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Public hesitancy for AI-based detection of neurodegenerative diseases in France

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Recent advances in artificial intelligence (AI) have made it possible to detect neurodegenerative diseases (NDDs) earlier, potentially improving patient outcomes. However, AI-based detection tools remain underutilized. We studied individual valuation for early diagnosis tests for NDDs. We conducted a discrete choice experiment with a representative sample of the French adult population (*N* = 1017). Participants were asked to choose between early diagnosis tests that differed in terms of: (1) type of test (saliva vs. AI-based tests analysing electronic health records); (2) identity of the person communicating the test results; (3) sensitivity; (4) specificity; and (5) price. We calculated the weights in the decision for each attribute and examined how socio-demographic characteristics influenced them. Respondents revealed a reduced utility value when AI-based testing was involved (valuated at an average of €36.08, CI [€22.13; €50.89]) and when results were communicated by a private company (€95.15, CI [€82.01; €109.82]). We interpret these figures as the shadow price that the public attaches to medical data privacy. Beyond monetization, our representative sample of the French population appears reluctant to adopt AI-powered screening, particularly when performed on large sets of personal data. However, they would be more supportive when medical expertise is associated with the tests.

Neurodegenerative diseases (hereafter NDDs) are characterized by the progressive degeneration of the central nervous system's structure and function, causing physical and cognitive disability[1]. NDDs affect a large group of patients, encompassing various diseases that include Alzheimer's disease (AD), Parkinson's disease (PD), Huntington's disease (HD), and amyotrophic lateral sclerosis (ALS). AD and PD are the first and second most common NDDs worldwide[2]. The most evident risk factor for developing these conditions is aging[3], and with the increase in the average age of the population, the prevalence of NDDs is remarkably increasing, currently affecting approximately 15% of the worldwide population[4]. This increase combined with the lack of effective treatments[5], leads to an enormous burden on patients and their caregivers[6] as well as on healthcare systems, both in terms of direct and indirect costs[7–13]. One of the identified ways to improve patient outcomes and reduce the economic burden on healthcare systems and society is to diagnose NDDs earlier in a patient's lifetime[14–20]. It has been suggested that earlier detection (even if imperfect, with sensitivity and specificity < 100%) may help patients plan for their future, achieve a better quality of life, and access clinical trials and possible future disease-modifying treatments[21].

Due to recent advances in artificial intelligence (AI), significant help can come from computational approaches targeting diagnosis and monitoring[22–27]. AI-based early diagnosis tests, using genetic data, imaging data, and clinical data such as that obtained in primacy care practices, have the potential to change the way we diagnose and manage NDDs[28]. AI-based diagnosis aims to identify patients at risk of developing NDDs before the onset of symptoms and has the potential to change the way practitioners manage NDDs[18,29]. This would allow for earlier intervention, which can potentially improve outcomes for patients[30]. AI-based diagnosis can process large amounts of data quickly and accurately, reducing the need for expensive and time-consuming tests[31]. Furthermore, as telemedicine has been shown to improve access to care in AD and PD[32], AI-based diagnosis can also help address disparities in access to care and diagnosis by reducing the reliance on specialized expertise[33]. Even in the absence of highly effective treatment options, predictive tests for NDDs may be useful to help patients and families prepare for decisions that need to be made in the future, including advance care planning[34–37]. However, the success of these tests will first depend on the willingness of individuals to adopt and use them[38,39]. A recent paper showed that the general population is mainly distrustful of AI in medicine[40].

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In this context of underuse of early detection tools for NDDs[41], we aim to investigate the factors influencing individual valuation of AI-based prediction tools. The objective is to measure the feasibility of adopting the NDDs-AI test among the general population, based on a representative national sample potentially targeted by these tests. The rest of the paper presents the survey methods and provides results and discussion.

Methods

The choice task

We conducted a discrete choice experiment (DCE) using a sample of participants from the general French adult population. DCE is a survey method that allows researchers to investigate how people make choices by presenting them with hypothetical goods that vary in certain attributes[42,43]. In short, the attributes qualify the performance of the good – here, a predictive test – and respondents are constrained to trade performance in one attribute for performance in another. For instance, DCE has recently been used to determine the relative importance of illness attributes that influence the value placed on alleviating that illness[44], to focus on patient preferences for different treatment aspects of cancer[45] or spinal muscular atrophy[46], or to measure the benefit-risk preferences of US adults with heart failure for artificial intelligence (AI)-assisted echocardiograms[47]. There are guidelines for conducting a DCE: reporting of this study complies with the DIRECT checklist[48] (see Appendix A5).

