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The subjective value of a life with Down syndrome: Evidence from amniocentesis decision

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Abstract

Using a simple theoretical decision model and an original database, we were able to elicit the distribution of the utility value of having a child with Down syndrome for a large sample of French pregnant women ($n = 28,341$) between 2003 and 2007. We found that, on a scale where the value of a fetal death is 0 and the value of a healthy child is 1, the mean value for a child with Down syndrome is about -0.6. Assuming that the policymaker used the same decision model as the women, we infer from the French amniocentesis reimbursement regulation an implicit social value for a child with Down syndrome of -2.5. We conclude from our study that the policymaker is more likely to prevent the birth of children with Down syndrome than French women themselves.

Keywords: Amniocentesis choices; Expected utility framework

JEL classification: C010, I10

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1 Introduction

Among the French population, the average risk of carrying a fetus with Down syndrome is about one in 700 (Seror, 2008). Amniocentesis provides an extremely reliable prenatal diagnosis.[1] However, it may involve a non-negligible risk of miscarriage (about 1%, see Alfirevic et al. 2009; Tabor et al. 1986) and has a significant monetary cost (approximately 500 Euros, see the French Health Authority survey, 2007). A preliminary screening test exists in the form of a blood sample that provides women with an estimation of their individual risk to give birth to a child with Down syndrome. About 80–90% of pregnant women have this preliminary test, which is very cheap and carries no risk. Therefore, a pregnant woman has to decide whether or not to have an amniocentesis test, being aware of the risk of giving birth to a child with Down syndrome. Under standard individual preferences, the choice will ultimately depend on the utility costs and benefits of the available options, i.e. the monetary costs associated with the amniocentesis procedure, the utility values of giving birth to a child with, or without, Down syndrome and the utility value of miscarriage. The policymaker may influence women's decisions by appropriately fixing the level of the amniocentesis reimbursement policy, thereby increasing or decreasing the individual costs associated with amniocentesis. Under standard welfare criteria, the socially optimal level of reimbursement should, in turn, depend on the social utility values of the different possible outcomes, and in particular, on the relative social utility value of the birth of a child with Down syndrome and the occurrence of miscarriage.

In this paper, we investigate the possibility of performing some "reverse engineering", so as to deduce individual values from women's revealed by their actual choices, and social values revealed by the amniocentesis reimbursement policy. For this purpose, we take advantage of an original database which provides information on age, risk and amniocentesis choices of pregnant women who had the screening test in French maternity hospitals between 2003 and 2007. Using a simple decision model based on the assumption that women behave as expected utility maximizers, the distribution of the utility of having a child with Down syndrome can be inferred from actual women's decisions observed in the database. Our results show that, on a scale where the utility value of a fetal death is 0 and the utility value of a healthy child is 1, the mean utility value of giving birth to a child with Down syndrome is about −0.6. On the other hand, according to the French legislation of that same period, amniocentesis was fully reimbursed for pregnant women aged 38 or above (up to the year 2009) and for women facing an individual risk of giving birth to a child with Down syndrome which is higher than 1/250. Thus, under a similar decision model, we infer the policymaker utility value of the birth of a child with Down syndrome of −2.5. Indeed, the social utility value of the birth of a child with Down syndrome is much lower than the average mean of women on our database. This difference might have two non-exclusive explanations. First, the case might be that women do not internalize all social costs involved in educating and taking care of these children. Secondly, it may be that the individual affective, organizational and monetary constraints, involved in having a child with Down syndrome, are overestimated by the social planner.

This paper is organized as follows: Section 2 describes the main features of the amniocentesis decision and the database. Section 3 presents a simple theoretical model of amniocentesis decision, on which the rest of the paper will be based. Section 4 discusses the empirical strategy. Section 5 contains our

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[1] Amniocentesis consists in collecting a sample of the amniotic fluid from a pregnant woman's abdomen for analysis.

empirical results. Finally, we further discuss the scope and limitations of our approach in the concluding section.

2 Institutional framework and Data

In France, prenatal diagnosis has been regulated since 1997. The detection rate is estimated at approximately 73% (Muller et al., 2002). The false-positive rate, estimated at 7%, corresponds to the percentage of women advised to have amniocentesis, but who do not have a child with Down syndrome. Amniocentesis was unnecessary in the above case and could have caused the miscarriage of a healthy fetus. The preliminary screening method calculates a Down syndrome risk for each pregnancy. The risk computation is based on the mother's age and two maternal serum markers – beta-human chorionic gonadotropin (β-hCG) and alpha-fetoprotein (AFP). In accordance with French regulations, written consent is required from all women who take the screening test. The resulting risk is communicated to each woman. If amniocentesis is performed, a second written consent is required for fetal karyotype. In this document, the risk of amniocentesis-related miscarriage is estimated at 1%. Women then decide whether or not to undergo amniocentesis. Lastly, if the fetus has Down syndrome, the mother decides whether to continue or to terminate her pregnancy. About 95% of women in this case decide to terminate their pregnancy. Thus amniocentesis gives women an accurate result for Down syndrome – whereas the result of the screening test is inaccurate. The screening test enables the computing of a probability of giving birth to a child with Down syndrome and, furthermore, carries no risk. The main drawback of the amniocentesis procedure, however, is that it is an invasive procedure that can cause complications (Garrouste et al., 2011).

Table 1: Descriptive statistics by risk levels.

	Low Risk ($< 1/250$)	High Risk ($\geq 1/250$)	Total
Amniocentesis (%)	3.2	62.8	10
Risk (%)	0.08	1.42	0.23
Fetuses with DS (%)	0.05	1.06	0.17
Age$\geq$38 (%)	4.5	27.4	7
Maternal age (years)	30	34.5	30.5
Maternal weight(kg)	64.8	65.4	64.9
Smoking (%)	10.5	9.7	10.4
European origin (%)	59.3	62.5	59.6
Maternal pathology (%)	1.46	4.79	1.84
Number of obs.	25,148	3,193	28,341

Our database contains a sample of 28,341 women who took the screening test between the 14th and the 18th week of pregnancy in French maternity hospitals, located mainly in Paris, between 2003 and 2007. There are 75 medical centers authorized to perform screening tests in France. These centers are

located mainly in Paris and the Paris area, with a few smaller centers outside. In our database, women aged 38 or above were not representative of the set of pregnant women aged 38 or more in France, owing to the fact that some of them had accepted amniocentesis directly without a screening test.[2] In addition, women who were reluctant to undertake any action are not included in the database because they refused to do the screening test.

