



RESEARCH ARTICLE

Italian public's views on sharing genetic information and medical information: findings from the 'Your DNA, Your Say' study [version 1; peer review: 1 approved, 2 approved with reservations]

Virginia Romano ^{1,2}, Richard Milne ^{3,4}, Deborah Mascialoni^{1,5}

¹Center for Research, Ethics and Bioethics, Uppsala University, Uppsala, Sweden, SE-751 05, Sweden

²Medical Ethics, Lund University, Lund, Sweden, 22362, Sweden

³Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK, UK

⁴Society and Ethics Research, Wellcome Connecting Science, Wellcome Genome Campus, Hinxton, UK, CB 10 1SA, UK

⁵Institute of Biomedicine, Eurac Research, Bolzano, Italy, 39100, Italy

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Abstract

Background: The collection and sharing of genomic and health data underpins global efforts to develop genomic medicine services. 'Your DNA, Your Say' is a cross-sectional survey with the goal of gathering lay public attitudes toward the access and sharing of deoxyribonucleic acid (DNA) information and medical information. It suggests significant international variation in the willingness to share information, and in trust in the actors associated with the collection and use of this information. This paper explores these questions in the Italian context.

Methods: The Italian Your DNA, Your Say campaign led to the collection of 1229 valid questionnaires. The sample was analysed using standard descriptive statistics. We described the sample in terms of gender, age ranges and self-reported religiosity, and split the sample amongst the five typically studied Italian macro-areas to explore regional variation. We analysed the relationship between these factors and trust and willingness to share medical and DNA information.

Results: The majority of the sample, across all socio-demographics, were willing to share DNA and health information with all entities considered except for-profit researchers. Respondents tended not to trust institutions beyond their own doctor. There was no difference between Italian regions.

Conclusions: Despite the generally positive attitude towards sharing, we suggest that the lack of trust in non-profit researchers and the government needs to be better understood to inform public communication projects around genomics in the future and to

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1. **Ellen Wright Clayton** , Vanderbilt University Medical Center, Nashville, USA
2. **Bastian Greshake Tzovaras** , Université de Paris, Paris, France
3. **Hüseyin Demirci** , University of Luxembourg, Esch-sur-Alzette, Luxembourg

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enhance awareness of DNA and medical information in Italy.

Keywords

DNA sharing, biobanks, bioethics, public attitudes, data sharing, Italy

Corresponding author: Virginia Romano (virginia.romano@crb.uu.se)

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Introduction

In order to achieve its potential to predict, diagnose, manage and treat genetic disease (Middleton *et al.*, 2018), clinicians and researchers working in genomic medicine need access to data from a diverse range of people across multiple datasets (Stark *et al.*, 2019). Public and patient support for and trust in the collection and sharing of genomic data is thus critical to realizing the potential of genomic medicine, making it imperative to understand the possible reasons against sharing and how to most effectively address these. It is therefore essential to both raise awareness of genomics among the general public and to better understand what issues, doubts and resistance the general public might have towards privacy issues (Kaye, 2012) and the responsible sharing and use of genomic information (Knoppers, 2014; Kosseim *et al.*, 2014; Phillips *et al.*, 2020). Empirical research examining public attitudes, values and beliefs is particularly relevant to give voice to those who are or will be directly affected by genomics (Middleton *et al.*, 2018), and because they allow us to explore the characteristics of those who are unwilling to share and their reasons (Middleton *et al.*, 2019). This is important in ensuring trust in genomic data sharing (Milne *et al.*, 2019).

The overall findings of the *Your DNA, Your Say* (YDYS) study suggest significant diversity between countries in the willingness to share DNA (or genetic) information, in trust in the different actors responsible for collecting and using DNA and health data, and in public familiarity with genomics (Middleton *et al.*, 2020). However, these overall patterns tell us little about the specific national, cultural, scientific and clinical contexts in which DNA and health data are collected, shared and used. In this paper we examine the *Your DNA, Your Say* data from Italy to consider in detail attitudes towards the sharing of genomics and health data in Italy.

Significant investment has been made by the Italian government in genomic data initiatives; the Italian Ministry of Health introduced a strategic policy plan on genomics and predictive medicine in 2010 (Mazzucco *et al.*, 2017), and Italy is among signatories to the [European 1+ Million Genomes initiative](#) (MEGA). However, research exploring familiarity and attitudes of Italian clinicians and health professionals towards genomic medicine, has suggested a need for additional clinical education (Boccia *et al.*, 2014; Marzuillo *et al.*, 2014). As yet however, there is little evidence on public attitudes towards the sharing of health and genomic data in the Italian context and the plans and activities of the Italian Ministry of Health in this area are far from being widely familiar to the general public (Simone *et al.*, 2013). A previous comparative analysis of the *Your DNA, Your Say* data (Middleton *et al.*, 2020), suggests that around 40% of Italians are familiar with DNA, genetics or genomics. In this paper, we draw on the *Your DNA, Your Say* data to examine how attitudes towards sharing vary across socio-demographic groups and what data about Italian respondents tells us about trust in this national context. In addition, we develop an exploratory analysis of variation between Italian regions in terms of the willingness to share and trust in actors responsible for collecting, sharing and storing genomic data.

Methods

The study is based on the Italian translation of the cross-sectional ‘Your DNA, Your Say’ survey that aims to gather lay public attitudes toward the sharing, access and sharing of DNA information and medical information (Middleton *et al.*, 2018). Data were collected using an online survey containing 29 questions presented in one of 22 languages – in this case, in Italian. The survey uses short video clips, presented in English and subtitled in Italian, to explain in lay terms the main reasons for and implications of the sharing and uses of DNA and medical information; moreover, it describes the different subjects to whom it is possible to share, the different purposes for which shared data may be used, and considers the ethical issues surrounding this decision. An English version of the survey can be found as extended data (Middleton *et al.*, 2021).

