



# KNOWLEDGE ABOUT GENETICS AND TRUST IN GENETIC TESTING IN A MID-SIZE CITY IN ARGENTINA



## CONOCIMIENTO SOBRE GENÉTICA Y CONFIANZA EN PRUEBAS GENÉTICAS EN UNA CIUDAD DE TAMAÑO MEDIO EN ARGENTINA

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### ABSTRACT

Public attitudes about genetics appear to depend on the local context. We analyzed survey responses obtained in 2015 from 293 residents of Luján, a city in the province of Buenos Aires, Argentina, who self-assessed their knowledge about genetics and their trust in genetic tests. The survey integrated a larger research project for which consenting adult participants shared demographic and genealogical information and provided saliva samples for genetic ancestry analyses. Participants reported little knowledge but high trust in genetic testing when questioned about knowledge and trust. Well-known media stories of DNA-based forensic genetic investigations to identify the victims of state repression during the military dictatorship may have contributed to the high self-assessment of their genetic knowledge expressed by some participants, regardless of educational attainment. Our analysis provides information that could be used as a baseline to begin unraveling the current level of public trust in genetics in a region of the Global South where genetic testing has become widespread, but people's knowledge of and trust in genetics remain poorly studied.

**Key words:** genetic tests, knowledge, public attitudes, trust.

### RESUMEN

Las actitudes del público sobre la genética parecen depender del contexto local. Analizamos las respuestas de una encuesta suministrada en 2015 a 293 residentes de Luján, una ciudad de la provincia de Buenos Aires, Argentina, quienes autoevaluaron su conocimiento sobre genética y su confianza en las pruebas genéticas. La encuesta integraba un proyecto de investigación más amplio en el que los adultos participantes que dieron su consentimiento compartieron información demográfica y genealógica y proporcionaron muestras de saliva para un estudio de ancestría genética. Cuando se les preguntó sobre su conocimiento y confianza, los participantes informaron tener poco conocimiento sobre genética, pero mucha confianza en las pruebas genéticas. Historias muy conocidas de los medios de comunicación sobre investigaciones genéticas forenses basadas en el ADN para identificar a las víctimas de la represión estatal durante la dictadura militar pueden haber contribuido a la alta autoevaluación del propio conocimiento genético manifestado por algunos participantes, independientemente de su nivel educativo. Nuestro análisis proporciona información que podría utilizarse como base para comenzar a desentrañar los niveles actuales de confianza pública en la genética en una región del Sur Global donde las pruebas genéticas se han generalizado, pero el conocimiento y confianza de las personas sobre genética están poco estudiados.

**Palabras clave:** pruebas genéticas, conocimiento, actitudes comunitarias, confianza.

## INTRODUCTION

Genetic testing is becoming more accessible and widely used everywhere, and researchers are now more interested than before in evaluating community awareness and attitudes about genetics in the public. These studies are often designed to give a better understanding of what factors influence public perspectives on testing and people's reactions to new medical technologies based on genomics (e.g., Bates, 2005; Molster *et al.*, 2009; Bíró *et al.*, 2020; Wang *et al.*, 2021). Studies of attitudes about genetic testing from a public health perspective often aim to understand whether (and under what conditions) receiving information about genes could influence people's health-related behaviors (e.g., Dar-Nimrod *et al.*, 2018; Eum *et al.*, 2018; Peterson *et al.*, 2018; Alvord *et al.*, 2020). Other studies aim to inform the public about privacy regarding healthcare procedures and to assess public opinion on potential outcomes of commercializing technology-based healthcare products (e.g., Horn *et al.*, 2011; Gibbon, 2016; Raz *et al.*, 2020; Gerdes *et al.*, 2021).

Recent literature reviews on knowledge and trust in genetics highlighted that people everywhere generally have positive attitudes about genetic testing that persist even if knowledge about genetics is self-described as low. However, public attitudes could vary according to the technologies and purposes for which genetic knowledge is applied (Condit, 2001, 2010; Etchegary *et al.*, 2009; Chapman *et al.*, 2019; ASHG, 2020; Calabrò *et al.*, 2020).

Earlier research on public attitudes about genetics was conducted with the assumption that attitudes would be stable and unequivocal rather than context-dependent and biased (Condit, 2010). However, more recent cross-sectional studies have uncovered differences in public knowledge and attitudes across multi-year periods (e.g., Henneman *et al.*, 2013). Thus, local sociocultural characteristics and local history could shape individual attitudes over time. Context and local history would have a lasting influence in people's trust in genetics (Cunningham-Burley, 2006; Jonassaint *et al.*, 2010; Canedo *et al.*, 2019).

Researchers have employed various sampling techniques to study public knowledge about genetics and public views on genetic testing, such as convenience sampling (Etchegary *et al.*, 2013; Arafah *et al.*, 2021) and randomized studies (Jallinjoa and Aro, 2000; Haga *et al.*, 2013; LePoire *et al.*, 2019; Wang *et al.*, 2021). Likewise, researchers have employed data collection instruments, such as telephone interviews (Molster *et al.*, 2009), postal surveys (Etchegary *et al.*, 2009), online surveys (Dye *et al.*, 2016; Arafah *et al.*, 2021), focus groups (Bates, 2005; Schumann *et al.*, 2021), Likert-scale questionnaires administered during in-person interviews (Chokoshvili *et al.*, 2017; Kvaratskhelia *et al.*, 2021), or self-administered surveys with fixed-choice

and open-ended items (Jonassaint *et al.*, 2010).

Like elsewhere, genetic testing integrated into health-related strategies is increasingly available in Argentina (e.g., Penchaszadeh, 2009, 2013; Vishnopolska *et al.*, 2018). Academic researchers have conducted genetic testing for various ancestry inferences since the 1990s (e.g., Martínez Marignac *et al.*, 1999; García and Demarchi, 2006; Corach *et al.*, 2009; Carnese *et al.*, 2011; Avena *et al.*, 2012, 2013). However, genetic ancestry testing to explore individual identities has been far less common (García *et al.*, 2016; Spina *et al.*, 2016; Di Fabio Rocca *et al.*, 2018, 2020). Therefore, local results of scholarly research on genetic ancestry inference were not widely known by the public when we carried out fieldwork for our project.