Table 2: Descriptive Statistics – Miscarriages.

| | Amniocentesis | | |
Miscarriage	0	1	Total
0	25,416	2,788	28,204
	99.58%	98.94%	99.52%
1	107	30	137
	0.42%	**1.06%**	**0.48%**
Total	25,523	2,818	28,341
	100%	100%	100%

Note: Bold values mean that 0.42% of women who did not have the amniocentesis test had a miscarriage, in comparison with 1.06% of the women who had the test (0.48% had a miscarriage in the all sample).

For each woman, our database includes age, some characteristics such as weight and pathology at the time of the screening test, smoking habits and geographic origins. It also includes individual risk, amniocentesis choice and post-amniocentesis outcomes. Table 1 presents descriptive statistics and enables the comparison between the low risk and the high risk group. Approximately 10% of women in our sample opted for amniocentesis. Their average age was around 30. The average women's weight was 65 kg. Approximately 10% of our sample smoked and 60% were European. Most of the women (88.7%) were in the low risk group. Approximately 3,2% of the pregnant women in the low-risk group decided to have amniocentesis, against 62,8% in the high-risk group. Women in the low-risk group are younger (30 versus 34,5 on average) owing to the fact that the risk of Down syndrome increases with age (see the French Health Authority survey, 2007). Overall, 0.17% of women were carrying a fetus with Down syndrome. The rate was around 1.06% in the high risk group and 0.05% in the low risk group. Thus, approximately 72% of fetuses with Down syndrome were in the high risk group[3] and 28% in the low risk group. This corresponds to the false-negative rate, i.e. about 30% of fetuses with Down syndrome were not detected by the screening strategy (with a risk of less than 1/250. Table 2 shows that 1.06% of the women who had the amniocentesis test had a miscarriage, in comparison with 0.42% of women who did not have the test.

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[2]The *Enquête Nationale Perinatale* survey conducted by the French Ministry of Health in 2003 found that approximately 2.3% of pregnant French women opt for amniocentesis without taking a screening test (Blondel et al., 2005).

[3]The proportion of fetuses with Down syndrome in the high risk group is calculated as: $(1.06 \times 3,193)/(0.05 \times 25,148 + 1.06 \times 3,193) \simeq 0.72$.
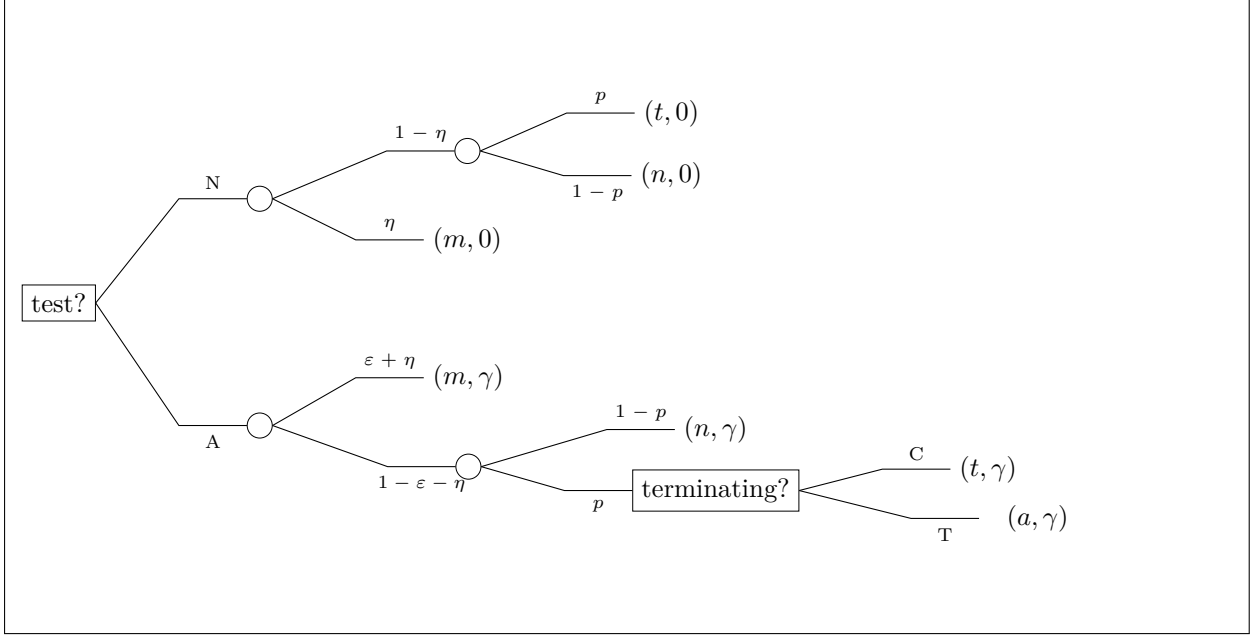
Figure 1: Decision tree for pregnant women

3 A simple model

3.1 The decision problem

The choice of a pregnant woman to have an amniocentesis test or not is illustrated in the decision tree in Figure 1. If she decides not to go for the test (option N), she will face the given probability η of miscarriage (denoted m). If miscarriage does not occur, she will have the probability p of giving birth to a child with Down syndrome (denoted t), and a probability $(1-p)$ to give birth to a healthy child (denoted n). Conversely, if she decides to have an amniocentesis test (option A), she will face the additional risk ε of miscarriage (and thus a total risk $\varepsilon + \eta$ of miscarriage). If miscarriage does not occur, she will know whether the foetus has from Down syndrome (probability p), and has to decide whether to continue her pregnancy (C) or to terminate it (T) and abort (denoted a). Finally, amniocentesis entails a monetary cost γ paid by the pregnant woman.[4] Thus, the possible outcomes of the women's choices can be described by a couple (x, γ), where $x \in X = \{n, d, a, m\}$ stands for the outcome of the pregnancy and $\gamma \in \mathbb{R}$ represents the monetary cost of the amniocentesis paid by the patient ($\gamma = 0$ if the woman does not undertake an amniocentesis test).

