



Role of Awareness in DNA Data Sharing and Public Opinion– Challenges Observed

How important is awareness for exercising trust and sharing DNA data?

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Your DNA Your Say-- Introduction

- **The 'Your DNA, Your Say' project is a global online survey gathering public attitudes towards genomic data sharing.**
- **Surveys were gathered in 15 languages from 22 different countries.**
- **The sample consisted of 36,263 participants.**
- **3 Publications:**
 - Global Public Perceptions of Genomic Data Sharing: What Shapes the Willingness to Donate DNA and Health Data?
 - What may ensure trustworthiness in the collection and sharing of genomic data? Public perspectives across 22 countries
 - Return of genomic results does not motivate intent to participate in research for all: Perspectives across 22 countries

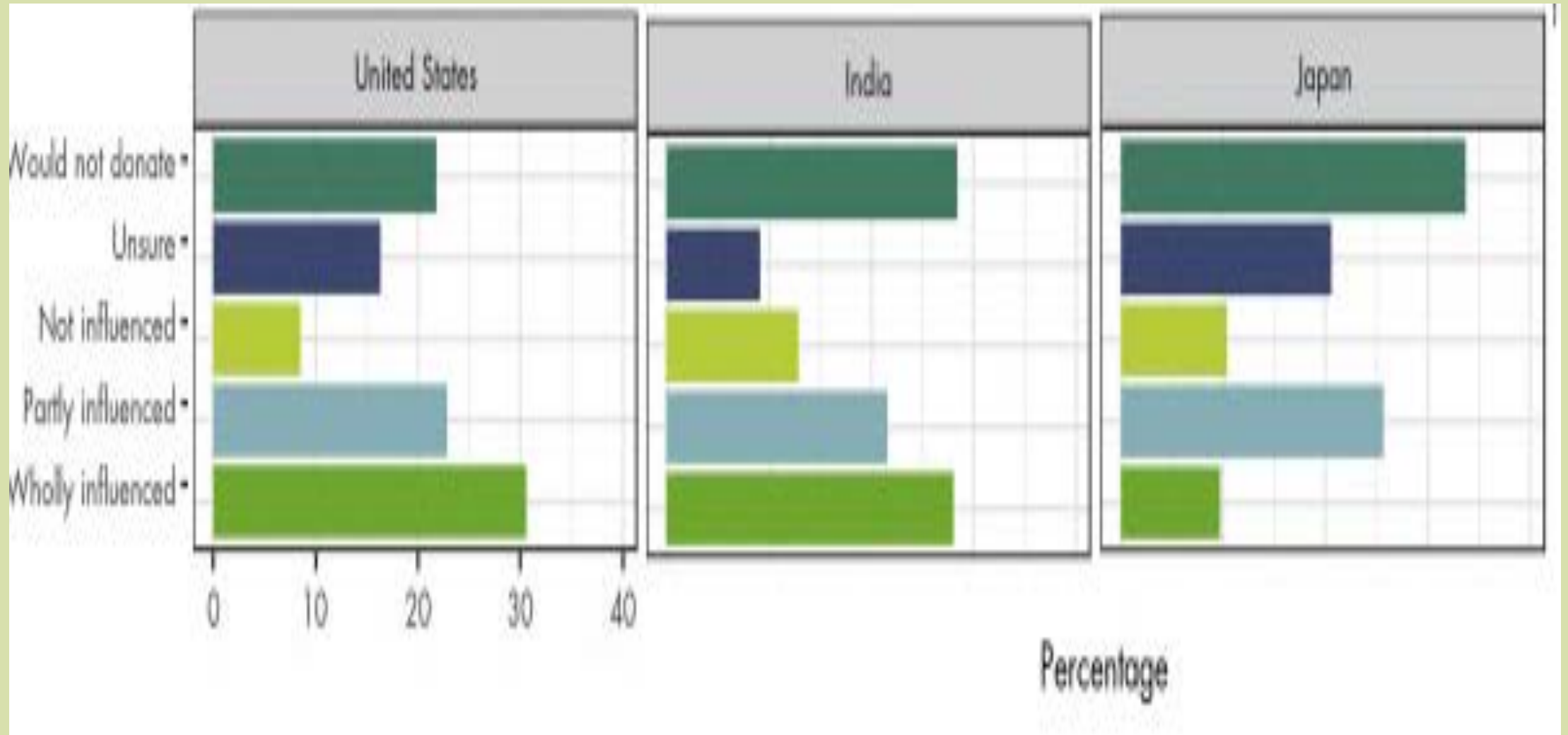


Previous YDYS Studies-- Indian Perspective

- Indian data (482 responses) showed that people were more willing to donate their DNA data to a doctor and **for-profit research** rather than not for profit research.
- This might be because Indians trust private healthcare systems compared to the public ones
- In Indian data there was a weak association between trust and willingness to donate DNA and medical information
- Endorsement was most variable for details about sanctions for misuse of data and Indian data stood at the range of 5%
- Return of results would majorly (28%) wholly influence Indian willingness to donate their data.

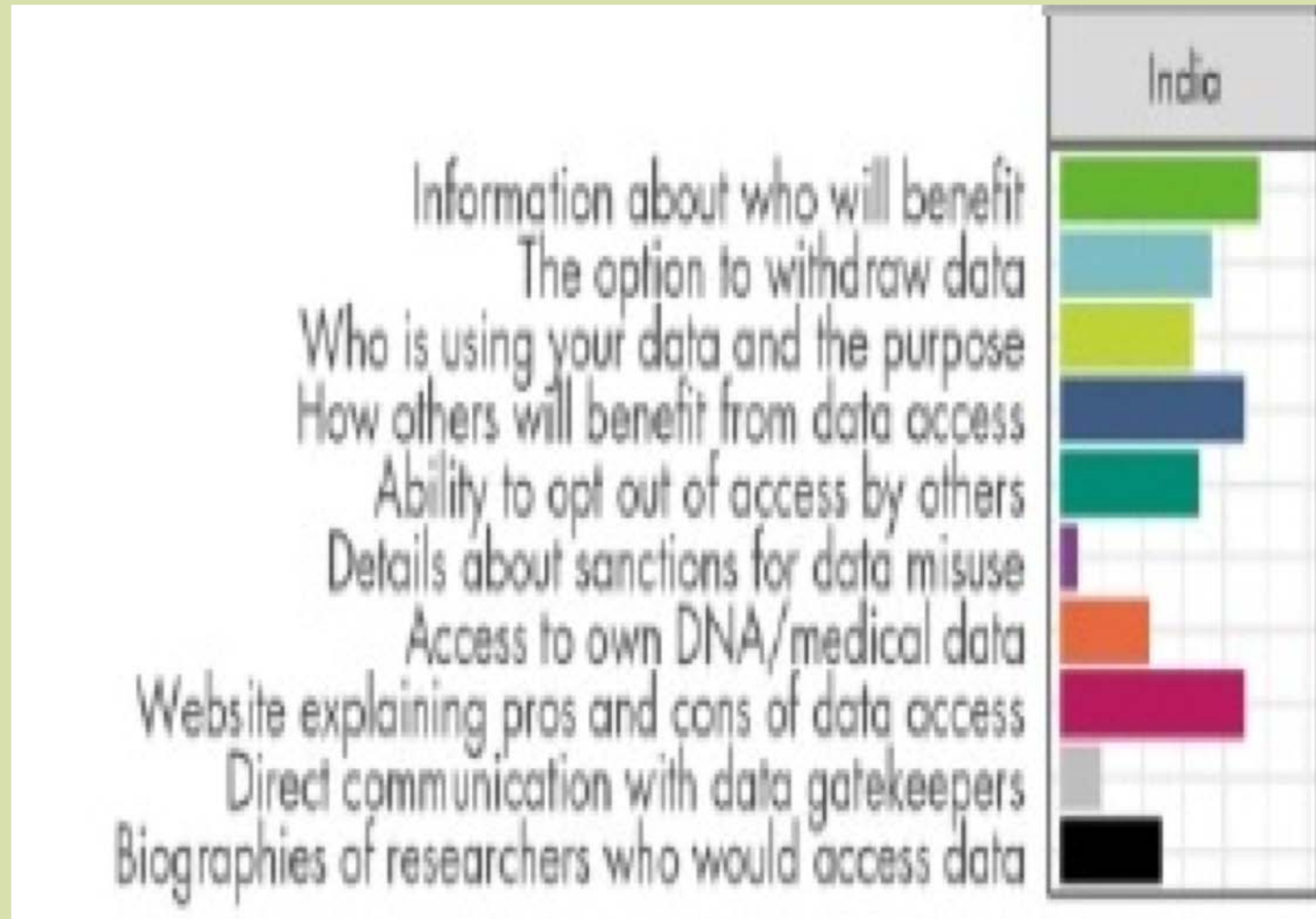


Percentage of participants willing to donate DNA/medical information - overall India stands in between US and Japan