Our overall project investigated how recent trends in genetic ancestry research in Argentina interacted with the participants' perspectives of national belonging. The study employed a multi-method research design through the generation, analysis, and interpretation of genomic and ethnographic data in a mid-size city in the province of Buenos Aires, Argentina. Over that period, our research team conducted genetic ancestry analyses, ethnographic interviews, and participant observation (Mendoza and Cabana, 2019; Cabana *et al.*, 2022; Mendoza *et al.*, 2022).

This work aims to explore the participants' views and self-assessed levels of knowledge and trust in genetics based on their responses to an in-person survey of adults who consented to participate in our project. The results of our analysis help to begin unraveling public attitudes and trust in genetics among urban populations of Argentina. Additionally, our study provides a preliminary baseline of data to conduct further research on individual's level of knowledge and level of public trust in genetics among other local populations, since this topic remains poorly studied in the country.

## MATERIALS AND METHODS

### *Research site, population sample, and survey*

Our research was carried out in two historic neighborhoods, locally known as El Centro and Santa Elena, in Luján (population: 78,346 inhabitants in 2010), a city with a long colonial history in the province of Buenos Aires, Argentina, now included in the megacity of Buenos Aires (Buzai and Montes Galbán, 2020; Buzai *et al.*, 2021).

The national decennial census divided the city into 87 census tracks. El Centro included 20 census tracks and Santa Elena included three census tracks. We operationalized the number of randomly selected households in those two historic neighborhoods using 2010 census tracks described by Buzai (2014) as social

maps of the city. The minimum number of households per track in El Centro was 142 and the maximum in Santa Elena was 419 (the average number of households per track in the targeted neighborhoods was 274, according to Principi (2021, pers. comm.). The two neighborhoods were characterized by socioeconomic levels varying from very high and high to medium (Principi and Buzai, 2020).

We attempted to recruit one resident per household by leaving recruitment letters at 300 randomly selected households, followed by a personal visit by a research team member. Moreover, the research team made three consecutive attempts to contact a household resident at different times of the day before moving to a different address. We also advertised our project in the local newspaper (Papaleo, 2015), on social media, and in public places, posting large-size announcements in the City Hall, the Public Library, and the local University.

Despite our efforts to engage with residents, many of them did not respond or were reluctant to participate in our project—which included face-to-face contact with team members. Those who declined to engage expressed feelings of lack of security at home, fear of letting anybody in, and overall concern about rising crime levels in the community. For those interested in participating, we offered to meet in public places, but most opted for completing our in-person survey and saliva collection in their homes. A handful of recruitments took place at the local university.

Our field team did not systematically record the census-track locations and verbatim opinions voiced by residents who were not interested in participating in our project. However, we learned some of the reasons expressed by residents who declined to participate during weekly meetings of the entire research team in the winter of 2015. Also, we recorded comments made by participants interested in our project during the initial meeting conducted to explain the informed consent process.

Due to the reasons expressed above, less than one-quarter of the research participants were recruited from the original randomized sample. Following the same criteria and protocol, we fulfilled any remaining openings in our stratified quota by word-of-mouth recruitment of residents of the same neighborhoods whose homes had been previously excluded from spatial randomization. These self-selected participants may have been especially moved by an interest in learning more about our project or by a deeper curiosity about the topic.

Before providing consent to participate, adult residents who expressed interest in our project met with a member of the research team and received a thorough explanation about the topic of genetic ancestry and our research protocols. Consenting residents later met with a member of the research team to answer the face-to-face survey that we analyzed here (they also gave saliva

samples that were analyzed elsewhere).

To ensure demographic representation, the sample was stratified a priori into seven age cohorts (from 18 to 71-plus) by asking participants for their chronological ages at the time of recruitment. In addition, we asked for gender identification as an open-ended question and found that participants only declared two categories: “woman” or “man”; we then stratified our sample by these two gender categories. Also, to ensure genomic representation, we did not accept participants who disclosed close biological relationships (i.e., immediate kin or first cousins) with any other enrolled participants.

On the survey form, the following was requested: (a) demographic information (current occupation, educational attainment, birthplace, and length of residence in Luján), (b) family tree information, and (c) responses to two ten-point Likert-scale questions that self-assessed overall knowledge of genetics and level of trust in genetic testing.

We asked: “On a scale of 1 (I know very little) to 10 (I know a lot), what is your level of knowledge of genetics?” and “On a scale of 1 (I trust very little) to 10 (I trust a lot), what is your level of trust in the results of a genetic test?”. Thus, participants self-assessed their understanding of genetics choosing from “no knowledge” to “perfect knowledge,” and self-assessed their trust in genetic testing choosing from “no trust” to “a great deal of trust” For this analysis, scores were assessed in five intervals: null or very low (1-2); low (3-4); medium (5-6); medium-high (7-8); high (9-10). Additionally, we recorded any pertinent comments offered during survey-taking on the back of the survey form.

In this paper, we analyzed the participants’ answers to those two questions and their brief comments. Our final sample consisted of 293 participants (51% women, 49% men, aged 18 years and over, Table 1) residing in the same number of households. Our sample represented 4.6% of all 6,302 households in the targeted neighborhoods.

We calculated the mode, median and relative frequencies of knowledge of genetics and trust in genetic testing. Then, Kendall’s Tau-b test ( $t_b$ ) was applied to explore the degree of association between both variables. Finally, we examined the relationship between gender, age, educational attainment, and occupation with the level of knowledge and trust in genetics through Somers’  $d$  test, considering the first four demographic variables as explanatory variables (Agresti, 2010). Both statistical tests are based on the number of concordant and discordant pairs of observations. Their values range between -1 and 1, where 1 indicates perfect association independently of the arithmetic sign. Positive associations indicate a higher frequency of concordant than discordant pairs, whereas negative values indicate the inverse. Statistical significance was set at 0.05 using IBM SPSS Statistics for Windows v. 24.0.