Assuming reduction of compound lotteries, the problem can be resumed by choosing among the lotteries generated by the three possible actions: not taking the test (N), taking the test and aborting in case of a positive result (A, T), taking the test and continuing the pregnancy whatever the result of the test is (A, C).

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[4]Amniocentesis is also likely to entail non monetary costs, e.g. anxiety, stress, which have not take into account in our analysis.

N ○
(1−η)(1−p) — (n, 0)
(1 − η)p — (d, 0)
0 — (a, 0)
η — (m, 0)

(A,T) ○
(1 − ε − η)(1 − p) — (n, γ)
0 — (d, γ)
(1 − ε − η)p — (a, γ)
ε + η — (m, γ)

(A,C) ○
(1 − ε − η)(1 − p) — (n, γ)
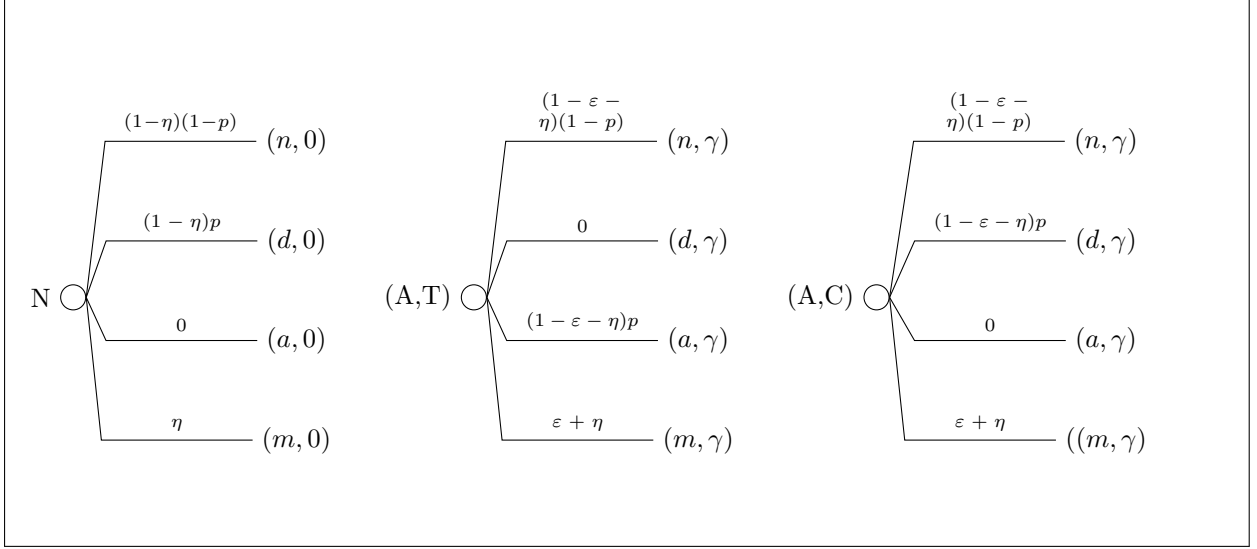(1 − ε − η)p — (d, γ)
0 — (a, γ)
ε + η — ((m, γ)

Figure 2: Available options

3.2 Decision model

We assume that pregnant women are expected utility maximizers. This implies that, for each woman, there exists a unique (up to an increasing transformation) utility function U on $X \times \mathbb{R}$ such that a prospect ℓ that delivers consequence (x_i, γ_i) with probability π_i ($i = 1, \ldots, n$) is evaluated by $U(\ell) = \sum_{i=1}^{n} \pi_i U(x_i, \gamma_i)$.

In order to empirically identify the decision model outlined above, we make some assumptions on women utility functions. First, we will assume that these utilities are quasi-linear with respect to the cost of the amniocentesis: $U(x, \gamma) = u(x) - \gamma$.

We also assume that having a healthy child without going through amniocentesis is always the best consequence. Furthermore, although women might experience different utilities in case of abortion versus miscarriage (the burden of responsibility may induce regret in the case of miscarriage due to amniocentesis, whereas terminating pregnancy also induces psychological stress), we nevertheless assume that these two consequences deliver the same utility. Therefore, we assume $u(m) = u(a)$. Note that these assumptions imply, in particular, that (A, C) can never be chosen, theoretically, due to the fact that choosing (A, C) against N amounts to exchanging a decrease in the probability of having a child with Down syndrome for an increase in the probability of miscarriage. This implies that the pregnant woman prefers miscarriage to having a child with Down syndrome, i.e, $u(m) > u(t)$. On the other hand, choosing (A, C) against (A, T) implies that the woman prefers having a child with Down syndrome rather than aborting, i.e., $u(t) > u(a)$. Such preferences are not consistent with the decision to go through amniocentesis, since choosing (A, C) implies $u(m) > u(t) > u(a)$. Our data are consistent with this result, as only 5% of the women in our database (2 subjects) chose (A, C).[5] Finally, without loss of generality (U is defined up to an increasing affine transformation), we will assume $u(n) = 1$ and $u(a) = 0$. These assumptions are

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[5]Note that this reasoning strongly depends on the fact that the amniocentesis only aims at detecting Down syndrome. The amniocentesis could be used to detect another illness which, if discovered, would lead to pregnancy termination. However, amniocentesis is mainly proposed to women to detect Down syndrome (Wald et al., 1997). Thus, we have excluded this quite exceptional case from our analysis.

summarized below.

Assumption 1. *Women are expected utility maximizers with quasi-linear utility functions* $U(x, \gamma) = u(x) - \gamma$. *Moreover,*

$$1 = u(n) > u(m) = u(a) = 0 > u(t).$$

We denote by θ the subjective value of a child with Down syndrome.