Willingness to donate DNA data based on different factors





Some Relevant facts about India's Health Economics

REF - WORLD BANK INPUTS FOR FIFTEENTH FINANCE COMMISSION

- India is slated to be the world's most populous country by 2025 and the third largest economy in the world by 2030.
- India's health system performance has varied widely over time periods, states, and indicators.
- On some key aspects of health system performance, India clearly lags behind both global and regional comparators.
- A government service delivery system which has traditionally focused on reproductive health and infectious disease while neglecting non-communicable diseases (NCDs), which are now the dominant share of the disease burden
- Fragmentation and lack of coordination between different levels and sectors, including a weakly regulated private sector which dominates service provision.



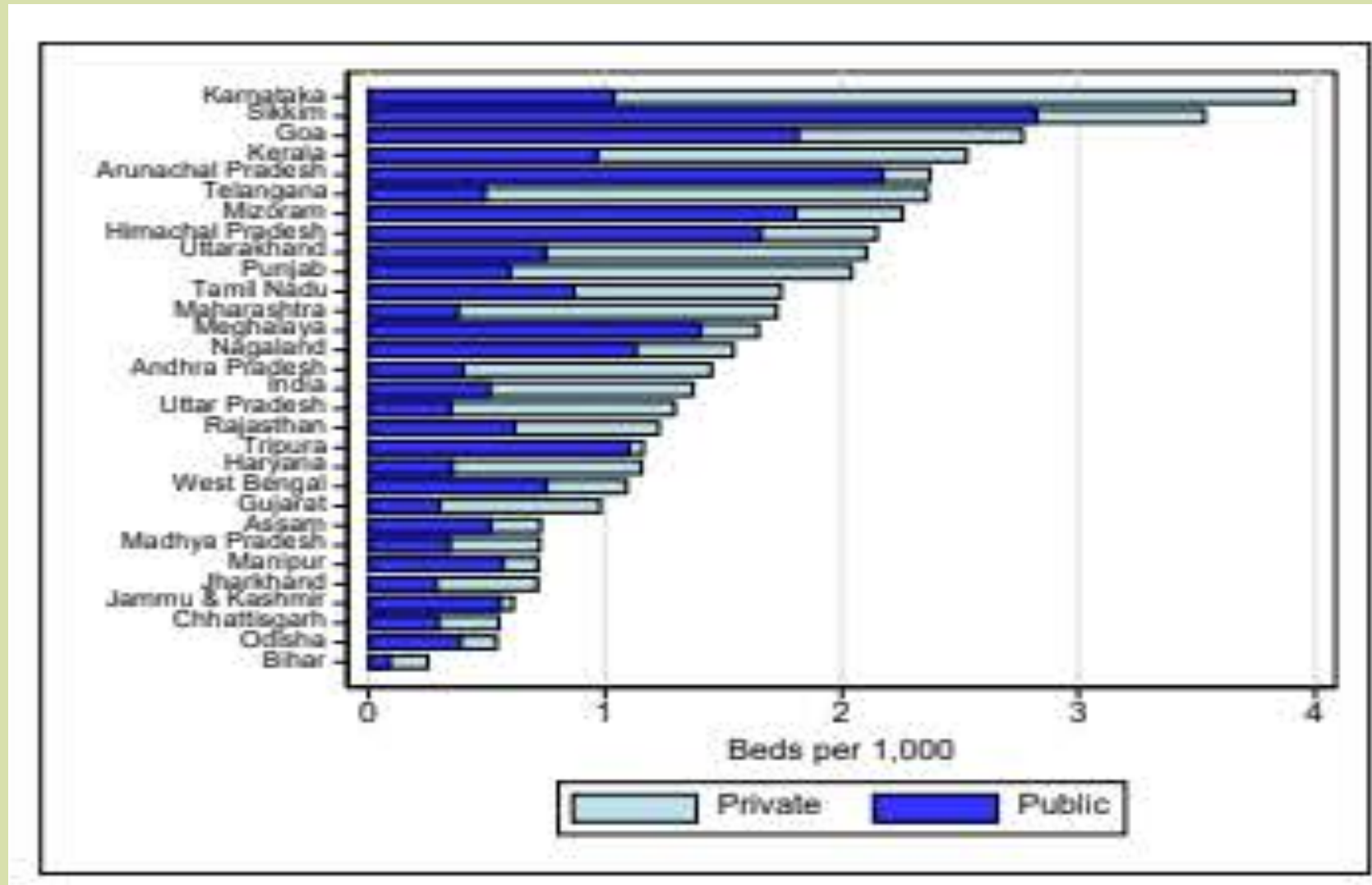
Health Sector