**Table 1.** Participants' age, educational attainment, and occupation

Characteristics	n	%
<i>Age Range</i>		
18-20	8	2.7
21-30	66	22.6
31-40	53	18.2
41-50	29	9.9
51-60	57	19.5
61-70	49	16.8
>70	30	10.3
<i>Educational attainment</i>		
Elementary School incomplete	4	1.4
Elementary School	16	5.5
High School incomplete	22	7.5
High School	47	16.1
2-year College incomplete	23	7.9
2-year College	40	13.7
University incomplete	74	25.3
University diploma	50	17.1
Post-graduate incomplete	8	2.7
Post-graduate diploma	8	2.7
<i>Occupation</i>		
Employed	195	66.8
Homemaker	11	3.8
Retired	46	15.8
Student	39	13.4
Unemployed	1	0.3

## RESULTS

Participants indicated relatively medium knowledge about genetics (Mode= 5; Median= 4.75) and high levels of trust in genetic testing (Mode= 10; Median= 9) (Figure 1). Knowledge about genetics and trust in genetic testing were significantly associated, but the level of association was low ( $t_p = 0.117, p = 0.025$ ). Figure 2 shows that the lowest levels of trust in genetic studies correspond with the lowest levels of knowledge about genetics. Still, there is no clear correspondence between the highest

levels of both variables. Some participants (n= 41, 14%) self-reported both null or very low knowledge and a great deal of trust in genetic testing.

Educational attainment was the only demographic variable associated with knowledge about genetics, but the association level was low ( $d = 0.139; p = 0.008$ ). The participants with incomplete elementary school were the only ones that did not declare a medium-high or high knowledge about genetics. In contrast, a large percentage of the participants with the highest level of education reported to have none to a low level of knowledge (Figure 3). No statistically significant associations were found between participants' level of educational attainment and trust in genetic testing nor with participants' knowledge and trust with gender, age, and occupation.

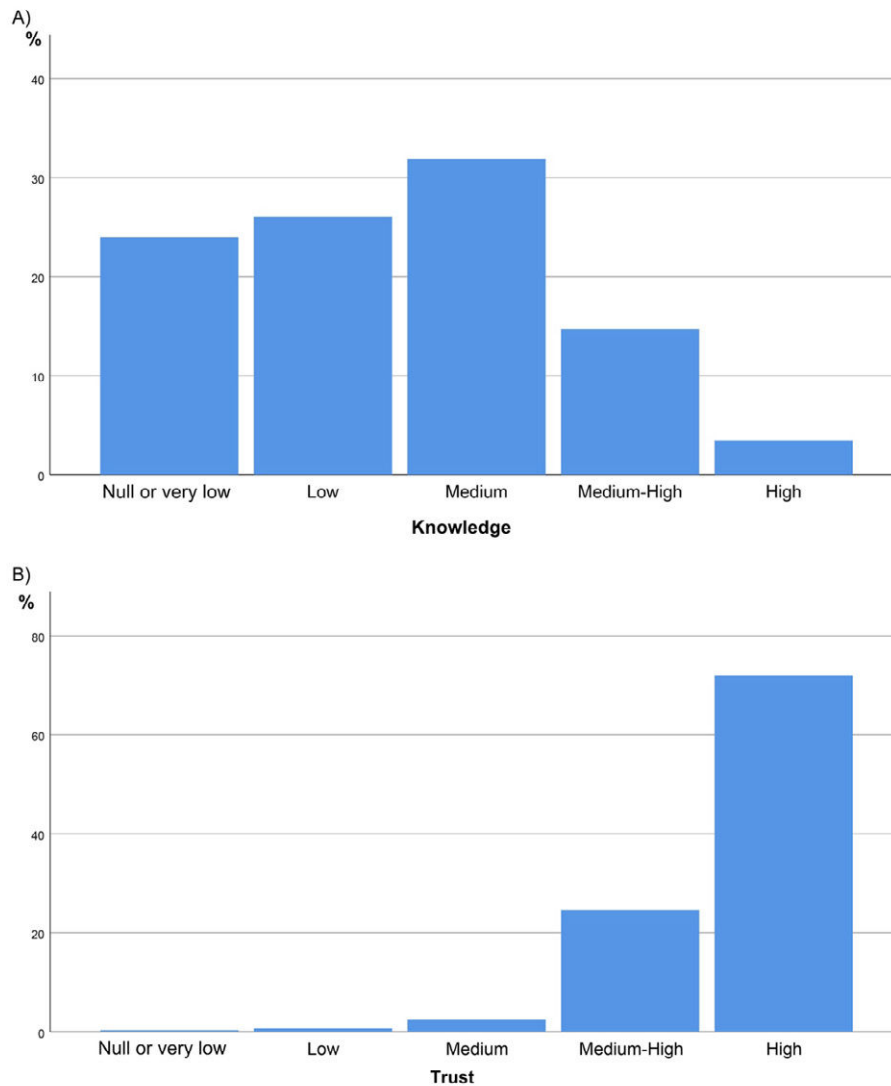
## DISCUSSION

Studies of trust (interpreted in our survey as *confianza*) often emphasize the optimistic acceptance of a vulnerable situation in which the person who trusts believes the trustee will care for the truster's interest (e.g., Hall *et al.*, 2001). Following Dietz (2011), we considered that trust is based on assessing the other party's trustworthiness. People generally develop their beliefs and assessments of trust in genetics and other matters using social experiences and any technical knowledge they may have (Condit, 2010).

A recent study of trust in genetics distinguished one of two components in the attitudes of the interviewees: (1) the interpersonal relationships of an individual with healthcare professionals and (2) a macro level of trust in institutions or systems (Schumann *et al.*, 2021). Some of the participants' comments recorded in the survey form suggest the presence of these two components in public levels of trust. For example, during survey-taking, some participants made the following comments:

- (a) "[Genetics]... is one of the greatest advances ever made."
- (b) "There is nothing more credible than genetics."
- (c) "[Genetics] ... is one of the few things still reliable in Argentina."
- (d) "[I trust it] 99.9 percent."
- (e) "[I trust it] with a margin of error."

Most participants self-assessed their level of trust as medium to high. This might appear as an expected outcome, possibly related to individual interest and curiosity about genomics. However, because studies carried out among different populations over time likewise detected high levels of public trust in genetics (Human Genetics Commission, 2001; Ishiyama *et al.*, 2008; Condit, 2010; Henneman *et al.*, 2013; Hishiyama *et al.*, 2019), the medium-to-high levels of trust among



**Figure 1.** Bar chart of score frequencies for participants' knowledge about genetics (A) and trust in genetic testing (B)

participants in our project could be related to additional variables that we do not currently understand.