3.3 Optimal decisions

The parameter θ is the key parameter in our model. The decision of woman i depends on a set of parameters describing the probabilities she is facing (ε_i, η_i, p_i), the monetary cost of the amniocentesis (γ_i), and the subjective utility of having a child with Down syndrome (θ_i). All parameters except θ_i are taken as objective data (see section 4 below). Given these objective parameters, the pregnant woman opts for amniocentesis if and only if:

$$U(A, T) > U(N)$$
$$\Leftrightarrow \quad (1 - \varepsilon_i - \eta_i)(1 - p_i) - \gamma_i \geq (1 - \eta_i)(1 - p_i) + (1 - \eta_i)p_i\theta_i$$
$$\Leftrightarrow \quad \theta_i \leq -\frac{\epsilon_i(1 - p_i) + \gamma_i}{(1 - \eta_i)p_i}$$

We can therefore define the threshold $\underline{\lambda_i}$ below which a pregnant woman will undertake an amniocentesis:

$$\underline{\lambda_i} = -\frac{\epsilon_i(1 - p_i) + \gamma_i}{(1 - \eta_i)p_i} \tag{1}$$

Put differently, a woman decides to undertake amniocentesis if the subjective value she assigns to a child with Down syndrome is lower than the threshold value $\underline{\lambda_i}$, determined by objective risk measures and financial costs.

The threshold value depends in particular on the monetary cost which the woman may have to pay. This cost depends on whether or not amniocentesis is covered by health insurance. Social insurance reimburses the cost in two cases: either the woman is aged 38 or older, or her individual probability of having an affected foetus is estimated to be above $1/250$. Let us denote by C_i the dummy variable indicating whether the woman is eligible for reimbursement or not. The individual cost for an amniocentesis is equal to $C_i\gamma_i$, where γ_i is the utility of the actual cost. We do not have information about the exact cost charged to each woman. While there might be some variations, the average price is 500 Euros. The French Health Authority (*Haute Autorité de la Santé (HAS)* 2007) shows that the procedure cost is around 70 Euros, plus the cost of the establishment of the fetal karyotype (350 Euros), totaling 420 Euros. This is a minimum cost, since the physician may establish a higher price. For non-eligible women, personal health insurance may provide some reimbursement, but cannot cover more than 25% of the total cost, which varies between 420 and more than 850 Euros, meaning that women have to pay around 500 Euros on average if they are not reimbursed by the Health system. We assume that this monetary cost is the same for each woman.

Comparative statics are straightforward. We obtain that:

$$
\begin{aligned}
\frac{\partial \underline{\lambda_i}}{\partial \varepsilon_i} &= -\frac{(1-p_i)}{(1-\eta_i)p_i} < 0 \\
\frac{\partial \underline{\lambda_i}}{\partial \eta_i} &= -\frac{\epsilon_i(1-p_i) + \gamma C_i}{(1-\eta_i)^2 p_i} < 0 \\
\frac{\partial \underline{\lambda_i}}{\partial p_i} &= \frac{\varepsilon + C_i \gamma}{(1-\eta_i)p_i{}^2} > 0 \\
\frac{\partial \underline{\lambda_i}}{\partial \gamma} &= -\frac{C_i}{(1-\eta_i)p_i} \leq 0
\end{aligned}
$$

The threshold value $\underline{\lambda_i}$ decreases with ε_i and η_i, increases with p_i, and decreases with γ when costs are not covered by social insurance. Not surprisingly, a woman is less likely to have amniocentesis when ε_i, the risk of miscarriage induced by the test, increases. Similarly, when the overall risk of miscarriage η_i increases, this also decreases the likelihood of the test. When the probability p_i that the child may suffer from Down syndrome increases, amniocentesis is more likely. Finally, when the procedure is more costly, amniocentesis is less likely.

The threshold value may also be rewritten as: $\underline{\lambda_i} = -\frac{\epsilon_i(1-p_i)}{(1-\eta_i)p_i} - \frac{C_i \gamma}{(1-\eta_i)p_i}$. If we denote by $\underline{\theta}_i = -\frac{\epsilon_i(1-p_i)}{(1-\eta_i)p_i}$ the value of the threshold under no monetary cost, we obtain a simple analysis of the decision rule to undertake amniocentesis or not.

Figure 3 shows the pairs (γ, θ) for which a woman has an amniocentesis ($A = 1$) or not ($A = 0$). The x-axis represents the utility of having a child with Down syndrome whereas the y-axis represents the monetary costs of the amniocentesis procedure. When these costs are covered by social insurance ($C = 0$, left), the decision amounts to $\theta \geq \underline{\theta}$. When they are not covered ($C = 1$, right), the decision is based on a trade off between this threshold $\underline{\theta}$ and the monetary cost.

4 The empirical strategy

Our main objective is to provide estimates of the individual utilities θ_i of having a child with Down syndrome, which will be done in two steps. First, according to our theoretical model, we will provide estimates for the individual threshold $\underline{\lambda_i}$ under which a women who behaves as in the model undertakes an amniocentesis. Then, observing each woman's actual decision, we will infer the values of θ_i using a probit model. We describe these two steps below.

4.1 Estimation of the threshold

As shown in Equation (1), $\underline{\lambda_i}$ depends on four parameters: the probability p_i of having a child with Down syndrome, the probability η_i of miscarriage when no amniocentesis is undertaken, the probability ϵ_i of miscarriage entailed by the amniocentesis, and finally the monetary cost γ paid by the pregnant woman in case of amniocentesis.