In our DCE design, each respondent was presented with successive scenarios featuring a varying set of intrinsic attributes for the test. To build the set of attributes, we relied on a prior literature review. Huang et al. notably emphasized 'accuracy' and 'anonymity'[49]; Neumann et al. suggested that people value testing for personal and financial reasons ('price') but also express the need to counsel tested persons about the accuracy and implications of test information ('doctor reading')[34]. The final selection of attributes was discussed during a meeting with specialists in the early detection of NDDs from the *Institut du Cerveau (Brain Institute)* in Paris. The intention was to focus on the difference in acceptability between AI and bio-saliva tests. Thus, the selection of attributes was based on what could fundamentally compensate, in people's preferences, for a variation in the test method (test reading / test performance / price). We ended up with five attributes: (1) the type of the test, (2) the reading of test results, (3) test sensitivity, (4) test specificity, and (5) test price.

Note that the curability of the disease, which is an important driver of testing decision[50,51] has been included as a general context opening the questionnaire. We preferred to "prefix" the nature of the disease for each respondent to focus on the characteristics of the test. We thought the elicitation task would be easier by restricting attributes to only test characteristics. For the same reason, we did not consider other characteristics (such as regulatory approval of the test method), which would make the DCE task more complex. Our questionnaire strongly suggests that all tests have been approved by health authorities, given the nature of the AI that was presented to participants (running on public health data stored by the national health insurance (NHI)).

Lastly, we selected the forced-choice method (no exit option), for two reasons: (i) according to the literature, this method seems acceptable and even preferable[52]; (ii) the task was cognitively challenging for respondents (they had to compare options with several attributes and figures, such as sensitivity and specificity) and was not incentivized, although other parts of the questionnaire were gamified and incentivized. This would expose us to a high risk of numerous "do not know" responses in this online study. More details of DCE methodology are provided in Appendix A1, including additional elements for the discussion on the forced-choice option. We also provided a sample of choice screens in Appendix A2.

Data collection

The research was performed in accordance with the Declaration of Helsinki. Each participant was informed through the consent form that the study would ask them about their testing behaviour for various illnesses, both infectious and chronic. In October 2022, the institute ViaVoice was tasked with recruiting participant to achieve targeted representativeness of the metropolitan French adult population in terms of age, gender, socio-professional status, and living area, using the quota method. The polling institute was responsible for anonymizing the data and monitoring ethical procedures with respect to participants (e.g., their right to control their personal data). Approval was obtained in September 2022 by the Ethic Committee of the Aix-Marseille University, Number: 2022-10-20-009.

In the DCE section of the questionnaire, participants were presented with an average hypothetical risk of developing a NDD in the future of 7% after the age of 65, along with the existence of tests able to predict their specific risk of developing the disease within 10 years. We randomized the curability of the disease between participants with equal probability: the symptoms were either "inevitable and incurable" (*Curable = 0*) or "preventable and treatable" (*Curable = 1*). See Appendix A2 for the exact verbatim.

We then presented the five different attributes of the tests to participants (Table 1). Details about the possible types of tests were available to participants once at the beginning of the experiment and at any time if they clicked on an "*info*" icon present on the decision screens.

The type of the test (attribute 1) could be either a biological analysis (*Type = Bio*), an AI numerical analysis of health data stored by the NHI (*Type = AI*), or an AI numerical analysis of health data stored by the NHI plus lifestyle habits and consumption patterns (*Type = AI+*). Reading of the results (attribute 2) could be done by their personal doctor (*Reading = doctor*), by the individuals themselves (*Reading = Self*), by the NHI (*Reading = NHI*), or by a private company selling the test (*Reading = Private*). Sensitivity (attribute 3) could take the values of either 60%, 70%, or 95%. Test sensitivity was presented within each decision screen as follows: "*[60% / 70% / 95%]* of the individuals who would develop the disease in the next 10 years would be correctly declared positive by the tests." Specificity (attribute 4) could take the values of either *60%*, *70%*, or *95%*, but was communicated using type II error rate (1-specificity), as we thought this concept was easier for the French general population, as follows: "*[5% / 30% / 40%] of the individuals with no risk of developing the disease in the next 10 years are*

