



## Parental intentions to enroll children in a voluntary expanded newborn screening program



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### ARTICLE INFO

#### Article history:

Received 25 February 2016

Received in revised form

16 July 2016

Accepted 26 July 2016

Available online 29 July 2016

#### Keywords:

United States

Expanded newborn screening

Informed decision

Reasoned action

Intentions

Theory of planned behavior

### ABSTRACT

**Background and objectives:** Nearly all babies in the United States are tested at birth for rare, serious, and treatable disorders through mandatory state newborn screening (NBS). Recently, there have been calls for an expanded, voluntary model to facilitate early diagnosis and treatment of a wider range of disorders. We applied the reasoned action framework to examine parental intentions to participate in voluntary expanded screening.

**Methods:** We recruited a national cohort of recent and expectant parents living in the U.S. who completed a self-administered online survey ( $N = 1001$ ). Using a mixed-level fractional factorial experiment, we studied parental participation intentions and preferences for timing of consent, cost, consent format, and testing options.

**Results:** We conducted a hierarchical regression analysis assessing parental intentions to participate in voluntary expanded NBS. Attitudes, perceived normative influence, and perceived behavioral control explained substantial variance in intention, with perceived normative influence emerging as the strongest predictor. We found no evidence that the manipulated program features altered mean levels of intention, but timing of parental permission, cost, and permission format moderated the relative importance of reasoned action constructs on intention.

**Conclusion:** Program design features may impact the psychological mechanisms underlying parental decision making for voluntary expanded screening. These results have important implications for parent education, outreach, and informed parental permission procedures.

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Nationwide endorsement of a standardized uniform newborn screening (NBS) panel has been called one of the great public health achievements of the first decade of the 21st Century, has saved the lives of thousands of children, and improved the quality of life of thousands of others (Centers for Disease Control and Prevention, 2011). NBS in the U.S. began more than 50 years ago, when screening was first offered using a heel stick blood test for phenylketonuria (Ross, 2010). In the ensuing years, NBS in the U.S. has grown into a mature public health program. The early decades of screening were characterized by considerable variability among states in the number and types of conditions included on NBS

panels (Watson et al., 2006). To promote greater harmonization, the Department of Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) provides national guidance on candidate conditions for newborn screening. The ACHDNC conducts a rigorous evidence-based review of nominated conditions, applying four primary considerations: (1) the condition represents a significant public health problem, (2) a low-cost and accurate screening test is available to detect it, (3) treatments with proven efficacy exist, and (4) states are capable of implementing screening and follow-up. The ACHDNC then makes a recommendation to the Secretary of Health and Human Services who determines whether the condition should be added to the Recommended Uniform Screening Panel (RUSP; Kemper et al., 2014). There are now 32 conditions on the RUSP, and all states offer screening for at least 29 disorders.

Historically, conditions placed on the RUSP have required urgent

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medical intervention, the benefits of which include dramatic improvements in quality of life and life expectancy. With this in mind, state NBS programs are generally mandatory; that is, many are conducted without formal requirements for informed parental permission and with limited options for parents to request an exemption. The moral justification for mandatory NBS largely rests in the promise of these public-health programs to protect child welfare and avert preventable harm (Goldenberg and Sharp, 2012).

Despite the success of NBS as a public health program, an alternative model has been suggested to enhance the potential for early diagnosis and treatment of a wider range of disorders, whereby screening for some conditions would remain mandatory while for others it would be voluntary. That is to say, parents would be free to choose whether or not to have screening for the expanded set of disorders, and this screening would only be done with informed parental permission. Underscoring the need for an expanded, voluntary screening option to augment regular NBS are four factors that have the potential to reintroduce state-by-state screening variability, burden state public health infrastructures, and increase inequities: (1) the slow, condition-by-condition ACHDNC review process in an era of rapid discovery and treatment potential; (2) frustration by patient advocates, who view the bar for evidence as too high; (3) the rapid emergence of commercial options for screening; and (4) new technologies, such as whole genome sequencing that, if adopted for regular NBS, would open the possibility of detecting many conditions that do not currently meet RUSP criteria (Bailey and Gehtland, 2015).