The Italian campaign was conducted through the market research company ResearchNow (now [Dynata](#)), and resulted in the collection of 1,229 valid questionnaires. The survey was designed to take 15–20 minutes to complete (Middleton *et al.*, 2018). Recruitment aimed at obtaining a sample that was as representative as possible of the Italian population with regard to gender, age, and education level. Italian data were downloaded on 27 August, 2019. Data were downloaded by country and then merged. The following initial cleaning rules were applied to the full data set (regardless of participant country):

- Removal of incomplete responses
- Removal of surveys which took five minutes or less to complete
- Removal of surveys in which the word ‘test’ (or some variant thereof) was included in free-text fields

Statistical analysis

The Italian sample was analysed using standard descriptive statistics and chi-squared tests using IBM [SPSS](#) Statistics version 27. The data can also be analysed using the open-source package [R](#). We started with an accurate description of the sample characteristics in terms of gender, age range and self-reported religiosity. Age was collected in ten-year categories from 16 onwards. Due to fewer responses in younger and older categories these were collapsed into categories of “30 years and under”, “31–40”, “41–50”, “51–60”, and “61 years and older” for analysis. Gender was self-described “Female” or “Male”. Whether participants had children was determined by a “Yes” or “No” answer. Level of education was categorized as “Tertiary”, “Secondary”, “Primary” or “Other” based on structured responses and free-text descriptions of respondents’ highest level of educational attainment. This was collapsed to a binary indicator of tertiary education. The exact age ranges associated with education categories vary between countries. However, we were interested in the highest level of educational attainment – particularly the difference between school and university education.

Religiosity was established based on responses to a question which asked “Whether you attend religious services or not,

would you say you are ... ?” with options “A religious person” or “Not a religious person”.

To explore regional variation, data were further split to capture the geographical distribution amongst the five typically studied Italian macro-areas, based on manual coding of participants’ responses to the question “Where do you live?”. Here we follow the Italian statistical standard whereby Italy is officially divided into five macro areas: Northwest (Piedmont, Aosta Valley, Liguria, Lombardia), Northeast (Trentino-Alto Adige, Veneto, Friuli-Venezia Giulia, Emilia-Romagna), Center (Toscana, Umbria, Marche, Lazio), South (Abruzzo, Molise, Campania, Puglia, Basilicata, Calabria) and Islands (Sicilia, Sardegna). Differences were explored using descriptive statistics and chi-square tests. Because the sample was not collected with reference to these regions, these sub-groups are necessarily small and less representative of regional populations than the overall sample is of the Italian population. However, given the potential importance of regional variation discussed above, this analysis may offer significant value and avenues for future exploration.

We then analysed the relationship between these descriptive variables and two main dependent variables using chi-square tests: trust towards different entities and willingness to share medical and DNA information to the same mentioned entities.

Ethics and consent

The online survey was fully anonymous. Participants were informed that their consent is given when they choose to click off the landing page and start answering the questions. On the landing page, the purpose of the project is explained as well as what participation involves, participants have a choice at any stage within the survey, to stop answering the questions and withdraw. The online project is physically based at the Wellcome Genome Campus with all data collected and stored in encrypted files at the Wellcome Sanger Institute in Cambridge. As part of the conditions of research delivery at this research institution the project passed ethical review by the Human Materials and Data Management Committee of the Wellcome Sanger Institute (Registration Number: 16/029) as well as legal review to ensure that it was compliant with ethical and legal standards for participant involvement, data collection and storage.

Results

The socio-demographic distribution of the sample is described in [Table 1](#) ([Middleton et al., 2021](#)). The largest group of respondents (301, 24.5%) was in the age range between 41 and 50 years, and the sample was balanced between males and females (627:602). The majority of the sample (846, 68.8%) obtained secondary education, while 64% (786) self-reported being “a religious person”.

In terms of the geographic distribution of the sample ([Table 2](#)), 334 (27.2%) respondents did not provide a response to this question that enabled their region to be classified, and as such are excluded from the regional analysis. Of those included, the

Table 1. Sociodemographics of Your DNA, Your Say (YDYS) Italy sample.

Variable	Categories	Italy	
		N	%
Age category (years)	30 and under	218	17.7
	31–40	215	17.5
	41–50	301	24.5
	51–60	237	19.3
	Over 60	258	21
Gender	Female	627	51
	Male	602	49
Has children	No	458	37.3
	Yes	761	61.9
	Missing	10	0.8
Highest education level	Tertiary	351	28.6
	Secondary	846	68.8
	Primary	18	1.5
	Other	13	1.1
	Missing	1	0.1
Religiosity	Not a religious person	443	36
	A religious person	786	64
	Missing	0	0

majority of the sample (35.4%) replied from northwest regions, while only 10.2% of respondents came from the two main Italian islands. As can be seen, while the distribution of respondents in the two northern regions differs from the overall Italian population, the split between North, Central, South and Islands approximates that of the [Istat \(2019\)](#) data.

Willingness to share

Overall, willingness to share is high amongst our sample ([Table 3](#)). Most (64%) declared they would be willing to share their DNA and medical information for use by at least one data user, while those who were unwilling (14%) and the undecided (22%) represent a minority of the sample as a whole.

Age. Overall, positive attitudes towards sharing – i.e. those who were willing to share data with at least one actor – were significantly higher for those 30 years and under (75.2%) and 31 to 40 years (74.4%) than other groups, declining substantially for the over 60s (53.1%, $p < 0.001$) but differences for specific recipients of data are not significant (see [Figure 1](#) and [Table 3](#)). The overall attitude towards sharing is positive (60% for sharing with their doctor and 57% for sharing with non-profit researchers).

Table 2. Geographic distribution of the Your DNA, Your Say (YDYS) Italy sample, compared to official population data.

Macro-area	Frequency	Percentage of sample (excluding missing)	Percentage of Italian population (iStat data)
Northwest	317	35.4%	26.8%
North East	112	12.5%	23.0%
Center	178	19.9%	19.8%
South	197	22.0%	19.5%
Islands	91	10.2%	10.9%
Total	895	100%	100%

Table 3. Variation in willingness to share medical and deoxyribonucleic acid (DNA) information by actor, demographics, religiousness, region and general trust.