The individual risk p_i is precisely the individual risk of Down syndrome computed from the mother's age and maternal serum marker which is available in the database. While this computed risk is only an
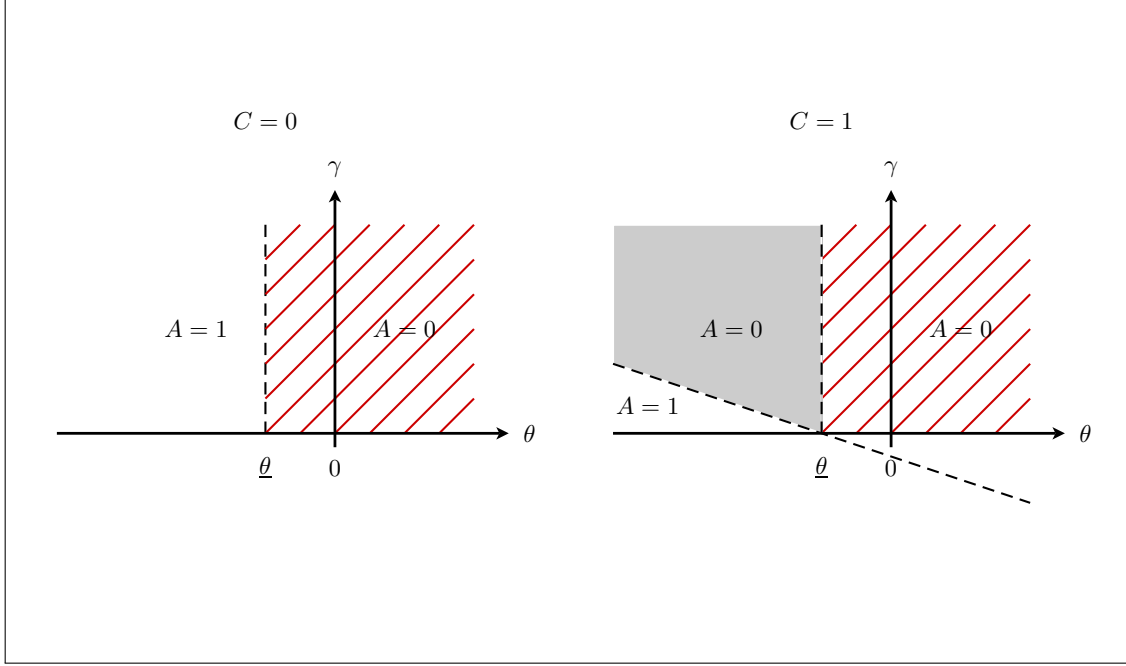
Figure 3: Couples (θ, γ).

approximation of the actual risk, this data is available to women on taking their decision. It is thus the relevant measure of individual risk.

The natural rate of miscarriage η_i can be approximated by the miscarriage rate of the women in the database who have not undertaken an amniocentesis test ($\eta_i = \eta = 0.004$ for all women, see Table 2).

The additional risk of miscarriage in case of amniocentesis is directly provided to the women in a document they have to sign before having an amniocentesis.[6] While the true probability may depend on each woman's characteristics, this document actually provides the same value to all women ($\varepsilon = 1/100$). It is reasonable to assume that this is precisely the value that women use when deciding whether or not to have amniocentesis, therefore we assume $\varepsilon_i = \varepsilon$ for all women.

4.2 Estimation of $\widehat{\theta}_i$

The subjective utility θ_i of having a child with Down syndrome depends on some observed individual characteristics like maternal age, maternal smoking, maternal weight, maternal pathology, maternity center and geographic origin. We denote this set of K variables as $X_i \in R^K$. But θ_i may also depend on other elements like moral values, family structure, income, education, etc. which are unknown to us, and are presumably heterogenous. We assume that θ_i is distributed according to:

$$\theta_i = X_i \beta + \nu_i$$
$$\nu_i \sim N(0, \sigma^2)$$

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[6]The supplementary risk of miscarriage due to amniocentesis is approximatively 0.64% in our database (see Table 2).

We denote by A_i the binary variable indicating whether patient i has opted for amniocentesis or not, which is the case if and only if $\theta_i \leq \underline{\lambda_i}$. This leads to the simple probit model:

$$P(A_i = 1|X_i) = P(\theta_i \leq \underline{\lambda_i}|X_i)) = P\left(\theta_i - \underline{\theta_i} + \frac{C_i}{p_i(1-\eta)}\gamma \leq 0 | X_i\right)$$

with $\underline{\lambda_i} = \underline{\theta_i} - \frac{C_i \gamma}{p_i(1-\eta)}$, moreover $\theta_i = X_i\beta + \nu_i$, straightforward algebra show that:

$$\theta_i \leq \underline{\lambda_i} \Leftrightarrow \frac{\nu_i}{\sigma} \leq \frac{\underline{\theta_i}}{\sigma} - \frac{C_i}{p_i(1-\eta)}\frac{\gamma}{\sigma} - \frac{X_i\beta}{\sigma}.$$

Under the assumption that $\nu_i \sim N(0, \sigma^2)$, we obtain that:

$$P(A_i = 1|X_i) = \Phi\left(\frac{\underline{\theta_i}}{\sigma} - \frac{C_i}{p_i(1-\eta)}\frac{\gamma}{\sigma} - \frac{X_i\beta}{\sigma}\right),$$

where Φ is the c.d.f. of the standard gaussian distribution.

The model is estimated by maximum likelihood, and the likelihood is given by[7]:

$$
\begin{aligned}
L(A|X) &= \prod_{i=1}^{N} P(A_i = 1|X_i)^{A_i} P(A_i = 0|X_i)^{1-A_i} \\
&= \prod_{i=1}^{N} \Phi\left(\frac{\underline{\theta_i}}{\sigma} - \frac{C_i}{p_i(1-\eta)}\frac{\gamma}{\sigma} - \frac{X_i\beta}{\sigma}\right)^{A_i} \left[1 - \Phi\left(\frac{\underline{\theta_i}}{\sigma} - \frac{C_i}{p_i(1-\eta)}\frac{\gamma}{\sigma} - \frac{X_i\beta}{\sigma}\right)\right]^{1-A_i}
\end{aligned}
$$

5 Results

The aim of the probit model is to estimate the real θ to obtain women's preferences relative to the birth of a child with Down syndrome. The probit estimation (Table 3) shows that the following factors are associated with a higher probability of having an amniocentesis: $\underline{\theta}$, European origin, smoking and the presence of a maternal disease at the time of the screening test, whereas having to pay for the procedure and maternal weight are associated with a lower probability of having an amniocentesis. A maternity center fixed effect is also included in our model.[8] Maternal age has a non linear effect on the probability of having an amniocentesis: it increases up to age 30 or 28 (without or with center fixed effect respectively).[9] In fact, increasing age increases both the risk of miscarriage and the risk of Down syndrome, but it also reduces the likelihood to have another pregnancy in case of miscarriage or an abortion (Fajnzylber et al., 2010), increasing the overall cost of amniocentesis.