Some participants in our project expressed what researchers have described as “healthy skepticism” or “selective mistrust” (Schumann *et al.*, 2021) by making, for example, the following comments during survey-taking:

(a) “It depends on the quality of the laboratory and the honesty of the professionals.”

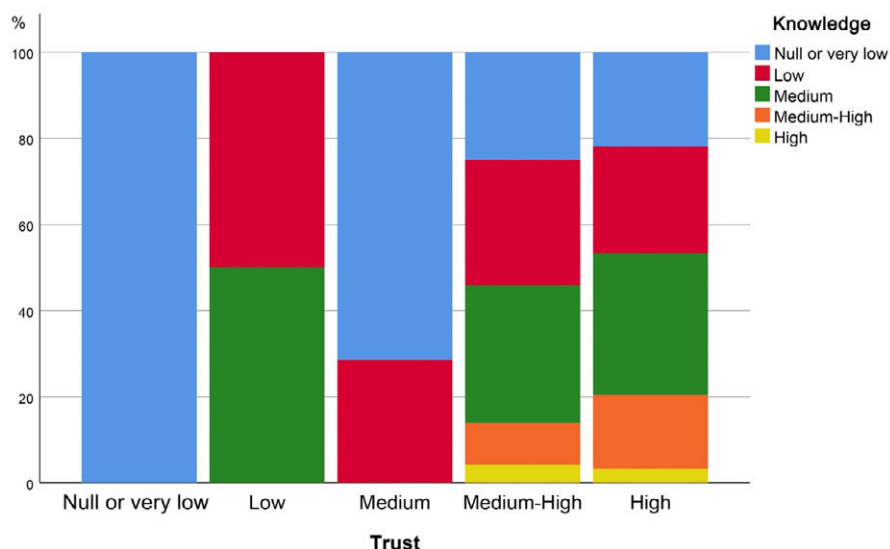
(b) “[It depends on] credibility/reputation.”

(c) “It depends on what it is used for.”

Comparable to attitudes of the public engaged in studies on trust in human genomics in the so-called Global South (de Vries *et al.*, 2014), participants in our project highlighted the importance of knowing whom to trust when explaining their level of trustworthiness

in geneticists and laboratories. Many of them, during the initial encounter to discuss the informed consent process, said that they would consent to participate because our project was a collaborative effort between faculty and assistants at the local university and researchers based in universities of the United States. These participants appreciated that our project was not an entirely “foreign” initiative. Thus, people’s participation was partially grounded in their trust in local institutions.

Other studies of trust in genetics in different populations over time found that people based their trust on their previous experiences of trusting local institutions (Human Genetics Commission, 2001; Ishiyama *et al.*, 2008; Condit, 2010; Moodley and Singh, 2016; Hishiyama *et al.*, 2019).



**Figure 2.** Relationship between participants’ self-assessed scores for knowledge about genetics and trust in genetic testing

Some residents who declined to participate expressed just the opposite arguments. They said that the foreign component of our collaborative research team, explained in the letter of invitation received by all the randomly selected households, made them feel distrust of our project.

A recent study highlighted the importance of analyzing both mistrust and trust because mistrust points to conditions considered problematic (Schumann *et al.*, 2021). In this work, participants who expressed misgivings referred to their interest in not being subjected to “imperialist” attitudes by research projects funded by scientific institutions in the United States. Residents who declined to participate also raised concerns about sharing personal genetic data with the research team.

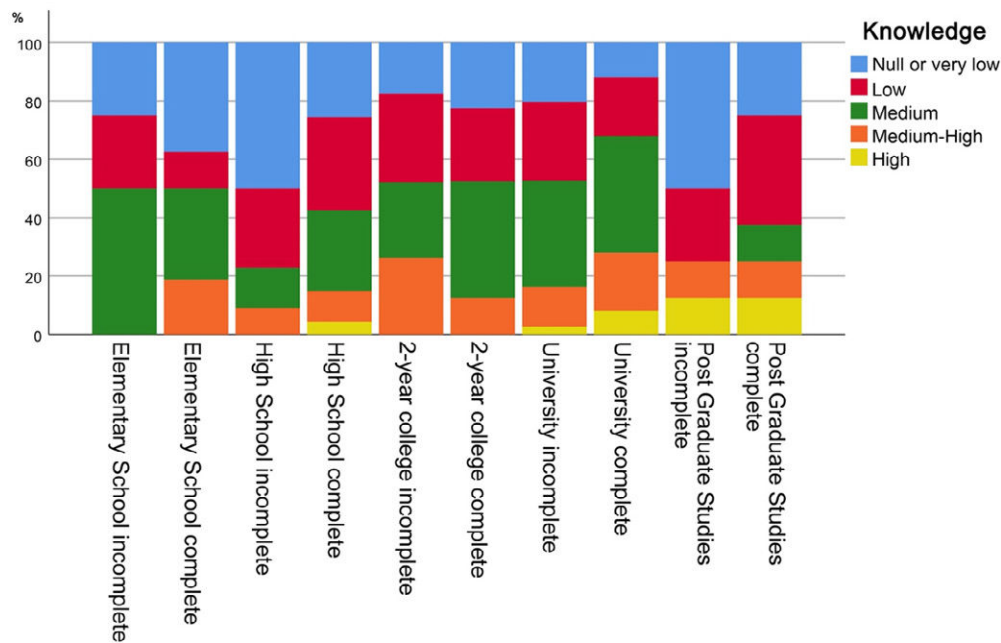
The issue of sharing genetic data seems to be very controversial everywhere, and people are hesitant, especially when it comes to sharing genomic data internationally. A review by Majumder *et al.*, (2016) indicated that concerns about misuse of DNA created public distrust and people resisted participating in projects that could potentially misuse or manipulate their genetic material. In the Global South, people recalled instances of “helicopter genetics,” describing occurrences of scientists from developed countries “descending” on developing countries to carry out research incompatible with standards of ethics and then using research data without proper credit to local teams and without sharing benefits with the local populations.

