than one developed by an individual working alone, even with excellent software.

As with all successful decision aids, the software should include procedures to help users explore and articulate their relevant preferences (value elicitation); their thoughtful assessments, supported with available data from well-validated studies, of the probabilities relevant to their child; and a structuring procedure such as a decision tree to help them integrate the several elements into an action recommendation. As noted earlier we are not currently convinced that a distinct error called "omission bias" has been demonstrated in the vaccination context. If new and convincing evidence demonstrating such a bias were to come to light, warnings against its biasing effect would be included in the aiding procedure. (The implementation of these decision aids would, in fact, provide an excellent test for existence of "omission bias". Such a bias would, as we understand it, manifest in caregivers declining vaccination despite a clear recommendation from their own personalized decision models that their beliefs and values show vaccination as their preferred option.)

SUMMARY AND CONCLUSION

We, like the editors and the other contributors to this Special Issue, see huge potential in using the Internet to improve decision making around vaccination choices, especially the potentially very hard choices concerning the vaccination of young children. We have tried to frame the issue ~~somewhat~~ more broadly than ~~simply~~ providing accurate, credible, and convincing ~~risk-related~~ information, be it in the form of probabilities, outcomes, narratives, or other forms useable via the Internet (blogs, videos etc). ~~to parents and care-givers~~. Decision makers can also benefit from assistance with integrating and processing information in a justifiable manner to arrive at a suggested choice.

As we have tried to show, even well-informed parents face a decision problem of considerable complexity, both psychological (Section 1) and computational/cognitive (Section 2) in deciding about vaccination. The rich, vivid personal narratives and patient testimonials that are common ~~provided by~~in Web 2.0 via blogs and discussion forums open up both new threats (such as a vivid anecdote distorting evidence-based estimates of the probability that a given vaccine will have significant side-effects) and new opportunities (such as improving a parent's ability to imagine realistically what a particular side-effect or disease state would be like). Well-established decision analytic techniques can help potential vaccinators to structure their information gathering and cope with the complexities of their decisions, but typically require the active involvement of a highly trained (and expensive) decision analyst. A core challenge will be to adapt these techniques to interactive ~~Internet~~ Web 2.0 form not requiring such professional assistance. Given the likely range of possible users of such help, we propose (Section 3) a hierarchy of options, ranging from straightforward advice-giving (Level 1) to full-scale decision analysis (Level 3), either self-driven (Level 3a) or chauffeur-assisted (Level 3b).

FOOTNOTES

1 An anonymous reviewer points out that this decision rule, maximizing individual self-interest, parallels that used by the CDC in forming its vaccination recommendations. Such a rule may not maximize overall population utility [40]. For example the personal utility of influenza vaccination is lower for young people than for the elderly, but the former are mainly responsible for transmission while the latter are most at risk. This divergence between individual and collective rationality raises important public policy issues too complex to be explored here. We point out only that the decision model sketched here and in Section 3, while focused on individually rational choice, does not constrain us to consider only narrow self-interest in evaluating possible decision outcomes. Positive payoffs to others in the form of a contribution to herd immunity might well be one element in the individual's evaluation of outcomes resulting from vaccination, an element that might be promoted in advertising campaigns and included in the individual utility assessment procedure, as suggested earlier. It is not clear how large an impact such rational altruism might have in moving from a Nash equilibrium towards overall utilitarian optimum. Alternatively, as the reviewer also points out, the approach we are presenting here might be appropriate only in cases where herd immunity is largely irrelevant.

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Figure 1: Simplified decision tree for a hypothetical vaccination decision