Eligibility for reimbursement appears to have a strong influence on the decision (see regressions in Tables 3 and 4). This finding is consistent with previous studies.[10] The way women solve the dilemma is strongly affected by the institution which determines eligibility for reimbursement of the prenatal diagnosis by the health care system. Having to pay for amniocentesis is linked to a decrease of about

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[7]It is standard to assume that $\sigma = 1$.

[8]The center fixed effect may capture the social condition of patients in the center, the policy of center, the influence of the medical team, etc. However, we do not have any information about the characteristics of the center.

[9]The probability is increasing with age (coefficient $a = 0.179$) but decreasing with age squared (coefficient $b = -0.003$), it shows a maximum at $-a/2b = 30$ (in the model without center fixed effect), and similarly in the model with center fixed effects.

[10]See Garrouste et al. (2011)

Table 3: Relationship between amniocentesis and women's characteristics (probit regression).

| Dep. variable	Amnio. coeffs (1)	Amnio. marginal effects (2)	Amnio. coeffs (3)	Amnio. marginal effects (4)
$\underline{\theta}$	0.012***	0.0014***	0.013***	0.0013***
	(0.0016)	(0.0002)	(0.0017)	(0.0002)
Copayment (C)	-2.026***	-0.4871***	-2.117***	-0.4943***
	(0.0419)	(0.0140)	(0.0436)	(0.0143)
Age	0.179***	0.0197***	0.168***	0.0166***
	(0.0302)	(0.0033)	(0.0308)	(0.0031)
$(\text{Age})^2$	-0.003***	-0.0004***	-0.003***	-0.0003***
	(0.0005)	(0.0001)	(0.0005)	(0.0000)
Weight	-0.005***	-0.0005***	-0.005***	-0.0005***
	(0.0013)	(0.0001)	(0.0014)	(0.0001)
European origin (vs African)	0.231***	0.0243***	0.251***	0.0237***
	(0.0567)	(0.0057)	(0.0584)	(0.0052)
Smoking habits	0.142***	0.0171***	0.154***	0.0169***
	(0.0483)	(0.0063)	(0.0493)	(0.0059)
Maternal pathology	0.369***	0.0532***	0.458***	0.0643***
	(0.0894)	(0.0163)	(0.0881)	(0.0165)
Center fixed effects	No	No	Yes	Yes
Observations	19,592	19,592	19,592	19,592

Note: robust standard errors in parentheses. * Significant at the 10% confidence level; ** at the 5% confidence level; *** at the 1% confidence level. Regressions are conducted for $\underline{\theta} > -60$.

Table 4: Relationship between amniocentesis and women's characteristics (probit regression).

Dep. variables	(1) Amnio.	(2) Amnio.	(3) Amnio.	(4) Amnio.	(5) Amnio.	(6) Amnio.
$\underline{\theta}$	0.0062***	0.0060***	0.0014***	0.0013***	0.0008**	0.0008**
	(0.0001)	(0.0001)	(0.0002)	(0.0002)	(0.0003)	(0.0003)
C			-0.4871***	-0.4943***		
			(0.0140)	(0.0143)		
$\frac{C}{p(1-\eta)}$					-0.0001***	-0.0001***
					(0.0000)	(0.0000)
Controls	Yes	Yes	Yes	Yes	Yes	Yes
Center fixed effects	No	Yes	No	Yes	No	Yes
Observations	19,592	19,592	19,592	19,592	19,592	19,592

Note: robust standard errors in parentheses. * Significant marginal effects at the 10% confidence level; ** at the 5% confidence level; *** at the 1% confidence level. Controls are age, $(\text{age})^2$, maternal weight, maternal pathology, geographic origin. Regressions are conducted for $\underline{\theta} > -60$.

Figure 4: Distribution of the threshold and the subjective value of giving birth to a child with Down syndrome.

(a) Distribution of the threshold ($\underline{\lambda_i}$) (b) Distribution of the subjective value ($\hat{\theta}_i$)
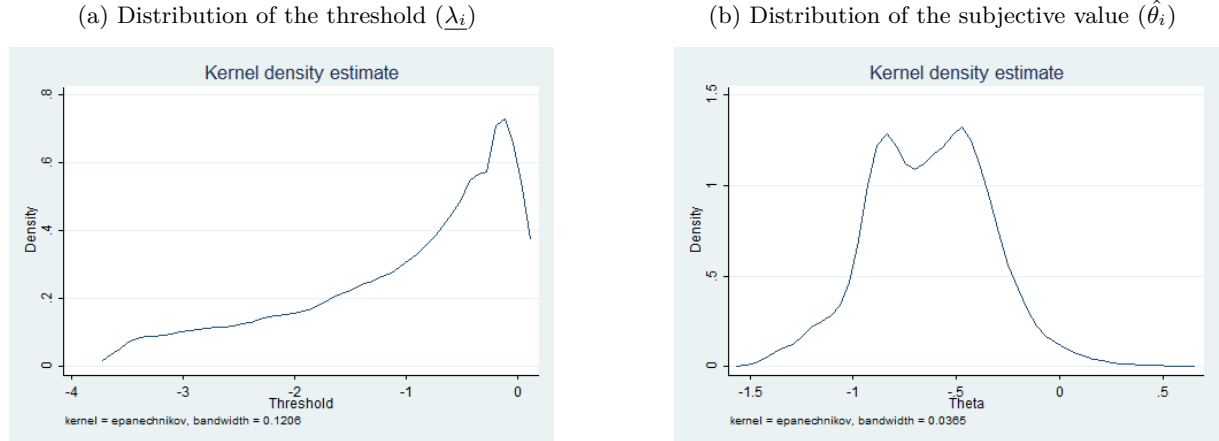
Note: The estimation of Figure 4b is done following specification (6). Controls are age, $(\text{age})^2$, maternal weight, maternal pathology, geographic origin and maternal centers. The estimations of Figure 4a and 4b are conducted for $\underline{\theta} > -60$.