Comparable to what was documented among the public of other countries (Majumder *et al.*, 2016; Schumann *et al.*, 2021), people’s suspicions in our survey could be interpreted as political statements, articulated critiques of researchers employed by private corporations that profit from accessing local genetics data, or both.

In recent literature reviews of empirical studies, reviewers argued that public understanding of genetic testing evolves over the years, and populations in different countries often hold particular views about genomics due to variable exposure to information about genetics and differences in their public health systems (e.g., Henneman *et al.*, 2013; Chokoshvili *et al.*, 2017; Kvaratskhelia *et al.*, 2021).

The participants in our study said (usually during the initial meeting to discuss the informed consent) that they learned Mendelian genetics from elementary through high school and expanded their understanding of molecular genetics as they advanced in their education. In the two urban neighborhoods of Luján, people said that they usually accessed information about genomics through TV programs, the Internet, print, and social media. Generally, people were familiar with concepts such as genes and DNA and understood that parents pass hereditary material to their children.

Rather than utilizing linear models of transmission of information to interpret the process of receiving and processing information -as was assumed by previous research (e.g., Michael and Carter, 2001; Petersen, 2001; Levitt, 2003)- the participants in those urban



**Figure 3.** Relationship between participants' self-assessed score for knowledge about genetics and participants' educational attainment

neighborhoods in Argentina, like elsewhere, appear to utilize complex and critical approaches to handle scientific information, not directly related to formal schooling. As argued by Bates (2005), formal schooling would only inform part of the public's understanding of recent advances in genetic technology. Typically, people would form their ideas by critically dealing with messages about genetics seen in news media, popular television, documentaries, and science-fiction films. Thus, to a large extent, popular culture, more than formal education, would shape people's understanding of genetics.

Elaborating on participant's knowledge of genetics during the initial meeting to discuss the process of informed consent, several of them mentioned their awareness of ongoing forensic anthropology investigations to identify the victims of state repression and the children of missing persons (*desaparecidos*) during Argentina's military dictatorship (1976-1983) (Jelin, 2009; Penchaszadeh, 2011; Guglielmucci, 2013; Kling *et al.*, 2017; Lerman, 2017). Widespread public awareness of DNA-based forensic genetics research in Argentina could have contributed to the participants' self-reported knowledge/understanding of genetics, regardless of their educational attainment. Also, well-known media stories of DNA-based forensic genetic identification may have contributed to the participants' self-assessed high level of trust.

Overall, researchers in other countries have found no clear statistical patterns connecting people's level of genetic knowledge and their attitudes toward genetics. Research and literature reviews suggest that the effects of education could be contradictory (Condit, 2010; Etchegary, 2014; Chapman *et al.*, 2019). Nonetheless, education continues to be a pertinent demographic variable in field studies about knowledge and trust in genetics. In our survey, educational attainment was associated with knowledge, but the association level was low. Some researchers found that greater knowledge about genetics was correlated with the level of education and associated with trust in the benefits of genetic testing, but other studies pointed to the opposite (Bíró *et al.*, 2020).

Highly educated people with considerable knowledge about science would sometimes express *more* criticism and be *less* trusting about genomic developments than individuals with lower levels of education (Jallinjoa and Aro, 2000). People in the so-called Global North have expressed skepticism about genetic tests, a development that Schumann *et al.* (2021) attribute to the decline of trust in authorities, experts, and institutions. The rather impressive level of self-assessed trust in genetics in our survey could instead point to the optimistic acceptance of science identified by Hall *et al.* (2001).

A limitation of our analysis is that with the two questions in our survey we assessed people's knowledge

of and trust in genetics only among those urban residents who consented to participate in our project. Further research is needed to examine responses by other residents in larger randomized samples residing in neighborhoods with different socioeconomic levels, and in rural locations. We did not systematically record the census-track location and verbatim opinions voiced by residents who declined to participate, but we learned about the reasons expressed by people who were not interested in our project during regular updates by members of our research team. Moreover, although our initial intention was to work with a probabilistic sample, the analyzed sample is not probabilistic. Thus, our inferential analysis of the results must be taken with caution.

## CONCLUSION

Studying the levels of trust (interpreted as *confianza*) that people place on genetics and learning how they self-assessed their knowledge (interpreted as *conocimiento*) about genetics are important because shifting individual perspectives may influence people's willingness to participate in research projects that incorporate genetic testing. The 293 responses to the two ten-point Likert-scale questions self-assessing the overall knowledge of genetics and the level of trust in genetic testing in Argentina, could offer a preliminary baseline to start developing new research paths for future studies on the topic. Our analysis leads us to conclude that paying attention to issues of trust and mistrust in the community could facilitate and improve the process of obtaining an ethically sound and socially acceptable informed consent for research projects.

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obtained from all participants for being included in the study.