		Willingness to share with at least 1			Share with Doctor			Share with non-profit user			Share with for profit user		
		No	Unsure	Yes	No	Unsure	Yes	No	Unsure	Yes	No	Unsure	Yes
		Row N %	Row N %	Row N %	Row N %	Row N %	Row N %	Row N %	Row N %	Row N %	Row N %	Row N %	Row N %
Age (years)	30 and under	13.8%	11.0%	75.2%	8.8%	25.8%	65.4%	13.3%	30.3%	56.4%	23.9%	39.0%	37.2%
	31–40	16.7%	8.8%	74.4%	9.3%	26.5%	64.2%	12.1%	25.6%	62.3%	25.7%	33.2%	41.1%
	41–50	21.6%	15.3%	63.1%	12.0%	31.6%	56.5%	14.3%	31.6%	54.2%	26.9%	33.9%	39.2%
	51–60	24.9%	18.6%	56.5%	14.8%	24.1%	61.2%	14.3%	25.3%	60.3%	29.1%	30.8%	40.1%
	Over 60	30.6%	16.3%	53.1%	14.7%	29.8%	55.4%	17.4%	27.9%	54.7%	27.5%	38.0%	34.5%
Gender	Male	18.6%	14.3%	67.1%	11.8%	25.8%	62.4%	13.8%	25.6%	60.6%	26.4%	34.6%	39.0%
	Female	25.0%	14.2%	60.8%	12.3%	29.8%	57.9%	15.0%	30.9%	54.1%	27.0%	35.3%	37.7%
Tertiary education	No	23.8%	17.0%	59.2%	12.5%	29.6%	57.8%	14.7%	30.0%	55.4%	26.5%	36.3%	37.3%
	Yes	17.1%	7.4%	75.5%	10.8%	23.4%	65.8%	13.7%	24.2%	62.1%	27.4%	31.6%	41.0%
Macro area	North West	24.6%	15.8%	59.6%	13.9%	29.0%	57.1%	14.8%	30.9%	54.3%	24.3%	35.0%	40.7%
	North East	16.1%	13.4%	70.5%	7.1%	21.4%	71.4%	9.8%	30.4%	59.8%	25.9%	37.5%	36.6%
	Central	19.1%	12.9%	68.0%	10.1%	29.2%	60.7%	12.4%	28.1%	59.6%	29.8%	32.0%	38.2%
	South	23.9%	15.7%	60.4%	10.7%	33.2%	56.1%	14.7%	31.5%	53.8%	27.0%	36.2%	36.7%
	Islands	20.9%	13.2%	65.9%	13.2%	18.7%	68.1%	12.1%	24.2%	63.7%	20.9%	38.5%	40.7%
Religion	A religious person	23.3%	16.0%	60.7%	12.7%	28.5%	58.7%	14.2%	29.1%	56.6%	24.7%	33.8%	41.5%
	Not a religious person	19.4%	11.1%	69.5%	10.8%	26.6%	62.5%	14.7%	26.9%	58.5%	30.2%	37.0%	32.7%
Trust	No	29.0%	17.2%	53.8%	16.5%	35.8%	47.7%	19.5%	36.4%	44.2%	33.9%	38.8%	27.3%
	Yes	11.0%	9.7%	79.3%	5.2%	15.7%	79.1%	6.6%	15.9%	77.5%	15.7%	28.9%	55.4%

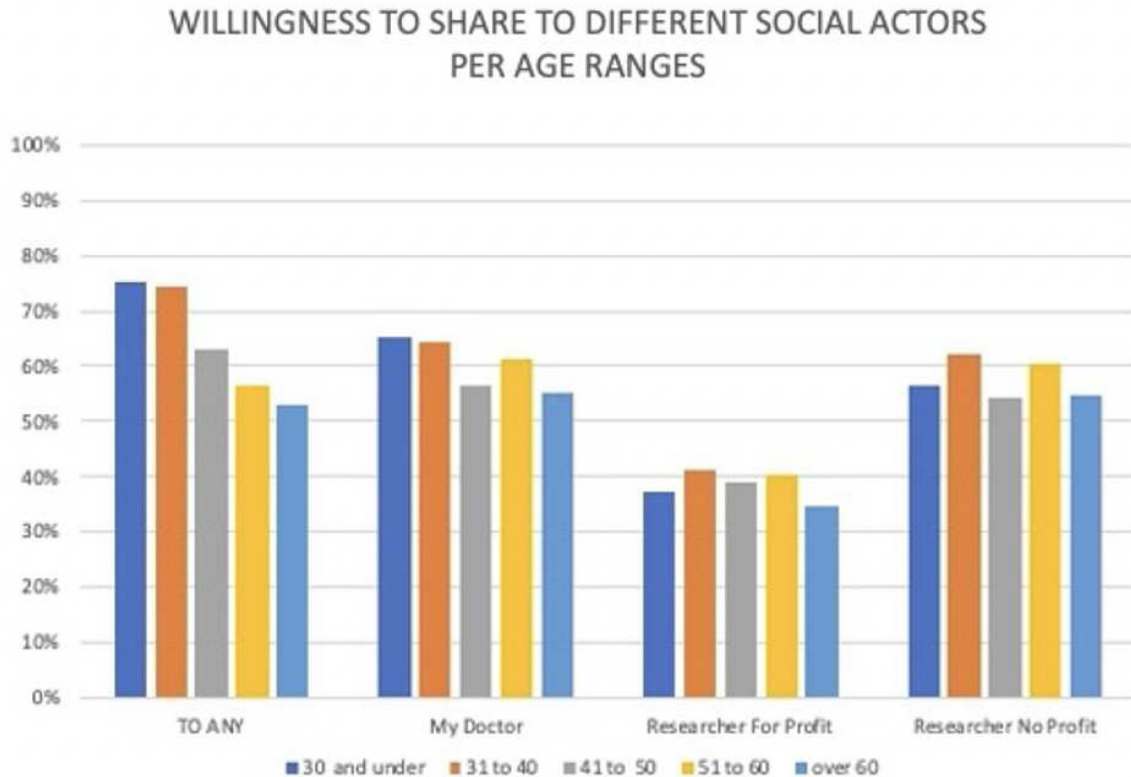


Figure 1. Willingness to share medical and deoxyribonucleic acid (DNA) data with different social actors by age group.

When asked about willingness to share with for-profit researchers, the overall percentage of uncertain respondents is higher (35%) —and for this category of recipient only— is higher than that of negative respondents (27%).

Regional analysis. The general attitude towards willingness to share seems stronger both in Northern regions (59.6% and 70.5% positive respondents, respectively, for North West and North East) followed by Islands (see Figure 2), across all categories of recipient social actors. Southern regions are less inclined for sharing (with a general positive attitude towards sharing of 60.4%), while central regions have a halfway position (68% of positive respondents to sharing in general). Although these variations are interesting, overall differences were not statistically significant.

Religiosity. Overall, non-religious respondents were significantly more likely to be willing to share with at least one data user than religious respondents (69.5 vs 60.5%, $p=0.006$, see Table 2). However, this varied substantially between data users. Both religious and non-religious respondents expressed a positive attitude towards sharing with a peak of 62.5% of non-religious persons to their doctor. This general trend has one main exception regarding attitudes towards for-profit researchers:

in this case, the percentage decreases to 34% and merges into the “uncertain” category (see Figure 3).