50 percentage points in the probability of having an amniocentesis (see columns (2) and (4) of Table 3 and columns (3) and (4) of Table 4). We present the results obtained with specification (6).[11] The utility of amniocentesis cost corresponds to the coefficient of $\frac{C}{p(1-\eta)}$ in the probit regression (Table A1 in Appendix). The cost has a huge impact on the decision (see Table 5). The cost of amniocentesis decreases the threshold $\underline{\lambda_i}$ for a woman who has to pay for an amniocentesis, which implies that this woman has a lower probability of opting for an amniocentesis because she has to pay the cost. Mean value of the threshold is -0.2 among women who opt for amniocentesis, whereas mean value is -1.14 for women who do not have amniocentesis. In fact, women who do not have amniocentesis have a lower risk (the lower the risk is, the lower the threshold is) and in general, they have to pay the cost of amniocentesis (budget constraints limit the uptake of amniocentesis). In the same way, $\underline{\lambda_i}$ is lower for low-risk women than for those who are at high-risk of having a child with Down syndrome. The threshold increases for women who are more than 38 (in the low-risk group) since they are reimbursed by the health system (see Figure A1a in Appendix). The threshold is around 0 for women in the high-risk group (see Figure A1b in Appendix).

In this paper, the scale is 0 for a fetal death and 1 for a normal child. The distribution of $\widehat{\theta_i}$ is represented in Figure 4b. Mean value is -0.63 in the all sample. Table 5 shows that the mean of the subjective value of having a child with Down syndrome is equal to -0.65 in the low risk group (-0.4 for women aged 38 or above and -0.67 for women aged less than 38) and -0.52 in the high risk group. The mean value of $\widehat{\theta}$ for women who do not have amniocentesis, whereas they are in the high-risk group and are older than 38, is -0.4 (which is higher than the mean value of the whole population in our database). The mean value of $\widehat{\theta}$ is equal to 0.08 for women who are more than 45, and 0.2 for women who are older than 46 (only 20% of them decided to have amniocentesis). Conversely, the mean value for women who have an amniocentesis, whereas they have a low-risk of giving birth to a child with Down syndrome and

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[11]Specification (5) gives almost the same results.

Table 5: Estimations by risk levels

	Mean	Std. Dev.	Min	Max	Observations
All sample					
$\widehat{\theta}$	-0.63	0.29	-1.53	0.62	19592
$\gamma/(p_i(1-\eta))$	0.89	0.85	0	3.14	19592
$\underline{\lambda_i}$	-1.03	0.97	-3.61	-0.0003	19592
Low-risk ($< 1/250$)					
$\widehat{\theta}$	-0.65	0.28	-1.53	0.62	16751
$\gamma/(p_i(1-\eta))$	1.04	0.83	0	3.14	16751
$\underline{\lambda_i}$	-1.20	0.94	-3.61	-0.02	16751
High-risk ($\geq 1/250$)					
$\widehat{\theta}$	-0.52	0.31	-1.44	0.51	2841
$\gamma/(p_i(1-\eta))$	0	0	0	0	2841
$\underline{\lambda_i}$	-0.01	0.01	-0.02	0.00	2841

Note: These estimations are done following specification (6). Controls are age, $(age)^2$, maternal weight, maternal pathology, geographic origin and maternal centers. Regressions are conducted for $\underline{\theta} > -60$.

are less than 38, is -0.5.

The threshold value, which corresponds to a risk p=1/250, is $\underline{\theta} = -2.52$. Below this level, amniocentesis is proposed by the physician and reimbursed by the national health care.

6 Discussion and Conclusion

Given the issues at stake (giving birth to a child with a severe genetic pathology on the one hand, miscarriage on the other hand) and the financial costs involved, it is important to understand women's decisions concerning amniocentesis, and to design social policies in accordance.

Using a simple decision model and an original database, we were able to elicit the distribution of the utility value of having a child with Down syndrome for a large sample of French pregnant women (28,341) between 2003 and 2007. We found that, on a scale where the value of a fetal death is 0 and the value of a healthy child is 1, the mean value for a child with Down syndrome is about -0.6. Assuming that the policymaker used the same decision model as the women, we found that the French amniocentesis reimbursement legislation implies an implicit social value for a child with Down syndrome of -2.5. We thus deduce from our study that the policymaker is more likely to prevent the birth of children with Down syndrome than French women themselves. Two obvious reasons could explain this gap: first, pregnant women might underestimate the social costs involved by educating and taking care of these children; secondly, the social planner might overestimate the individual affective, organizational and monetary constraints of raising a child suffering from Down syndrome. While our data prevents differentiating between these two explanations, the size of the gap between the social value and the women's value suggests that it might be worthwhile carefully reconsidering the parameters of public policies concerning

amniocentesis.

Our approach is based on actual choices, along the lines of the "revealed preferences" paradigm. We use information from women's actual decisions as regards amniocentesis, rather than basing our information on their statements about their preferences. This methodology stands in stark contrast with previous studies, as far as we know. To the best of our knowledge, all previous empirical studies on women's preferences in a context of prenatal diagnosis were carried out by asking women to make hypothetical choices. Utilities were then elicited through the standard gamble paradigm (Grobman et al., 2002; Kuppermann et al., 2004, 2000; Seror, 2008). For instance, in Seror (2008), women had to imagine they were four months pregnant and to make a fictitious decision about the prenatal diagnosis of Down syndrome (Seror, 2008).[12] In a similar vein, Grobman et al. (2002) interviewed 186 pregnant women at a university hospital in Chicago, while Kuppermann et al. (2004, 2000) conducted a study of 584 pregnant women aged 16–47 years old from 23 San Francisco Bay Area practices. While certainly useful, the use of questionnaires raises some important issues. If the questionnaire is performed *a posteriori*, women's actual history is likely to influence their answers. For instance, a woman who experienced a fetal loss due to amniocentesis is likely to feel regrets, and thus to provide an answer substantially different from the one she would have given when the decision to have amniocentesis had to be made. In addition, Lamiraud and Geoffard (2007) points out the well-recognized limits of this approach. There is no clear incentive for the patients to reveal their true preferences, the type and degree of information provided former to the procedure may affect the answers. Furthermore, patients are likely to react differently when confronted with reality as opposed to fictitious choices.