- Lack of accountability in the service delivery model.
- Focus on inputs and infrastructure instead of outputs, outcomes, and accountability.
- Under-performance of government health facilities and the emergence of a large private sector as patients seek care elsewhere.
- Almost 70% of outpatient utilization and 58% of all inpatient utilization now occurs in the private sector, but this is fragmented and largely unregulated

When members of your household get sick, where do they generally go for treatment?

	<i>Urban (richest 20%)</i>	<i>Urban (poorest 20%)</i>	<i>Urban (slum)</i>	<i>Rural (all)</i>	<i>All</i>
All Government hospital	16.7%	34.4%	39.2%	16.1%	29.8%
SC/PHC/CHC	2.7%	16.9%	2.7%	27.5%	8.8%
Private hospital	40.6%	13.2%	26.1%	15.1%	24.0%
Private doctor/clinic	36.2%	24.4%	24.7%	29.5%	28.7%

Demonstration of Public Private healthcare- State-wise

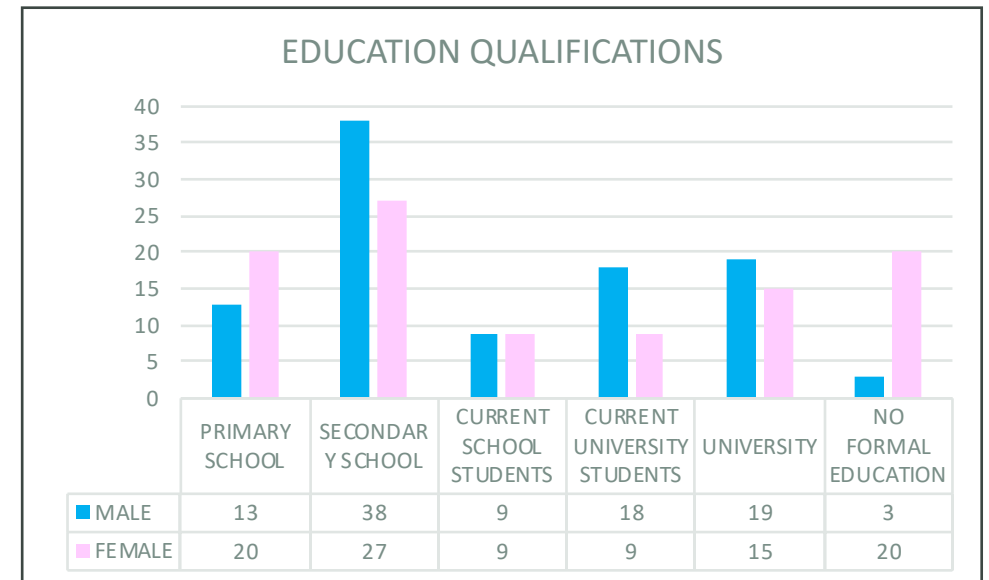
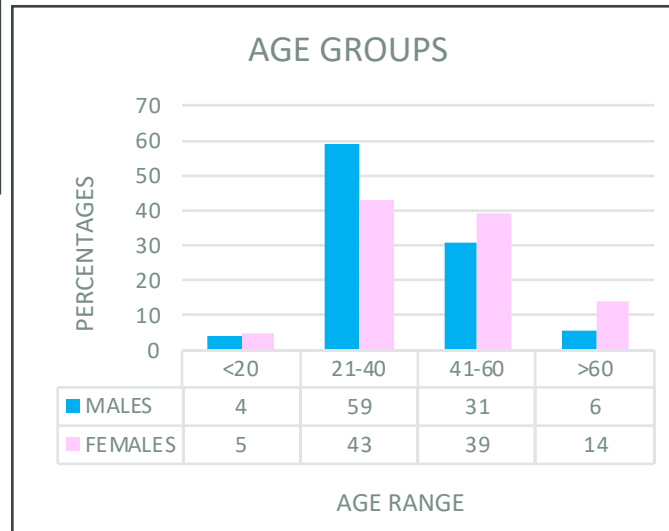
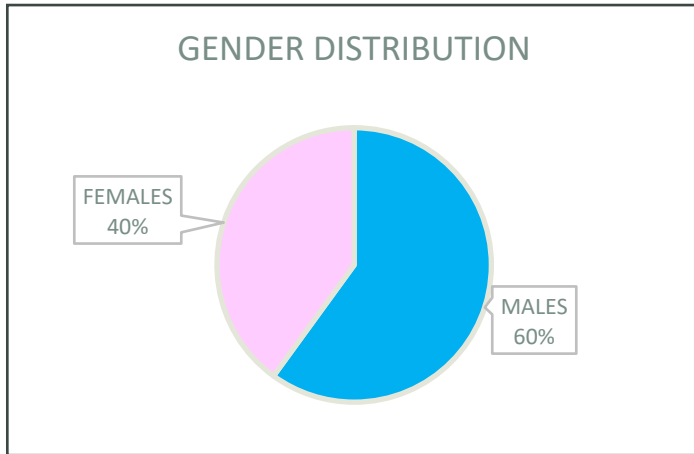