Overall, religious participants appear more cautious in terms of their attitude towards sharing. However, in terms of willingness to share to for-profit researchers, there is a significantly higher positive response among those who describe themselves as religious (41.5%) than among non-religious people (32.7%; $p=0.05$). However, the distance between positive attitude between religious and non-religious respondents does not appear as significant as the distance between attitudes towards the recipients of sharing.

Trust. Overall, those people with the highest level of trust – i.e. those who state that they trust two or more actors – are significantly more likely to be willing to share. In the following section, we consider who is most likely to trust, and how this varies across the Italian sample.

Age. The level of trust varies by actor, but is low for all categories except My Doctor, on average lower than 30% and as low as 8% when respondents are asked whether or not they trust their government (Table 4). When the category changed to other doctors, social actors and institutions, stated trust dropped to

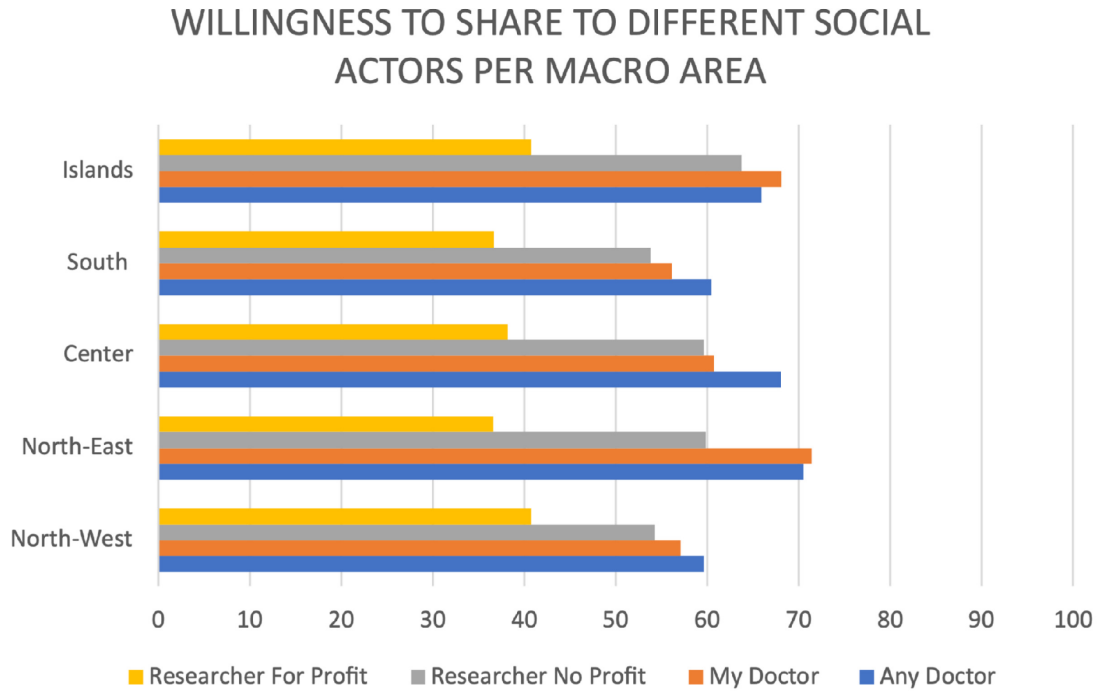


Figure 2. Willingness to share medical and deoxyribonucleic acid (DNA) data by actor and macro area.

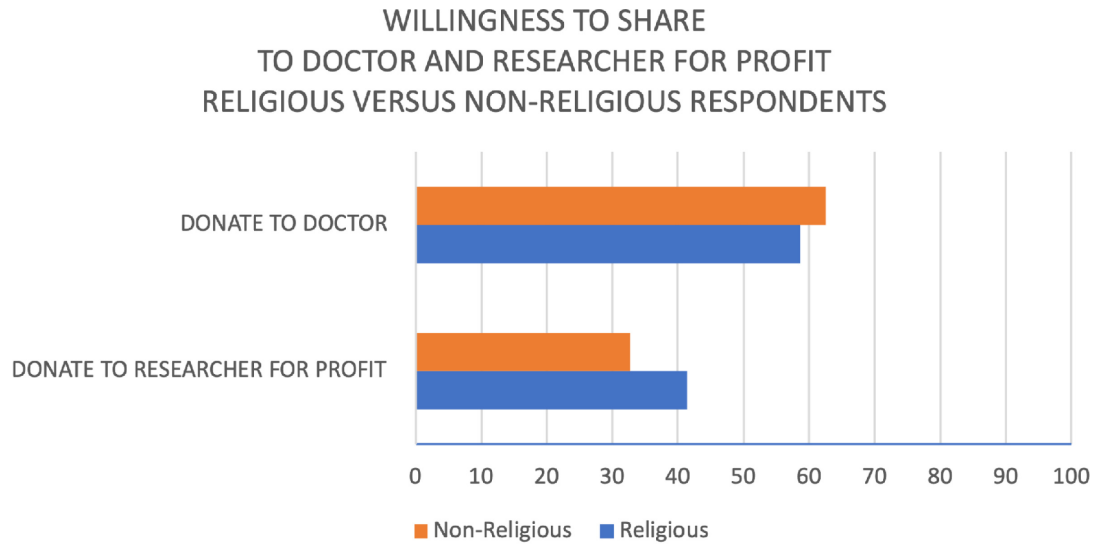


Figure 3. Willingness to share medical and deoxyribonucleic acid (DNA) data to doctor or researcher for profit by religion.

a low of 8.6% (for-profit researcher) and a maximum of 36.7% (non-profit researcher). There was no significant difference in trust by age - the majority of people in all age ranges (71.4%) declared they trust their own doctors, varying from 77.1% (for people over 60) to a minimum of 66% (for people between 41 and 50 years).

Regional analysis. Levels of trust towards different subjects and institutions considered per macro regional area follow the same overall pattern, with the greatest trust in doctors, followed by non-profit researchers and finally for-profit research and government. Regions belonging to the islands consistently show the highest levels of self-reported trust i.e. towards their doctor

Table 4. Variation in trust by actor, demographics and region.