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## REFERENCES

- Agresti A. (2010) Analysis of Ordinal Categorical Data. John Wiley & Sons, Canada.
- Alvord T.W., Marriott L.K., Nguyen P.T., Shafer A., Brown K., Stoller W. ... Shannon J. (2020) Public perception of predictive cancer genetic testing and research in Oregon. *J. Genet. Couns.* 29(2): 259–281. <https://doi.org/10.1002/jgc4.1262>
- American Society of Human Genetics (ASHG) (2020) Public Attitudes Toward Genetics & Genomics Research Literature and Polling Review Report. <https://www.ashg.org/wp-content/uploads/2020/01/2020-Public-Views-Genetics-Literature-Review.pdf> (accessed 10/9/2020)
- Arafah A., AlJawadi M.H., Aldheefi M., Rehman M.U. (2021) Attitude and awareness of public towards genetic testing in Riyadh, Saudi Arabia. *Saudi J. Biol. Sci.* 28(1): 251–261. <https://doi.org/10.1016/j.sjbs.2020.09.057>
- Avena S., Via M., Ziv E., Pérez-Stable E.J., Gignoux C.R., Dejean C. ... and Fejerman L. (2012) Heterogeneity in genetic admixture across different regions of Argentina. *PLoS ONE*, 7(4): e34695. <https://doi.org/10.1371/journal.pone.0034695>
- Avena S., Di Fabio Rocca F., Postillone M.B., Dejean C. (2013) ¿Existió el crisol de razas en Argentina? Una respuesta desde la antropogenética. In: Gurevich B. (Ed.) *La complejidad después de Babel. Diásporas, culturas y transnacionalización*. Lumiere, Buenos Aires, pp. 279–312.
- Bates B.R. (2005) Public culture and public understanding of genetics: a focus group study. *Public Underst. Sci.* 14(1): 47–65. <https://doi.org/10.1177/0963662505048409>
- Bíró K., Dombrádi V., Fekete Z., Bányai G., Boruzs K., Nagy A., Ádány R. (2020) Investigating the knowledge of and public attitudes towards genetic testing within the Visegrad countries: a cross-sectional study. *BMC Public Health*, 20(1): 1380. <https://doi.org/10.1186/s12889-020-09473-z>
- Buzai G.D. (2014) El mapa social de Luján, 2010. Modelo socioespacial basado en linkage analysis. *Revista de Geografía*, 18: 49–61.
- Buzai G.D., Baxendale C.A., Montes Galbán E. (2021) Megacity of Buenos Aires and its most recent conurbation impact. In: Czerny M. and Serna Mendoza C.A. (Eds.) *Sustainable Development Crossing Borders, Breaking Stereotypes*. University of Warsaw Press, Warsaw, Poland, pp. 101–113.
- Buzai G.D., Montes Galbán E. (2020) Megaciudad Buenos Aires: Cartografía de su última expansión y conurbación mediante el procesamiento digital de imágenes satelitales nocturnas. *Revista Cartográfica*, 100: 215–238.
- Cabana G.S., Mendoza M., Smith L.A., Delfino H.; Martínez C.; Mazza B. ... Di Fabio Rocca F. (2022) Crossing at y/our own peril: Biocultural boundary crossing in anthropology. *Am Anthropol.* 124(3): 479–489.