Methodology

- Phase I: Online Questionnaire and Quantitative Data Analysis
 - A) Previous Indian YDYS Survey
 - 482 responses
 - Recruitment was conducted by market research companies (Foresight and Maction) and methods were varied to account for lower internet access.
 - Participants completed the questionnaire on tablets provided by field researchers.
 - B) Current Indian YDYS Survey
 - 1050 responses
 - Recruitment was furthered by voluntary participation and snowballing
- Phase II: Focused Group Discussions
 - Educated and Aware (Genetic counsellors, students of Genetics and health practitioners involved with genetic aspects of disease)
 - Educated and Unaware (Primary & Secondary school teachers)
- Phase III: Qualitative Data Analysis, Literature & Policy Review

Demography of Participants – Online Survey Phase 1B



The survey was mostly completed by individuals familiar with English And Urdu. Hence, it may not be a true representation of Indian population.



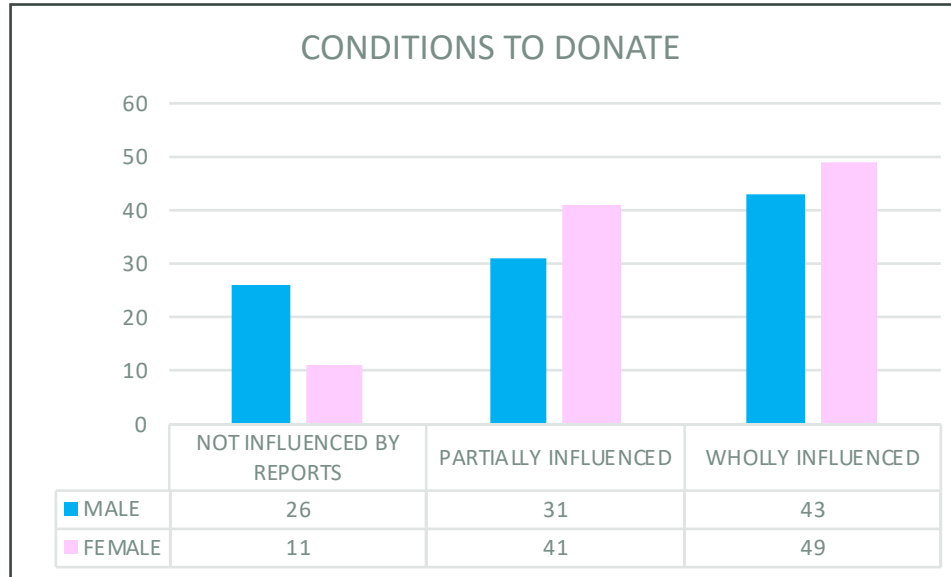
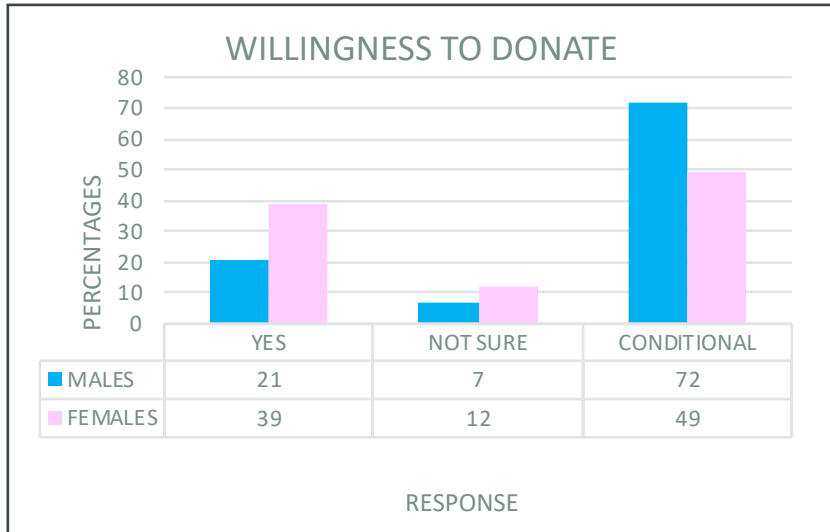
This study pushes forward the idea of how factors like :