Attributes	Possible values
(1) Type	Bio vs. AI vs. AI+
(2) Reading	Doctor vs. NHI vs. Self vs. Company
(3) Sensitivity	60% vs. 70% vs. 95%
(4) Specificity	60% vs. 70% vs. 95%
(5) Price	€0 vs. €20 vs. €90

Table 1. Attributes for the discrete choice experiment. *AI* artificial intelligence, *NHI* national health insurance.

incorrectly declared positive by the test". The price of the test (attribute 5) could be 0 euros, 20 euros, or 90 euros, paid out of pocket by the person taking the test.

To reduce the number of scenarios to be proposed, we chose a D-efficient fractional design rather than an orthogonal fractional design. Each respondent has had to make 5 consecutive decisions (5 scenarios presenting two options, A and B, that vary on attributes – see an example in Appendix A2) among a set of 35 potential scenarios (the complete list of possible scenarios is in Appendix A1). Overall, the correlation between Price, Sensitivity, and Specificity attributes in the scenarios was lower than 0.091, and the squared scaled generalized variance inflation factor was lower than 1.12 for all the attributes, supporting the absence of multicollinearity (see Appendix A1). After the DCE, we collected the following characteristics for the participants: gender (48.48% women), age (M = 52.54, SD = 16.31), monthly household income (M = €3,759, SD = €2,312), level of education (25% high school or less, 34% graduate), and cognitive abilities through the Cognitive Reflection Test (CRT)[53]. A table on the socio-demographics of the sample is presented in Appendix A3.

Statistical methodology

We assumed that when facing the choice set $_k$, the individual *i* chooses the test j (either A or B), to maximize the following random utility function:

$$U\_ijk = \alpha\ \_j + X\prime\ \_jk \times\ (\beta\ + Curable\_i \times\ \beta\ \_C\ ) + e\_ijk$$

With $X\prime\ \_jk = (AI, AI + \_\ , Self, Company, NHI, Sensitivity,\ Specificity,\ Price)\_jk,$ the vector attributes of the alternative *j* of scenario *k*; $\alpha\ \_j$ a constant that equals to 0 if $j = B$; $Curable_i$=1 if the individual *i* was presented with a curable disease; β and $\beta_{\ c}$ the vectors of marginal utilities associated with each attribute (according to disease curability), and e_{ijk} an error term independently distributed with an extreme value distribution. We also tested an alternative model without the assumption of linearity in the Price, Sensitivity, and Specificity attributes (Appendix A4). This alternative specification led to qualitatively similar results and did not outperform the linear model (LR–test: $\hat{\chi}(6)$=7.92, p=0.244). We decided to keep the linear form as it facilitated the interpretation in monetary terms (willingness to pay -WTP - for increments in attributes). We estimated by maximum likelihood the probability of choosing option *j*, using a conditional logit function, for the general population.

Accounting for heterogeneity of preferences is a significant challenge in modelling choices derived from DCE. Several approaches are feasible (subsamples, interactions, mixed logit, latent class model, etc.). As we mainly aimed to check the stability of the aggregate results across various individual profiles, we opted for subsamples and ran the analysis for several subsamples, according to individuals' gender, age ("*lower*" if age $\leq$ 34 and "*higher*" if age $\geq$ 64), education ("*lower*" if high school or less; and "*higher*" if master or more), income ("*lower*" if household income $\leq$ 2k€ per month and "*higher*" if $\geq$ 5k€), CRT ("*higher*" if CRT $\geq$ 2 and "*lower*" if CRT $\leq$ 1), and risk-tolerance in the health domain, measured on a 0–10 scale ("*lower*" *if* $\leq$ 6 and *higher>6*).