This being said, it is tempting to compare our results to those obtained in the literature. The comparison with Grobman et al. (2002); Kuppermann et al. (2004, 2000) is impossible, as they use the death of the pregnant woman as the worst possible outcome, that we would never consider as possible. However, we can compare our results directly to those obtained by Seror (2008). This paper uses the birth of a child with Down syndrome as the worst outcome, with a utility 0, and the birth of a healthy child as the best outcome, with a utility 1.[13] In the case of the outcome of an amniocentesis-related miscarriage, the mean utility value obtained by Seror (2008) is 0.65. In order to compare this result to ours, we converted the value obtained by Seror (2008) to our scale. This is easy to do, and yields a utility for having a child with Down syndrome of -0.6, a value actually very close to the one we obtained (-0.63).[14]

While our methodology has a significant innovation with respect to previous studies, it must, nevertheless, be stressed that this innovation also has drawbacks. First, our findings depend on sample selection. Women in our database accept the screening process and, therefore, are prepared for a potential abortion if Down syndrome is detected. Thus our results can not be generalized for the whole population.

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[12]This study is based on face-to-face interviews of 78 women who have had previous pregnancy experiences and were 25–35 years old.

[13]Seror (2008) allows the worst and the best outcomes to be different for each woman, however all the women reported that the best outcome was the birth of a healthy child, and the worst outcome, for most women, was the birth of a child with Down syndrome.

[14]In order to compare Seror (2008)'s results to ours, denote by u_s the utilities on Seror (2008)'s scale (with $u_s(t) = 0$ and $u_s(n) = 1$), and v the very same utilities on the scale we used (i.e., with $v(m) = 0$ and $v(n) = 1$). We must have $v = \alpha u_s + \beta$, for some positive α and real number β. In particular, $v(m) = 0 = \alpha u_s(m) + \beta = 0.65 + \beta$ and $v(n) = 1 = \alpha u_s(n) + \beta = 1$. These two equalities yield $\alpha = 1.6$ and $\beta = -0.6$, from which we deduce $v(t) = 1.6 \times 0 - 0.6 = -0.6$.

However, the perceived value of a child with Down syndrome would be higher for women who did not have the screening process, thus we may have underestimated the perceived value of a child with Down syndrome.[15] Secondly, our database includes few variables relative to the women's characteristics or the relationship between women and physicians. It has been shown that several factors may weigh in the decision-making process of amniocentesis, such as the expertise and skill of the information the physicians give to women, the level of education, level of income, ethnicity, psychological factors, marital status, reproductive history and religious factors (Browner et al., 1999; Chilaka et al., 2001; Favre et al., 2007; Grobman et al., 2002; Julian-Reynier et al., 1994; Karni et al., 2014; O'Connor et al., 2009; Pryde et al., 1993; Seror and Ville, 2009). Other studies highlight the major role of parental anxiety (Marteau et al. 1992, Kobelka et al. 2009). Recently, Karni et al. (2014) emphasized that the risk of miscarriage depends on the expertise and skill of the physician who performs the amniocentesis. Karni et al. (2014) developed a questionnaire to offer a procedure helping physicians and patients in the process of making medical decisions, especially in the case of amniocentesis decision making, using an axiomatic model (Karni, 2009). Building more comprehensive databases, by collecting more data and combining actual choices and interviews therefore seems a promising approach for the future.

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[15]For women older than 38, our database is biased because in France these women may undergo amniocentesis without maternal serum screening. Therefore, the older women included in our database prefer maternal serum screening instead of having an amniocentesis directly. Furthermore, we may have underestimated the perceived value of a child with Down syndrome.

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Appendix

Table A1: Relationship between amniocentesis and women's characteristics (probit regression).

Dep. variables	(1) Amnio.	(2) Amnio.	(3) Amnio.	(4) Amnio.	(5) Amnio.	(6) Amnio.
$\underline{\theta}$	0.0526***	0.0547***	0.0124***	0.0132***	0.0073**	0.0078**
	(0.0029)	(0.0030)	(0.0016)	(0.0017)	(0.0031)	(0.0031)
C			-2.0265***	-2.1166***		
			(0.0419)	(0.0436)		
$\frac{C}{p(1-\eta)}$					-0.0005***	-0.0005***
					(0.0000)	(0.0000)
Controls	Yes	Yes	Yes	Yes	Yes	Yes
Center fixed effects	No	Yes	No	Yes	No	Yes
Observations	19,592	19,592	19,592	19,592	19,592	19,592

Note: robust standard errors in parentheses. * Significant coefficients at the 10% confidence level; ** at the 5% confidence level; *** at the 1% confidence level. Controls are age, $(\text{age})^2$, maternal weight, maternal pathology, geographic origin. Regressions are conducted for $\underline{\theta} > -60$.

Figure A1: Means of the threshold by age.

(a) Mean of $\underline{\lambda_i}$ by maternal age (low-risk group)
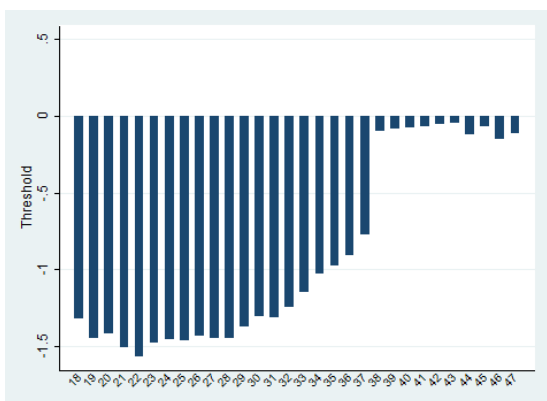
(b) Mean of $\underline{\lambda_i}$ by maternal age (high-risk group)