- Age,
- Gender,
- Educational qualification

affects societal willingness to donate their DNA data.



Willingness To Donate DNA data – 28%



Females appear to be more influenced by getting readouts/reports while men appear to expect something else in return – Remuneration (?)

MALES - 21.37%

FEMALES – 38.96%

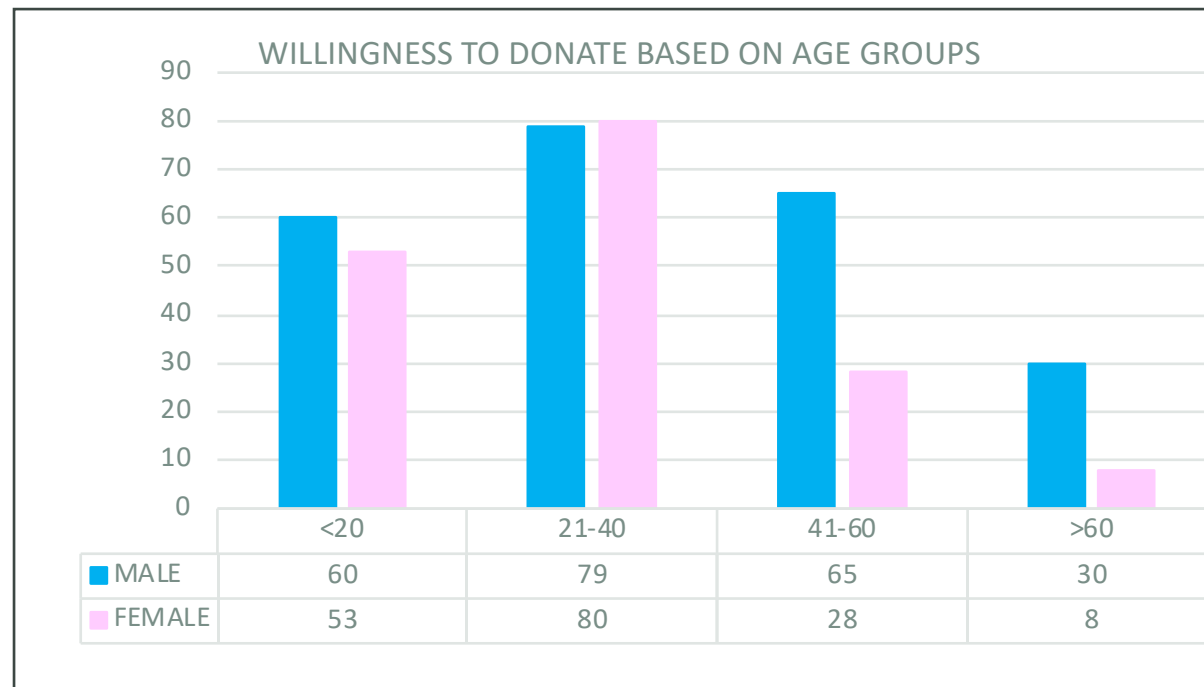
Gender	Males	Females
Religious	92.75%	89.09%
Non religious	7.25%	10.9%
Willing to donate and are religious	66.5%	40.5%
Willing to donate and are non-religious	60%	76%

Although, it was hypothesised people who claim to be religious claim to be altruistic – but this was not seen in our data.