Based on the model specification, we estimated incremental WTP for each attribute described in $X\prime$ (except *Price*), by dividing each attribute's estimated marginal utility (e.g., $\beta_{\ AI}$, for AI) by the estimated marginal utility of money $(\beta_{\ Price})$. Confidence intervals (CI) of the WTP estimates were calculated according to Krinsky and Robb's simulation method[54], using the R package "*support.CEs*" (version 0.3-0 - Following Krinsky and Robb, the estimation parameters are randomly drawn from a multivariate normal distribution built with the vector of parameter estimates as the mean, n = 10,000 draws. Then, different WTPs and consecutive CI are calculated for each draw of simulated parameters).

Results

In October 2022, a total of 2,280 individuals clicked on the online invitation link sent by ViaVoice. Among them, 221 participants dropped out immediately after the presentation page, and 200 participants abandoned the study during the first questionnaire (on COVID-19). Dropouts occurring during the DCE task were 258 (13.95%). Ultimately, 1,017 participants completed the entire study (see Appendix A3 for more details). Table 2 presents the regression results. Both columns represent results from the same regression in our representative sample of the French general population. The first column shows the marginal effect of each attribute on utility when the disease is not curable, while the second column shows the additional effect of each attribute when the disease is curable.

As expected, we observed a positive impact of sensitivity and specificity on the utility of the predictive tests, and a negative impact of price on the test utility. We observed a disutility of AI tests compared to biological tests. Who is reading the test was also important: individuals exhibited an aversion to self-reading, reading by the NHI, or reading by a private company (compared to reading by a family doctor). All these effects were significant

	Direct effect	Interaction with Curability
Test type (Ref = Biological)		
AI	-0.480*** (0.120)	−0.073 (0.122)
AI+	-0.874*** (0.162)	−0.0025 (0.120)
Test reading (Ref = Family Doctor)		
Self	-0.581*** (0.114)	−0.267 (0.155)
NHI	-0.545*** (0.111)	−0.238 (0.147)
Private company	-1.186*** (0.112)	−0.358* (0.164)
Sensitivity	0.031*** (0.003)	0.002 (0.004)
Specificity	0.038*** (0.003)	−0.001 (0.004)
Price	-0.014*** (0.001)	−0.001 (0.001)
N	10,170	
Likelihood Ratio	2214***	
Wald	1316***	

Table 2. Regression results of attributes on utility. *AI* artificial intelligence, *NHI* national health insurance. $p < 0.1$; *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$. Standard errors in parenthesis. $N = 10,170 = 1,017 \times 5 \times 2$ (as 1,017 subjects had to make 5 choice tasks between 2 testing options).

at the 0.001 level. Note that reading by a private company was significantly worse than self-reading and reading by the NHI ($p < 0.001$).

The interaction with curability (column 2) was only significant for this "reading" attribute: curability adds a negative value for reading by a private company ($p = 0.018$), compared to reading by a family doctor. Aversion to self-reading was marginally strengthened ($p = 0.085$). The non-significance of the other coefficients on column 2 suggests that the framing of curability does not significantly influence much the relative valuation of specificity, sensitivity, price, and test type.

The DCE makes it possible to study how attributes can be traded with each other, using the monetary attribute as a common standard. Figure 1 provides this information ("incremental WTP"), for the whole sample and for stratifications based on a selection of relevant individual variables such as gender and income (as in[55], money-equivalent values are estimated for a change/improvement between attribute levels within the range used in the survey). Note that this design of the DCE study -using forced-choice method- is not intended to examine absolute levels of WTP in relation to individual variables. Instead, it can study variations of WTP – "incremental WTP" – under changes in the test characteristics, in relation to individual variables (using strata). This is illustrated in (Fig. 1).

Concerning the type of the test (Fig. 1A), compared to a biological test, individuals are on average willing to pay €36.08 (CI = [€22.13; €50.89]) to avoid an AI test based on health records and €61.32 (CI = [€41.12; €83.07]) to avoid it when it also exploits consumption and lifestyle personal data provided by another company (AI+). We did not observe statistical differences between subpopulations.