- <https://doi.org/10.1111/aman.13729>
- Calabrò G.E., Sassano M., Tognetto A., Boccia S. (2020) Citizens' Attitudes, Knowledge, and Educational Needs in the Field of Omics Sciences: A Systematic Literature Review. *Front. Genet.* 11: 570649. <https://doi.org/10.3389/fgene.2020.570649>
- Canedo J.R., Miller S.T., Myers H.F., Sanderson M. (2019) Racial and ethnic differences in knowledge and attitudes about genetic testing in the US: Systematic review. *J. Genet. Couns.* 28(3): 587-601. <https://doi.org/10.1002/jgc4.1078>
- Carnese F.R., Avena S.A., Parolín M.L., Postillone M.B., Dejean C.B. (2011) Gene admixture estimation through genetic markers and demographic data in a sample from Buenos Aires Metropolitan Area. In: Gibbon S., Ventura Santos R., Sans M. (Eds.) *Racial Identities, Genetic Ancestry and Health in South America: Brazil, Argentina, Uruguay and Colombia*. Palgrave Macmillan, New York, NY, pp. 177-194.
- Chapman R., Likhanov M., Selita F., Zakharov I., Smith-Woolley E., Kovas Y. (2019) New literacy challenge for the twenty-first century: genetic knowledge is poor even among well educated. *J. Community Genet.* 10:73-84. <https://doi.org/10.1007/s12687-018-0363-7>
- Chokoshvili D., Belmans C., Poncelet R., Sanders S., Vaes D., Vears D. ...Borry P. (2017) Public Views on Genetics and Genetic Testing: A Survey of the General Public in Belgium. *Genet. Test. Mol. Biomarkers*, 21(3): 195-201. <https://doi.org/10.1089/gtmb.2016.0418>
- Condit C. (2001) What is 'public opinion' about genetics? *Nat. Rev. Genet.* 2(10): 811-815. <https://doi.org/10.1038/35093580>
- Condit C.M. (2010) Public Attitudes and Beliefs About Genetics. *Annu. Rev. Genomics Hum. Genet.* 11: 339-59. <https://doi.org/10.1146/annurev-genom-082509-141740>
- Corach D., Lao O., Bobillo C., Van Der Gaag K., Zuniga S., Vermeulen M., Kayser M. (2009) Inferring continental ancestry of Argentinians from autosomal, Y-chromosomal and mitochondrial DNA. *Ann. Hum. Genet.* 74(1): 65-76. 2009. <https://doi.org/10.1111/j.1469-1809.2009.00556.x>
- Cunningham-Burley S. (2006) Public Knowledge and Public Trust. *J. Community Genet.* 9(3): 204-210. <https://doi.org/10.1159/000092658>
- Dar-Nimrod I., MacNevin G., Godwina A., Lynch K., Magory Cohend T., Ganesana A., Morandinia J. (2018) Genetic Knowledge within a National Australian Sample: Comparisons with Other Diverse Populations. *Public Health Genom.* 21(3-4): 133-143. <https://doi.org/10.1159/000496381>
- de Vries J., Williams T.N., Bojang K., Kwiatkowski D.P., Fitzpatrick R., Parker M. (2014) Knowing who to trust: exploring the role of 'ethical metadata' in mediating risk of harm in collaborative genomics research in Africa. *BMC Med. Ethics*, 15: 62. <https://doi.org/10.1186/1472-6939-15-62>
- Dietz G. (2011) Going back to the source: Why do people trust each other? *J. Trust Res.* 1(2): 215-222. <https://doi.org/10.1080/21515581.2011.603514>
- Di Fabio Rocca F., Spina S., Coirini E., Gago J., Patiño Rico J., Dejean C., Avena S. (2018) Mestizaje e identidad en Buenos Aires, Argentina. Experiencias desde la búsqueda individual de datos genéticos. *An. Antropol.* 52(1): 165-177. <http://dx.doi.org/10.22201/ia.24486221e.2018.1.62655>
- Di Fabio Rocca F., Smietniansky S., Spina S., Coirini E., Gago J., Juárez J... Avena S. (2020) Perspectivas, motivaciones e intereses en la búsqueda de ancestrías genéticas en Buenos Aires, Argentina. *Revista Colombiana de Antropología*, 56(2): 265-287. <http://dx.doi.org/10.22380/2539472X.1157>
- Dye T., Li D., Demment M., Growth S., Fernandez D., Dozier A., Chang J. (2016) Socio-cultural variation in attitudes toward use of genetic information and participation in genetic research by race in the United States: implications for precision medicine. *JAMIA Open*, 23(4): 782-786. <https://doi.org/10.1093/jamia/ocv214>
- Etchegary H. (2014) Public attitudes toward genetic risk testing and its role in health-care. *Personalized Medicine*, 11(5): 509-522. <https://doi.org/10.2217/PME.14.35>
- Etchegary H., Cappelli M., Potter B., Vloet M., Graham I., Walker M., Wilson B. (2009) Attitude and knowledge about genetics and genetic testing. *Public Health Genom.* 13(2): 80-88. <https://doi.org/10.1159/000220034>
- Etchegary H., Green J., Parfrey P., Street C., Pullman D. (2013) Community engagement with genetics: public perceptions and expectations about genetics research. *Health Expect.* 18(5): 1413-1425. <https://doi.org/10.1111/hex.12122>
- Eum H., Lee M., Yoon J., Cho J., Lee E.S., Choi K.S. ... Chang Y.J. (2018) Differences in attitudes toward genetic testing among the public, patients, and health-care professionals in Korea. *Eur. J. Hum. Genet.* 26:1432-1440. <https://doi.org/10.1038/s41431-018-0191-6>
- García A., Demarchi D. (2006) Linajes parentales amerindios en poblaciones del norte de Córdoba. *Rev. Argent. Antropol. Biol.* 8 (1): 57-71. <https://revistas.unlp.edu.ar/raab/article/view/280>
- García A., Oliveira Rufino R., Bergese A.B., Agüero J.F., Cuevas A., Díaz-Rousseau G., Demarchi D.A. (2016) El cruce entre las Antropologías. Una mirada interdisciplinaria en torno a la genética de poblaciones, las memorias familiares y la construcción identitaria. *Revista del Museo de Antropología*, 9(2): 105-112.
- Gerdes A-M., Nicolaisen L., Husum E., Bayer Andersen J., Dræbye Gantzhorn M., Roos L., Rode Diness B. (2021) Direct to consumer genetic testing in Denmark—public knowledge, use, and attitudes. *Eur. J. Hum. Genet.* 29: 851-860. <https://doi.org/10.1038/s41431-021-00810-3>
- Gibbon S. (2016) Translating Population Difference: The Use and ReUse of Genetic Ancestry in Brazilian Cancer Genetics. *Med. Anthropol.* 35(1):58-72. <https://doi.org/10.1080/01459740.2015.1091818>
- Guglielmucci A. (2013) La Consagración de la Memoria. Editorial Antropofagia, Buenos Aires, Argentina.
- Haga S.B., Barry W.T., Mills R., Ginsburg G.S., Svetkey L., Sullivan J., Willard H.F. (2013) Public knowledge of and attitudes toward genetics and genetic testing. *Genet. Test. Mol. Biomarkers*, 17(4): 327-35. <https://doi.org/10.1089/gtmb.2012.0350>
- Hall M.A., Dugan E., Zheng B., Mishra A.K. (2001) Trust in physicians and medical institutions: what is it, can it be measured, and does it matter? *Milbank Q.* 79(4): 613-639. <https://doi.org/10.1111/1468-0009.00223>
- Henneman L., Vermeulen E., van El C.G., Claassen L., Timmermans D.R.M., Cornel M.C. (2013) Public attitudes towards genetic testing revisited: comparing opinions between 2002 and 2010. *Eur. J. Hum. Genet.* 8: 793-799. <https://doi.org/10.1038/ejhg.2012.271>
- Hishiyama H., Minari J., Suganuma N. (2019) The survey of public perception and general knowledge of genomic research and medicine in Japan conducted by the Japan Agency for Medical Research and Development. *J. Hum. Genet.* 64: 397-407. <https://doi.org/10.1038/s10038-019-0587-3>
- Horn E.J., Edwards K., Terry S.F. (2011) Engaging Research Participants and Building Trust. *Genet. Test. Mol. Biomarkers*, 15(12): 839-840. <https://doi.org/10.1089/gtmb.2011.1526>
- Human Genetics Commission (2001) Public attitudes to human genetic information: People's Panel quantitative study conducted for the Human Genetics Commission. London, U.K. <https://health.ucdavis.edu/biorepositories/pdfs/genomics-biobank/Public-attitudes-to-human-genetic-information.pdf> (accessed 3/21/2020)
- Ishiyama I., Nagai A., Muto K., Tamakoshi A., Kokado M., Mimura K. ... Yamagata Z. (2008) Relationship Between Public Attitudes Toward Genomic Studies Related to Medicine and Their Level of Genomic Literacy in Japan. *Am. J. Med. Genet. A.* 146A: 1696-1706. <https://doi.org/10.1002/ajmg.a.32322>
- Jallinjoa P., Aro A.R. (2000) Does Knowledge Make a Difference? The Association Between Knowledge About Genes and Attitudes Toward Gene Tests. *J.*