		Trust in more than one actor		Trust in my doctor		Trust in any doctor in my country		Trust in non-profit researcher in my country		Trust in for-profit researcher in my country		Trust in the government of my country	
		No	Yes	No/Not sure	Yes	No/Not sure	Yes	No/Not sure	Yes	No/Not sure	Yes	No/Not sure	Yes
Age	30 and under	58.3%	41.7%	27.5%	72.5%	73.9%	26.1%	65.1%	34.9%	86.7%	13.3%	88.5%	11.5%
	31–40	55.8%	44.2%	29.3%	70.7%	69.2%	30.8%	63.3%	36.7%	87.0%	13.0%	86.5%	13.5%
	41–50	65.1%	34.9%	33.2%	66.8%	79.4%	20.6%	71.1%	28.9%	91.4%	8.6%	91.7%	8.3%
	51–60	62.0%	38.0%	29.1%	70.9%	77.1%	22.9%	68.8%	31.2%	91.1%	8.9%	89.4%	10.6%
	Over 60	60.1%	39.9%	22.9%	77.1%	77.5%	22.5%	66.3%	33.7%	92.2%	7.8%	88.0%	12.0%
Gender	Male	59.0%	41.0%	28.7%	71.3%	75.9%	24.1%	65.1%	34.9%	89.5%	10.5%	86.9%	13.1%
	Female	62.2%	37.8%	28.4%	71.6%	75.7%	24.3%	69.2%	30.8%	90.3%	9.7%	91.1%	8.9%
Tertiary education	No	61.2%	38.8%	29.0%	71.0%	76.1%	23.9%	68.3%	31.7%	89.5%	10.5%	89.1%	10.9%
	Yes	59.3%	40.7%	27.4%	72.6%	74.9%	25.1%	64.4%	35.6%	90.9%	9.1%	88.9%	11.1%
Macro area	North West	83.2%	16.8%	24.3%	75.7%	74.1%	25.9%	65.3%	34.7%	89.3%	10.7%	90.2%	9.8%
	North East	81.3%	18.8%	25.0%	75.0%	72.3%	27.7%	64.3%	35.7%	89.3%	10.7%	90.2%	9.8%
	Central	85.4%	14.6%	29.8%	70.2%	76.4%	23.6%	63.5%	36.5%	88.8%	11.2%	91.0%	9.0%
	South	87.3%	12.7%	32.0%	68.0%	78.1%	21.9%	74.6%	25.4%	90.4%	9.6%	88.8%	11.2%
	Islands	83.5%	16.5%	23.1%	76.9%	79.1%	20.9%	67.0%	33.0%	87.9%	12.1%	79.1%	20.9%
Religion	A religious person	60.7%	39.3%	28.8%	71.2%	75.8%	24.2%	68.4%	31.6%	89.4%	10.6%	87.5%	12.5%
	Not a religious person	60.5%	39.5%	28.2%	71.8%	75.8%	24.2%	65.0%	35.0%	90.7%	9.3%	91.6%	8.4%

(76.9% of positive respondents), followed by Northern regions (respectively scoring 75.7 % of positive respondents in north west and 75% in north east). Central regions (70.2%) come next, followed by southern regions (68%). Northern regions (both east and west) generally tend to have scores that are closer to islands than other macro areas (see [Figure 2](#)). However, these differences by region in the levels of trust in each actor are not significant (My doctor $p=0.259$; Country Doctor $p=.673$, Any doctor $p=.624$, non-profit $p=.138$, for profit, $p=.977$).

Religiosity. No significant difference in trust towards different social actors was associated with religiosity (My doctor $p=.842$; Country Doctor $p=.975$, Any doctor $p=.495$; non-profit $p=.218$, for profit, $p=.466$).

Discussion

In the Italian Your DNA, Your Say sample, overall willingness to share DNA and health information varies along key demographics. Specifically, older age, being female, having less than tertiary education, and expressing religious beliefs are associated with lower overall willingness to share. Overall trust

(that is, trust in multiple data users) is also strongly associated with the willingness to share. However, no clear relationship can be identified between socio-demographic characteristics and either overall trust or trust in specific data users.

When considering overall willingness to share as a whole, we found similar attitudes towards doctors and non-profit researchers, suggesting that these actors are considered in a similar way. In contrast, when asked about willingness to share with for-profit researchers, the percentage of uncertain respondents was higher than that of negative respondents (Not sure 35%; No 27%). This strong uncertainty appears consistent with the general pattern of trust among our respondents.

Public trust in genomic data sharing is a complex matter ([Critchley et al., 2015](#); [Milne et al., 2019](#)) it depends both on personal attitudes as well as on the potential recipients and users of data, how their goals are perceived to be connected to the common good and how these matters are communicated to the wider lay public. Generally, Italian respondents reveal a low level of trust towards social actors such as doctors and

institutions, with the major exception of the figure of their personal doctor.

The distinctive attitudes towards personal doctor strengthens and consolidates the importance of trust as a key factor to understand willingness to share overall. Among the different potential recipients and users of data, the personal doctor is someone participants have known for a long time, who is seen as the main point of contact for their own health and who has had the chance to gain their trust in many different occasions (Mechanic, 1998; Rowe & Calnan, 2006). As such, the personal doctor is the one actor participants are more likely to have a personal reason to trust. This pattern of responses also highlights the persistent importance of the family doctor in an Italian context, suggesting this professional figure could play a pivotal role in facilitating engagement about the sharing of DNA and medical information due to issues of access to and familiarity with patients. While more evidence is needed to clearly understand the role that this professional figure might play in the context of the different Italian regional health systems, our findings suggest that public health communication campaigns around genetic medicine could benefit from involving the family doctor to promote personalized forms of communication and facilitate recruitment.

Indeed, the data show low levels of trust in social actors that participants have little direct experience of, and whose interests and goals may be unknown. Our data suggests that trust in institutions or social entities perceived as distant and abstract cannot be taken for granted in the Italian context. The finding corroborates the overall pattern of responses found in the wider YDYS dataset as well as data specific to the Italian context (Istat, 2019; Middleton *et al.*, 2020). Italian respondents show the highest levels of mistrust towards two specific categories: researchers for profit and their government. Trust towards government may be related to the historically high mistrust of Italian people towards institutions (Hooghe & Stolle, 2003). However, the question of trust in for-profit researchers emphasizes the importance of motives when considering willingness to share data for use by different actors. In relation to for-profit research, previous studies have suggested that many people show a ‘natural prejudice’ (Nicol *et al.*, 2016) against commercial use of health and genetic data. Issues surrounding the commercialization of health data, in general, and more specifically of genetic information are increasingly conceptualized as multi-faceted, recognizing the importance of bioethical and regulatory considerations related to the management of biobanks as well as their need to survive through some sort of compromise with the market (Caulfield *et al.*, 2014; IPSOS Mori, 2016; McWhirter *et al.*, 2020). Nevertheless, even if commercialization of genetic data tends to generate a negative reaction, research in this field underscores how good communication and a better engagement of the public about the possible benefits for the common good deriving from commercial involvement (Skovgaard *et al.*, 2019; Solum Steinsbekk *et al.*, 2013) could result in more positive public attitudes towards the involvement of for-profit actors. Economic and scientific interests are not extremes on a spectrum, and can be aligned and work together in the interest of the public. Effective science education and communication —before even

considering questions surrounding DNA—might be a good starting point to be able to engage with complexity.