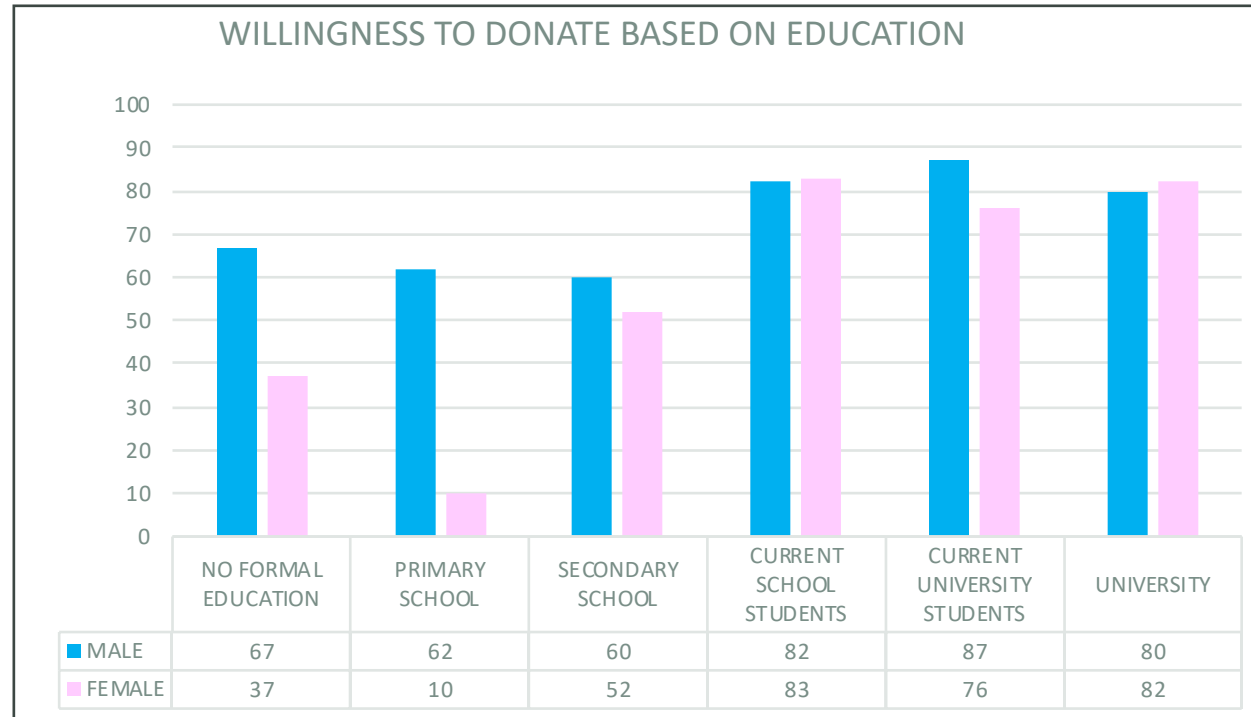
28% Individuals are willing to donate irrespective of their age.

However, as age increases more males than females were willing to donate





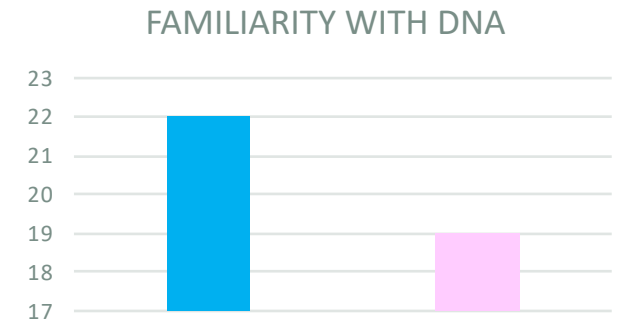
Willingness to donate based on education



Education is an equalizer – with both 80 % males and females willing to donate when they have University education. The same trend is also seen in students



How is Indian Data Different?



- Familiarity with DNA increases with increasing educational qualification
- Men are more familiar with DNA compared to women.
- Willingness to donate increases if the participants were told about a regulatory law in place that safeguards their privacy.
- There is a weak negative correlation between age and worry about privacy of DNA data. Elderly people are somewhat worried or they are not bothered about the privacy of their DNA data
- The willingness to donate is dependent upon an altruistic foundation—people were willing to donate their DNA for a greater good.