- Health Commun. 5(1): 29-39. <https://doi.org/10.1080/10810730050019546>
- Jelin E. (2009) Victims, Relatives, and Citizens in Argentina: Whose Voice Is Legitimate Enough? In: Wilson R.A.; Brown R.D. (Eds.) Humanitarianism and Suffering: The Mobilization of Empathy. Cambridge University Press, New York, pp. 177-201.
- Jonassaint C.R., Santos E.R., Glover C.M., Payne P.W., Fasaye G.-A., Oji-Njideka N., Hooker S. ... Royal C.D. (2010) Regional differences in awareness and attitudes regarding genetic testing for disease risk and ancestry. *J. Hum. Genet.* 128: 249-260. <https://doi.org/10.1007/s00439-010-0845-0>
- Kvaratskhelia E., Chokoshvili D., Kvintradze M., Surmava S., Dzagoevi K., Borry P., Abzianidze E. (2021) Public attitudes towards the genetic testing in Georgia. *J. Comm. Genet.* 12: 407-411. <https://doi.org/10.1007/s12687-021-00522-7>
- Kling D., Egeland T., Herrera Piñero M., Vigeland M.V. (2017) Evaluating the statistical power of DNA-based identification, exemplified by 'The missing grandchildren of Argentina'. *FSI Genetics*, 31:57-76. <https://doi.org/10.1016/j.fsigen.2017.08.006>
- LePoire E., Basu B., Walker L., Bowen D.J. (2019) What do people think about genetics? A systematic review. *J. Comm. Genet.* 10(2): 171-187. <https://doi.org/10.1007/s12687-018-0394-0>
- Lerman G. (Ed.) (2017) Una pregunta. 30 años: Memoria escrita del Banco Nacional de Datos Genéticos. Ministerio Argentino de Ciencia, Tecnología e Innovación Productiva, Buenos Aires, Argentina.
- Levitt M. (2003) Public Consultation in Bioethics: What's the Point of Asking the Public When They Have neither Scientific nor Ethical Expertise? *Health Care Analysis*, 11(1): 15-25. <http://doi.org/10.1023/A:1025381828650>
- Majumder M.A., Cook-Deegan R., McGuire A.L. (2016) Beyond Our Borders? Public Resistance to Global Genomic Data Sharing. *PLoS Biol*, 14(11): e2000206. <https://doi.org/10.1371/journal.pbio.2000206>
- Martínez Marignac V., Bravi C., Lahitte H., Bianchi N. (1999) Estudio del ADN mitocondrial de una muestra de la ciudad de La Plata. *Rev. Argent. Antropol. Biol.* 2: 281-300. <http://sedici.unlp.edu.ar/handle/10915/6003>
- Mendoza M., Cabana G.S. (2019) Ancestría Genética en la Ciudad de Luján. In: Buzai G.; Lanzelotti S. (Eds.) Atlas de Geografía Humana de la Cuenca del Río Luján. Universidad Nacional de Luján, Luján, Buenos Aires, Argentina, pp. 196-97.
- Mendoza M., Mazza B., Cabana G.S., Smith L., Di Fabio Rocca F., Delfino H., Martínez C. (2022) Intergenerational Transmission of Ancestry Information in Argentina. *Latin American and Caribbean Ethnic Studies*. Published Online 2022-09-27 <http://doi.org/10.1080/1744222.2022.2120730>
- Michael M., Carter S. (2001) The Facts about Fictions and Vice Versa: Public Understanding of Human Genetics. *Science as Culture*, 10: 5-32. <https://doi.org/10.1080/09505430020025483>
- Molster C., Charles T., Samanek A., O' Leary P. (2009) Australian Study on Public Knowledge of Human Genetics and Health. *Public Health Genomics*, 12(2): 84-91. <http://doi.org/10.1159/000164684>
- Moodley K., Singh S. (2016) It's all about trust<sup>TM</sup>: reflections of researchers on the complexity and controversy surrounding biobanking in South Africa. *BMC Med. Ethics*, 17: 57. <https://doi.org/10.1186/s12910-016-0140-2>
- Papaleo H. (2015) Toman muestras para 'ancestralidad genética' en el Centro de Luján. *El Civismo*, July 12th edition. <http://www.elcivismo.com.ar/notas/21088> (accessed 7/13/2015)
- Penchaszadeh V.B. (2009) Argentina: Public Health Genomics. *Public Health Genomics*, 12: 59-65. <https://doi.org/10.1159/000153429>
- Penchaszadeh V.B. (2011) Forced disappearance and suppression of identity in children in Argentina. In: Gibbon S., Ventura Santos R., Sans M. (Eds.) Racial Identities, Genetic Ancestry and Health in South America: Brazil, Argentina, Uruguay and Colombia. Palgrave Macmillan, New York, NY, pp. 213-244.
- Penchaszadeh V.B. (2013) Genetic testing and services in Argentina. *J. Community Genet.* 4: 343-354. <https://doi.org/10.1007/s12687-012-0093-1>
- Petersen A. (2001) Biofantasies: Genetics and Medicine in the Print News Media. *Social Science and Medicine*, 52: 1255-68. [http://doi.org/10.1016/S0277-9536\(00\)00229-X](http://doi.org/10.1016/S0277-9536(00)00229-X)
- Peterson E.B., Chou W.S., Gaysynsky A., Krakow M., Elrick A., Khoury M.J., Kaphingst K.A. (2018) Communication of cancer-related genetic and genomic information: A landscape analysis of reviews. *Transl. Behav. Med.* 8(1): 59-70. <https://doi.org/10.1093/tbm/ibx063>
- Principi N., Buzai G. (2020) Análisis espacial de la vulnerabilidad socioeconómica de la ciudad de Luján (Argentina): interpretación modelística a partir de su mapa social para la identificación de áreas prioritarias de planificación. *Estudios Socioterritoriales Revista de Geografía*, 28: 1-16.
- Raz A.E., Niemiec E., Howard H.C., Sterck S., Cockbain J., Prainsack B. (2020) Transparency, consent and trust in the use of customers' data by an online genetic testing company: an Exploratory survey among 23andMe users. *New Genet. Soc.* 39(4): 459-482. <https://doi.org/10.1080/14636778.2020.1755636>
- Schumann S., Gschmeidler B., Pellegrini G. (2021) Knowing, relationships and trust—citizens' perceptions of whole genome sequencing for the Genetics Clinic of the Future. *J. Community Genet.* 12: 67-80. <https://doi.org/10.1007/s12687-020-00486-0>
- Spina S., Coirini E., Gago J., Patiño Rico J., Dejean C., Di Fabio Rocca F., Avena S. (2016) Reflexiones sobre identidad: Búsqueda de la ancestría genética en la ciudad de Buenos Aires. *Actas VIII Jornadas de Investigación en Antropología Social Santiago Wallace*, 27-29 julio 2016, Buenos Aires; pp. 2201-2214.
- Vishnopolaska S.A., Turjanski A.G., Herrera Piñero M., Groisman B., Liascovich R., Chiesa A., Marti M.A. (2018) Genetics and genomic medicine in Argentina. *Mol. Genet. Genomic Med.* 6(4): 481-491. <https://doi.org/10.1002/mgg3.455>
- Wang Q., Pang C., Meng L., Wang G. (2021) Public perceived knowledge of, attitude toward, and use of genetic testing in urban China. *J. Genet. Couns.* 00: 1-11. <https://doi.org/10.1002/jgc4.1428>