Privacy is a big issue in Italian culture (Rodotà, 1995) especially if considered in the wider context of lack of trust towards institutions (Hooghe & Stolle, 2003; Huyseune, 2003; Putnam *et al.*, 1993). We therefore feel confident in formulating the hypothesis that attitudes towards sharing is closely associated with issues of privacy and trust, and that these factors should be at the centre of further research on public views on the sharing of genomic data in Italy. It should also be noted that some of the strongest data we have on attitudes about willingness to share pertain to the percentages of uncertain respondents. Specifically, the number of people replying “I don’t know” to questions about their willingness to share medical and genetic information was consistently high, and often even higher than the number of people expressing positive or negative answers. In light of this finding, we suggest that this issue needs further investigation through both qualitative and quantitative methods, as this doubtful attitude could indicate a greater need for better communication about genetics and data sharing that is specifically targeted to the general public and to all age groups.

Macro areas

Regional differences are potentially important in the Italian context for historical, statistical and administrative reasons (Felice, 2011; Wagstaff, 1999), and in light of the regionalisation of the Italian health system (Pavolini & Vicarelli, 2012; Toth, 2014; Vicarelli, 2015). However, the results presented do not allow to draw substantial conclusions about the differences between Italian regions, despite wider evidence of strong and persistent regional differences in people’s relationships towards institutions (Putnam *et al.*, 1993). The lack of difference between regions may be partly due to the *post hoc* sampling and the high proportion of respondents who did not provide an accurate location within Italy. Nevertheless, the subtle variation we have started to observe suggests the potential value of further exploration building on historical and sociological work on cultural differences between Italian regions, particularly on differences in social and cultural capital (Putnam *et al.*, 1993; Putnam, 2000).

Religiosity

Allum and colleagues suggest that religion may act as a “perceptual filter”, moderating the relationship between knowledge and attitudes. (Allum *et al.*, 2014: 846). Existing surveys on issues surrounding genomics, gene editing, gene therapy and bioethical issues associated with this technology have often identified (lower) religiosity as an explanation for a more positive attitude towards DNA sharing (Pew Research, 2016; Sanderson *et al.*, 2017). However, attitudes towards medical genetics are connected to religious beliefs in complex ways (Allum *et al.*, 2014); a clear connection between religious affiliation and attitudes towards genetics is complicated by the need to consider a wider array of variables that may have a bigger impact on those very attitudes than religiosity (i.e. the severity of the condition for which genetic testing or similar tools are being accessed) (Botosaneanu *et al.*, 2011).

In particular, an exception to this general association between (low) religiosity and willingness to share was evident in attitudes towards for-profit researchers. Though self-reported religious people appeared overall more cautious about sharing, this group was more willing than non-religious people to share data with for-profit researchers. More data is needed to fully understand the reasons behind these responses, particularly in light of the high percentage of uncertain responses. One hypothesis could be the potentially greater propensity of religious people to trust institutions. Against the general lack of trust in institutions that characterizes contemporary Italian society (Hooghe & Stolle, 2003), religiosity may be a booster of social cohesion and, in a way, protect respondents from distrust. However, in our work, the difference in trust between self-reported religious and non-religious people is not significant, while the difference in willingness to share is, suggesting that on such a complex and multi-faceted issue such as DNA and medical information sharing, we do not yet have enough evidence to explain the role that religiosity plays and its interaction with factors such as familiarity with genetic disease (cf Porter *et al.*, 2014). Future research on this theme might aim to understand better the specific influence of religiosity on public attitudes.

Limitations

The overall limitations of the YDYS questionnaire have been reported elsewhere (Middleton *et al.*, 2018). As an exploratory cross-sectional online survey, the study is limited in that it captures intended behaviour at a single time point. One specific limitation is the reliance in this analysis on self-reported data, particularly related to location and religiosity.

Conclusions

The findings of the Your DNA, Your Say in Italy have value in starting to describe what the Italian population think about sharing genetic and health data, allowing an initial analysis of themes such as willingness to donate and trust in this specific sociocultural environment. As our data clearly show, given the average high occurrence of the answer “I don’t know” in any of the variables taken into consideration, there is still a great need to engage the Italian public with issues surrounding

genomics, its clinical potential and risks. We believe that the findings presented in this article can be used to inform educational and engagement strategies and initiatives aimed at improving public awareness of genomics and data sharing in Italy. Specifically, the findings clearly point to two directions of future work: i) further research to better define a precise sociocultural profile of people positively and negatively oriented to both trust and sharing and ii) involvement of family doctors as facilitators.

Data availability

Underlying data

Open Science Framework: Your DNA Your Say data file. <https://doi.org/10.17605/OSF.IO/ZPFGM> (Middleton *et al.*, 2021).

This project contains the following underlying data:

- YDYS dataset for sharing.csv

Extended data

Open Science Framework: Your DNA Your Say data file. <https://doi.org/10.17605/OSF.IO/ZPFGM> (Middleton *et al.*, 2021).

This project contains the following extended data:

- dataDictionary.csv
- pme-2018-0032.pdf (Description of study design)
- Word Version GA4GH Survey.docx

Data are available under the terms of the [Creative Commons Attribution 4.0 International license](https://creativecommons.org/licenses/by/4.0/) (CC-BY 4.0).

Acknowledgements

Our work is part of the [Your DNA Your Say](https://www.yourdna.org/) global project. We would like to thank Alessia Costa for editing the final version of this work. We would like to thank Anna Middleton and Heidi C. Howard for their roles in bringing the Italian study into the Your DNA, Your Say project.