Concerning the reading of the results and compared to a reading by their family doctor (Fig. 1B), individuals are willing to pay €49.97 (CI = [€39.15; €61.29]) to avoid reading the results themselves, €46.68 (CI = [€34.13; €60.45]) to avoid results communicated directly by the NHI, and €95.15 (CI = [€82.01; €109.82]) to avoid results read by a private company commercializing the test. (Beyond the monetary valuation in Fig. 1, this result fundamentally derives from the following order of preferences for who reads the test: family doctor > > NHI > patient herself >>> private company, as exhibited in Table 2). Notably, individuals reporting relatively high aversion to health risks would be willing to pay more for their family doctor to interpret the test results rather than themselves (slight difference, CIs overlap).

Finally, concerning test accuracy (Fig. 1C), on average, individuals are willing to pay €2.30 (CI = [€1.99; €2.65]) to increase sensitivity by 1% point and €2.60 (CI = [€2.26; €2.99]) to increase specificity by 1% point. Individuals with higher income are willing to pay more for increasing sensitivity (M = €3.80, CI = [€2.86; €5.05]) compared to individuals with lower income (M = €1.61, CI = [€1.11; €2.18]). The willingness to pay for specificity is also higher for individuals with higher cognitive abilities (M = €3.59, CI = [€2.93; €4.39]), income (M = €3.58, CI = [€2.64; €4.86]), and education (M = €3.13, CI = [€2.54; €3.86]), compared to individuals with lower cognitive abilities (M = €1.98, CI = [€1.59; €2.42]), income (M = €1.81, CI = [€1.29; €2.43]), and education (M = €1.59, CI = [€0.98; €2.31]).

Discussion

Early detection of NDDs is an important factor in disease prognosis throughout life. This study aimed to investigate the factors influencing individual valuation of AI-based prediction tools for NDDs. The objective