Although the idea of a voluntary expanded screening program to augment current NBS has been suggested before (Grosse et al., 2006; American Academy of Pediatrics, 2000; President's Council on Bioethics, 2008; Ross, 2010) the social and ethical challenges inherent in implementing state-level public education and establishing a process for informed parental permission remain formidable barriers (Bailey et al., 2008). Voluntary expanded screening will require fundamental infrastructure changes to support testing, counseling, education, parental decision making, and follow-up (Dhondt, 2010). Parents tend to support optional population-based screening for conditions not currently part of the RUSP (Bailey et al., 2012; Cyrus et al., 2012; Rothwell et al., 2013; Wood et al., 2014) but theory-driven analyses examining parental intentions to use voluntary NBS are needed to guide program design and to develop educational tools supporting informed decision making.

Here we report an experimental study of recent and expectant parents to determine reactions to a hypothetical voluntary expanded screening program, described as a combined state-level public health and research initiative to test infants for several health conditions not currently part of the RUSP. Such research is vital because the success of expanded NBS depends on the ability of program administrators to build awareness and ensure that parents are given the tools to make informed choices about enrolling their children. To begin addressing the many communication challenges facing a voluntary expanded NBS program, we applied the reasoned action framework to examine the psychosocial mechanisms underlying parental willingness and intentions to have a child participate in expanded NBS.

## 1. The reasoned action framework

The *reasoned action framework* is a cumulative model of behavior prediction that subsumes the theory of reasoned action (Fishbein and Ajzen, 1975), the theory of planned behavior (Ajzen, 1985), and the integrative model of behavioral prediction (Fishbein et al., 2001). Like its precursors, the framework postulates that behavioral intention—the subjective likelihood of performing a

given behavior—is the most important and immediate predictor of whether people will engage in a behavior (Fishbein and Ajzen, 2010). In turn, behavioral intention arises from the attitudes, perceived normative influence, and perceived behavioral control a person holds with regard to the behavior in question. Generally, the framework suggests that people with more favorable attitudes, more intense perceptions of approval from others, and a greater sense of control over a behavior will have stronger behavioral intentions, and thus be more likely to perform the behavior (Fishbein et al., 2003). Past meta-analyses have shown that on average the framework accounts for between 39 and 50% of the variance in intention and 19–36% of the variance in behavior (Armitage and Conner, 2001; McEachan et al., 2011; Sutton, 1998). A recent meta-analysis of 33 studies that applied the reasoned action framework to screening behaviors (but not newborn screening, specifically) found that overall attitudes had large associations with intention, norms and perceived behavioral control had medium-sized associations with intention, and intention had medium-sized associations with behavior (Cooke and French, 2008).

Although each of the reasoned action constructs independently influences intention, the relative strength of their association is partially determined by the specific behavior under consideration, characteristics of the population, or temporary contextual factors. Understanding how these factors moderate the relative importance of the direct antecedents of intention (i.e., attitudes, perceived normative influence, and perceived behavioral control) is useful for anticipating and empirically validating the idiosyncrasies of the population and behavior of interest. One such contextual factor relates directly to the way a behavior is defined in the framework. According to the principle of correspondence, all variables should define the behavior in terms of the same action, target, context, and time (Fishbein, 2008). Even seemingly trivial changes on one or more of these dimensions may fundamentally alter the behavior being examined, and can lead to observable differences within a population in the relative importance of the direct antecedents of intention. From an applied perspective, evidence that program features moderate the psychological pathways underlying parental interest in participating in voluntary expanded screening would have important implications for program design and delivery. For example, education and outreach efforts aimed at promoting informed parental permission for a program with one set of features may require a different communication strategy than would be needed for a program with a different set of features. With this in mind, we set out to answer two research questions:

RQ1: What is the relative importance of attitude, perceived normative influence, and perceived behavioral control as factors associated with parental intentions to participate in an expanded screening program for infants?

RQ2: How do selected variations in screening program features alter the relative importance of attitude, perceived normative influence and perceived behavioral control as factors associated with parental intentions to participate in an expanded screening program for infants?

## 2. Method

### 2.1. Participants

We worked with a survey-sampling firm, Research Now, to recruit a nonprobability-based national cohort of participants. All participants were adults living in the U.S. aged 18 years or older. Our target population was currently expectant parents or parents of young children ages three years or less. Women who self-identified

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