References

- Allum N, Sibley E, Sturgis P, *et al.*: **Religious beliefs, knowledge about science and attitudes towards medical genetics.** *Public Underst Sci.* 2014; **23**(7): 833–49.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Boccia S, Antonio F, Marco C, *et al.*: **Le Policy Di Genomica in Sanità Pubblica in Italia: Le Sfide Nella Implementazione Delle Linee Guida Nel Sistema Sanitario Nazionale.** *Epidemiol Prev.* 2014; **38**(6 Suppl 2): 29–34.
[Reference Source](#)
- Botosaneanu A, Alexander JA, Banaszak-Holl J: **To test or not to test? The role of attitudes, knowledge, and religious involvement among U.S. adults on intent-to-obtain adult genetic testing.** *Health Educ Behav.* 2011; **38**(6): 617–28.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Caulfield T, Burningham S, Joly Y, *et al.*: **A review of the key issues associated with the commercialization of biobanks.** *J Law Biosci.* 2014; **1**(1): 94–110.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Critchley C, Nicol D, Otlowsky DNM: **The impact of commercialisation and genetic data sharing arrangements on public trust and the intention to participate in biobank research.** *Public Health Genomics.* 2015; **18**(3): 160–172.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Felice E: **Regional value added in Italy, 1891–2001, and the foundation of a long-term picture.** *Econ Hist Rev.* 2011; **64**(3): 929–950.
[Publisher Full Text](#)
- Funk C, Kennedy B, Scrupac EP: **U.S. Public Wary of Biomedical Technologies to ‘Enhance’ Human Abilities.** *Pew Research Center.* 2016.
[Reference Source](#)
- Gaskell G, Bard I, Allansdottir A, *et al.*: **Public views on gene editing and its uses.** *Nat Biotechnol.* 2017; **35**(11): 1021–1023.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Hooghe M, Stolle D: **Generating Social Capital. Civil Society and Institutions in Comparative Perspective.** Palgrave MacMillan, New York. 2003.
[Publisher Full Text](#)
- Huyseune M: **Institutions and Their Impact on Social Capital and Civic**

- Culture: The Case of Italy.** In: Hooghe M., Stolle D. (eds) *Generating Social Capital*. Palgrave Macmillan, New York. 2003.
[Publisher Full Text](#)
- Ipsos MORI: **The One-Way Mirror: Public Attitudes to Commercial Access to Health Data.** London: The Wellcome Trust. 2016.
[Reference Source](#)
- Istat: **Il Benessere Equo e Solidale in Italia.** Istituto Nazionale di Statistica, Roma. 2019.
[Reference Source](#)
- Kaye J: **The Tension Between Data Sharing and the Protection of Privacy in Genomics Research.** *Annu Rev Genomics Hum Genet.* 2012; **13**(1): 415–31.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Knoppers BM: **Framework for Responsible Sharing of Genomic and Health-Related Data.** *Hugo J.* 2014; **8**(1): 3.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Kosseim P, Dove ES, Baggaley C, et al.: **Building a Data Sharing Model for Global Genomic Research.** *Genome Biol.* 2014; **15**(8): 430.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Kulynych J, Greely HT: **Clinical genomics, big data, and electronic medical records: reconciling patient rights with research when privacy and science collide.** *J Law Biosci.* 2017; **4**(1): 94–132.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Leshner AI: **Public engagement with science.** *Science.* 2003; **299**(5609): 977.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Lunshof JE, Chadwick R, Vorhaus DB, et al.: **From genetic privacy to open consent.** *Nature Reviews. Nat Rev Genet.* 2008; **9**(5): 406–411.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Mai JE: **Big data privacy: The datafication of personal information.** *Inform Soc.* 2016; **32**(3): 192–199.
[Publisher Full Text](#)
- Marzuillo C, De Vito C, D'Addario M, et al.: **Are Public Health Professionals Prepared for Public Health Genomics? A Cross-Sectional Survey in Italy.** *BMC Health Serv Res.* 2014; **14**(1): 239.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Mazzucco W, Pastorino R, Lagerberg T, et al.: **Current State of Genomic Policies in Healthcare among EU Member States: Results of a Survey of Chief Medical Officers.** *Eur J Public Health.* 2017; **27**(5): 931–37.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- McCaughey T, Sanfilippo PG, Gooden GEC, et al.: **A Global Social Media Survey of Attitudes to Human Genome Editing.** *Cell Stem Cell.* Elsevier Inc. 2016; **18**(5): 569–572.
[PubMed Abstract](#) | [Publisher Full Text](#)
- McWhirter R, Eckstein L, Chalmers D, et al.: **A Scenario-Based Methodology for Analyzing the Ethical, Legal, and Social Issues in Genomic Data Sharing.** *J Empir Res Hum Res Ethics.* 2020; **15**(4): 355–364.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Mechanic D: **The Functions and Limitations of Trust in the Provision of Medical Care.** *J Health Polit Policy Law.* 1998; **23**(4): 661–86.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Middleton A, Niemiec E, Prainsack B, et al.: **'Your DNA, Your Say': Global Survey Gathering Attitudes toward Genomics: Design, Delivery and Methods.** *Per Med.* 2018; **15**(4): 311–18.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Middleton A, Milne R, Almarri MA, et al.: **Global Public Perceptions of Genomic Data Sharing: What Shapes the Willingness to Donate DNA and Health Data?** *Am J Hum Genet.* 2020; **107**(4): 743–52.
[Publisher Full Text](#)
- Middleton A, Milne R, Morley KI, et al.: **Your DNA Your Say data file.** 2021. <http://www.doi.org/10.17605/OSF.IO/ZPFGM>
- Middleton A, Milne R, Thorogood A, et al.: **Attitudes of publics who are unwilling to donate DNA data for research.** *Eur J Med Genet.* 2019; **62**(5): 316–323.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Milne R, Morley KI, Howard H, et al.: **Trust in Genomic Data Sharing among Members of the General Public in the UK, USA, Canada and Australia.** *Hum Genet.* 2019; **138**(11–12): 1237–1246.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Nicol D, Critchley C, McWhirter R, et al.: **Understanding public reactions to commercialization of biobanks and use of biobank resources.** *Soc Sci Med.* 2016; **162**(2016): 79–87.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Pavolini E, Vicarelli G: **Is Decentralization Good for Your Health? Transformations in the Italian NHS.** *Curr Sociol.* 2012; **60**(4): 472–88.
[Publisher Full Text](#)
- Pew Research Center, Funk C, Hefferon M: **Public Views of Gene Editing for Babies Depend on How It Would Be Used.** 2018; 1–34.
[Reference Source](#)
- Phillips M, Molnár-Gábor F, Korbel JO, et al.: **Genomics: Data Sharing Needs an International Code of Conduct.** *Nature.* 2020; **578**(7793): 31–33.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Porteri C, Pasqualetti P, Togni E, et al.: **Public's attitudes on participation in a biobank for research: an Italian survey.** *BMC Med Ethics.* 2014; **15**: 81.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Putnam RD, Leonardi R, Nonetti RY: **Making Democracy Work: Civic Traditions in Modern Italy.** Princeton, Princeton University Press, 1993.
[Reference Source](#)
- Putnam RD: **Bowling alone. The Collapse and Revival of American Community.** Simon & Schuster Paperbacks, New York. 2000.
[Reference Source](#)
- Rodotà S: **Tecnologia e Diritti, Il Mulino, Bologna.** 1995.
[Reference Source](#)
- Rowe R, Calnan M: **Trust Relations in Health Care—the New Agenda.** *Eur J Public Health.* 2006; **16**(1): 4–6.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Sanderson SC, Brothers KB, Mercaldo ND, et al.: **Public Attitudes toward Consent and Data Sharing in Biobank Research: A Large Multi-site Experimental Survey in the US.** *Am J Hum Genet.* 2017; **100**(3): 414–427.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Schadt EE: **The changing privacy landscape in the era of big data.** *Mol Syst Biol.* 2012; **8**: 612.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Scheufele DA, Xenos MA, Howell EL, et al.: **U.S. attitudes on human genome editing.** *Science.* 2017; **357**(6351): 553–554.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Simone B, Mazzucco W, Gualano MR, et al.: **The Policy of Public Health Genomics in Italy.** *Health Policy.* 2013; **110**(2–3): 214–19.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Skovgaard LL, Wadmann S, Hoeyer K, et al.: **A review of attitudes towards the reuse of health data among people in the European Union: The primacy of purpose and the common good.** *Health Policy.* 2019; **123**(6): 564–571.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- STAT, Harvard T.H. Chan School of Public Health: **The Public and Genetic Editing, Testing and Therapy.** 2016.
[Reference Source](#)
- Stark Z, Dolman L, Manolio TA, et al.: **Integrating Genomics into Healthcare: A Global Responsibility.** *Am J Hum Genet.* 2019; **104**(1): 13–20.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Solum Steinsbekk K, Ursin LO, Skolbekken JA, et al.: **We're not in it for the money-lay people's moral intuitions on commercial use of 'their' biobank.** *Med Health Care Philos.* 2013; **16**(2): 151–162.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Toth F: **How Health Care Regionalisation in Italy Is Widening the North-South Gap.** *Health Econ Policy Law.* 2014; **9**(3): 231–50.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Vicarelli: **Healthcare: Difficult paths to reform.** In Ascoli, Ugo, Pavolini E: *The Italian Welfare State in a European Perspective: A Comparative Analysis.* Policy Press, 2015.
[Publisher Full Text](#)
- Wagstaff P: **Regionalism in the European Union.** Intellect, Exter, England. 1999.
[Reference Source](#)
- Wjst M: **Caught you: threats to confidentiality due to the public release of large-scale genetic data sets.** *BMC Med Ethics.* 2010; **11**: 21.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)