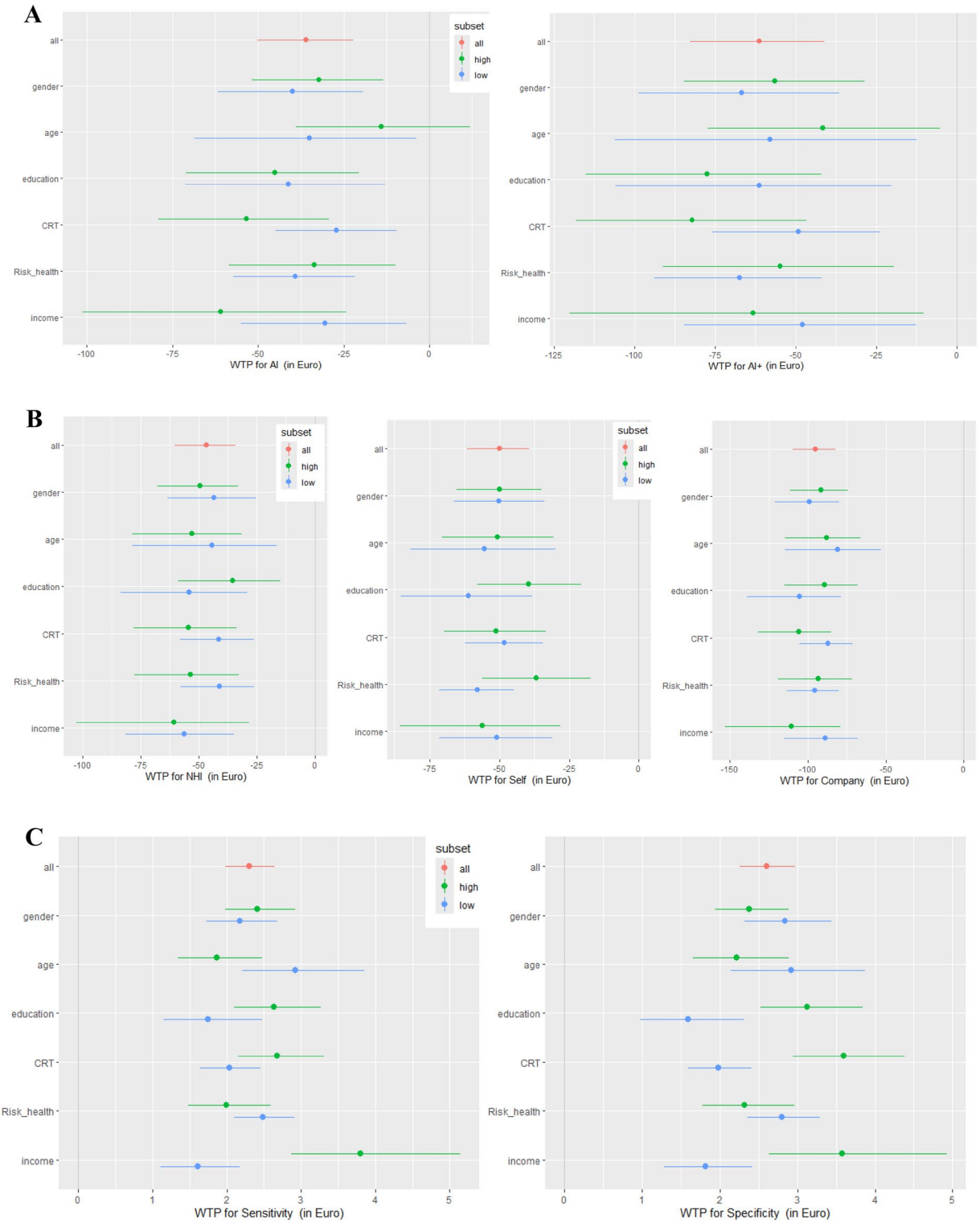

Fig. 1. Willingness to pay for test attributes. (**A**) Incremental WTP for AI attribute, in Euros (reference = Biological). (**B**) Incremental WTP for reading attribute, in Euros (reference = Family Doctor). All stratifications consist in replicating the main analysis but restricted to the participants that are higher or lower with respect to the specific variable (except for the "gender variable", where "higher" corresponds to women and "lower" corresponds to men). Risk-health stands for individual risk-aversion in the health domain, on a 0-10 tolerance scale, as in Dohmen et al.[75].

was to measure the likelihood of AI-test adoption and identify other key attributes of tests that could drive their adoption in the French general population. To do this, an econometric model aggregating the average preferences of a representative sample was applied to DCE data. Using the monetary attribute as a reference allows an assessment of WTPs for the other test attributes, established for a given individual profile (e.g., an average French adult, in the first model without stratification). Since the WTPs for attributes are not expressed directly but inferred from the DCE data, this helps reduce the potential risk of strategic responses that may arise with a direct method.

Our results suggest that there is a general reluctance towards AI detection compared to non-invasive biological tests. Expressed in monetary terms, individuals should be "subsidized" (by approximately €35) for an AI-powered diagnosis test (compared to a saliva test). Thus, this monetary valuation can be interpreted as the shadow price associated with the use of AI. Beyond monetization (which, we acknowledge, depends on the assumptions used in the modelling), the study reveals the trade-offs that individuals would be willing to make to better accept an AI-based test for NDDs detection. For example, they would be more likely to accept the test if the result was read and interpreted by their family doctor, rather than by themselves, the NHI, or the company selling the tests (there is a weak difference between NHI and self-reading; we think this is quite logical, considering that the dataset on which the AI runs is presented as being managed by the NHI). Another result is that individuals are also willing to pay for both sensitivity and specificity, which both positively impact the probability of opting for a test. We found results already present in the literature: the general population has a general reluctance towards AI in medicine[41,56], although the level of hesitancy depends on the medical field studied[40]. We provided new elements for the case of early detection in NDDs.

We conducted stratified analysis to investigate how attribute values depend on individuals' sociodemographic data. We found that, while individual characteristics do not significantly impact the valuation for the type of test (AI vs. Saliva) or the attribute of who reads the test, they could impact the monetary trade-off for specificity and sensitivity. For example, individuals with higher income were more willing to pay for improvements in sensitivity than other parts of society, and specificity is more important for individuals with higher levels of education, income, or cognitive abilities. The stability of the "who is the reader" attribute across stratifications is important research finding. Combined with the other stable characteristics of test (the dis-preference for AI/AI + testing), the constant priority given to the family doctor suggests that the population is genuinely concerned about the potential loss of confidentiality in medical data and/or the information that follows the potential risk of NDD diagnosis.

We were surprised that the curability of the disease only plays a significant role in the valuation of the "who is the reader" attribute. The result concerning the reader can be explained: when a therapy exists, individuals value the expertise of their family doctor more (e.g., to prescribe the appropriate treatment). The absence of influence on other attributes is surprising, particularly for sensitivity, since theory predicts that willingness for appropriate testing should be higher when the disease is curable[57]. Public knowledge about NDDs remains poor[58]; we might suppose that respondents have "automatically" associated NDDs with no curability[59], like cancer[60].

Lastly, considering the reluctance to have their tests read and interpreted by a private company and the extra loss associated with the use of algorithmic analysis on extended commercial datasets (AI + vs. AI), results show that our representative sample of the French population mainly has privacy concerns with their medical data, which could be a significant barrier to AI adoption. The literature shows that patients are open to the usage of AI in healthcare[61], but there are also concerns over information, privacy, and safety[62], including for NDDs such Alzheimer's[63]. Given that personal medical information is among the most private and legally protected forms of data, future scaling-up of commercial healthcare AI will first have to face serious privacy challenges. Several articles already highlight data security and privacy concerns as the root cause of scepticism towards AI in all areas of healthcare[64–66], or for specific areas (mental health, radiology, genomics)[67–70]. Some articles also point out that the public is sometimes willing to trade these privacy concerns for some of the positive elements of AI detection: better accuracy of the information form the detection tools[71] (which, moreover, people trust more due to "automation bias"[72]), and saving time in diagnostic[73]. This paper highlights two additional points that may mitigate public hesitancy toward AI: lower price and the identity of the test reader.

Although the analyses undertaken in this study used a large representative sample and rigorous methods, some practical limitations should be recognized before generalizing the results. The first is the question of the intelligibility of the decision task (choice of tests) and the scenarios presented in the DCE survey. This is a weakness true for all DCE studies that include many attributes, which we tried to limit by being very restrictive on the number of attributes (5 is an acceptable figure, considering the literature, e.g[74]). However, we must recognize that we did not ask a question of intelligibility at the end of the DCE part. In the same vein, certain individual variables may appear to be missing: for instance, family history of NDDs, prior exposure to AI in healthcare, or individual mental health, which could affect the choice of tests. As the questionnaire was followed by other parts (dedicated to infectious diseases), we had to limit ourselves on the number of questions to ask.

The second limitation could lie in the choice set (5 attributes) and the "forced-choice methodology" adopted in the DCE. We chose a choice task limited to the essential intrinsic characteristics of the test. Our intention was to contrast the two methods of testing (AI vs. bio-saliva), without providing more information on the specificity of a given test-method in a particular context. We felt that these reduced deliberations were more appropriate to be valid in all contexts, as they did not depend on external factors that may influence the subject's weighting of these fundamental attributes (e.g., regulatory approval of the test-method is a factor, but it may change over time). This was, in our opinion, a condition for good generalizability of the trade-offs revealed by the subjects in DCE. However, we recognize that our survey focuses on a representative sample of the French population; they -like any other population- may have their own cultural biases and/or beliefs about the impact of technological innovations in medicine. In short, French people are globally risk-averse[75], which may bias our AI hesitancy result upwards. As far as the "forced-choice methodology" is concerned, we provided a discussion

of this methodological option in the methods section (Appendix A1 also extents the discussion). In our view, this option could change upwards the crude levels of WTP inferred from the DCE, but not the relative ones (those obtained for varying levels in the other attributes).

Conclusion

This DCE study shows that our representative sample of the French general population is reluctant to adopt AI screening on their health data, particularly when these screening tests are carried out on large sets of personal data and when the test is read by a private company. These findings indicate that concerns around data privacy and the potential misuse of sensitive medical information represent primary barriers to AI-test acceptance. If public authorities wish to increase the use of these AI detection methods, they should consider better guaranteeing the confidentiality and honest use of personal medical information. For example, a policy of access to low-cost testing, combined with certain regulatory constraints that establish the general practitioner as the expert in reading and interpreting the AI test, should ensure greater acceptability.

Data availability

The datasets generated and/or analysed during the current study are not publicly available due to participant confidentiality agreement, signed at the request of the Internal Review Board (data management plan), but are available from the corresponding author on reasonable request.

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Declarations

Competing interests
The authors declare no competing interests.

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