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Current Peer Review Status: ? ? ✓

Version 1

Reviewer Report 17 February 2022

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Hüseyin Demirci 

SnT, University of Luxembourg, Esch-sur-Alzette, Luxembourg

In this paper, the authors have analyzed the data from an Italian group of 'Your DNA, Your Say project' participants. While genome sequencing and direct-to-consumer services are becoming more available, this kind of study is crucial to better understand the privacy expectations of users.

The authors have analyzed the acceptance of genomics sharing against variables such as age, gender, residence location, education level, and religiosity. They analyzed the willingness to share with their special doctor, any doctor, for-profit and non-profit research purposes. The paper is generally well written and easy to read. The data analysis from the national and regional points of view gives important insights.

I just have a minor comment that for instance Figure 1 has low image quality, which probably may be related to the DPI resolution. Otherwise, I suggest approving the paper since we need more work in this area.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.**Reviewer Expertise:** Privacy-preserving methods for genomics privacy.**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 02 February 2022

<https://doi.org/10.21956/wellcomeopenres.18654.r48298>

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**Bastian Greshake Tzovaras** 

Université de Paris, Paris, France

This article contributes to existing literature on attitudes towards genetic/medical data sharing by presenting the results of the Italian branch of the international *Your DNA, Your Say* study and giving an overview of the attitudes towards the sharing of DNA & medical information among the Italian's public.

The article itself is well written and presents its arguments clearly. The main limitation I see with respect to presenting the results are within Table 3 & 4. For these, the sizes and focus on only giving percentages makes them hard to interpret the data easily. It could be worthwhile to split these large tables up into more manageable chunks while adding the raw counts of survey answers to allow a better contextualization of the percentages.

On a methodological level I concur with the review of Ellen Wright Clayton regarding the statistical significance: It would be of value to clearly state how many statistical tests were performed overall, as the number given seems rather high based on the p-values reported in the main text. Correspondingly, and adjustment the significance levels for the multiple testing might be worth consideration.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Partly

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Direct-To-Consumer genetic testing and its societal implications.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 04 August 2021

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Ellen Wright Clayton 

Center for Biomedical Ethics and Society, Vanderbilt University Medical Center, Nashville, TN, USA

This article adds to the wealth of research from about the world about attitudes regarding data sharing. The authors would do well to cite some of the recent systematic reviews of the empirical data on this topic. see, e.g., Kalkman S, van Delden J, Banerjee A, *et al.* (2019)¹, as well as articles from Italy Colombo C, Roberto A, Krleza-Jeric K, *et al.* (2019)². These authors' findings largely align with those reported by others, which is reassuring.

My biggest reservation is how the data are presented. The tables should present the raw numbers in each box instead of or in addition to the percentages. More important, both the tables and the figures need to identify which differences are statistically significant. At present, these are buried in the text where it is hard to dig them out. In addition, given how many comparisons they did, they should be more careful about claiming significance at 0.05, and there are a lot of percentages given with no comment about significance at all.

Thanks for the chance to read this.

References

1. Kalkman S, van Delden J, Banerjee A, Tyl B, et al.: Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence. *J Med*

Ethics. 2019. [PubMed Abstract](#) | [Publisher Full Text](#)

2. Colombo C, Roberto A, Krleza-Jeric K, Parmelli E, et al.: Sharing individual participant data from clinical studies: a cross-sectional online survey among Italian patient and citizen groups. *BMJ Open*. 2019; **9** (2). [Publisher Full Text](#)

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Partly

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Ethical legal and social implications of genomics research

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.