Problem Statement –

During the data collection phase, the study found that most Indians filling in the YDYS survey were unaware of what “DNA” was

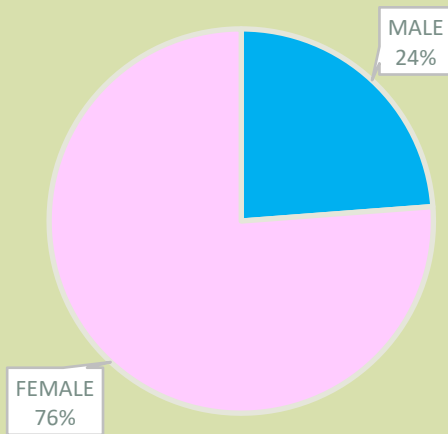
This made it difficult for them to channelize trusting their DNA data as they could not comprehend the existence and relevance of it.



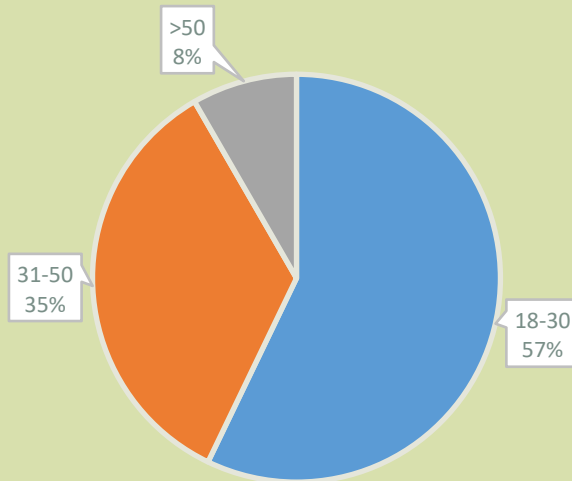
Focused Group Discussion with educated individuals familiar with Genetics: (Educated and Aware Group)

- An online questionnaire (100 responses) was made to assess the thoughts of educated individuals familiar with Genetics which included Genetic Counselors, students of life sciences with Genetics as a specialty and health care providers dealing with genetic disorders
- Followed by a FGD conducted with a sample of 20 chosen from the above cohort.

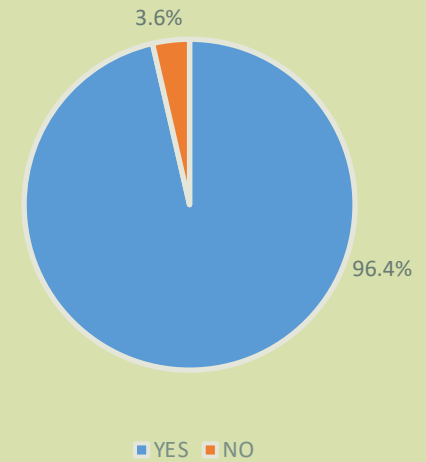
COUNT OF GENDER



AGE GROUPS

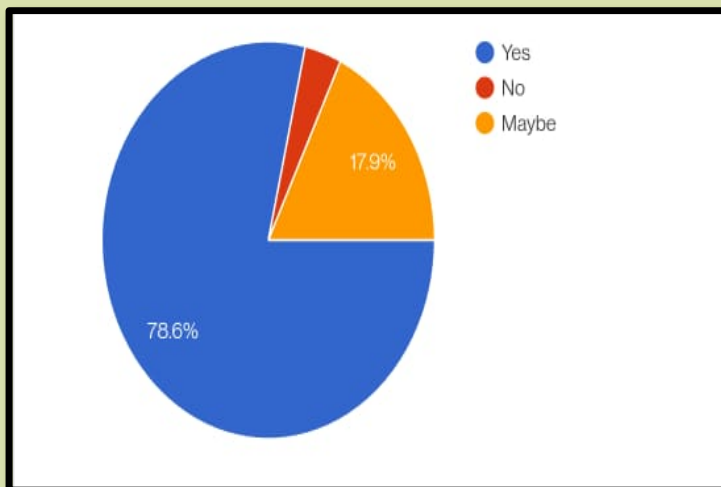


FAMILIARITY WITH DNA

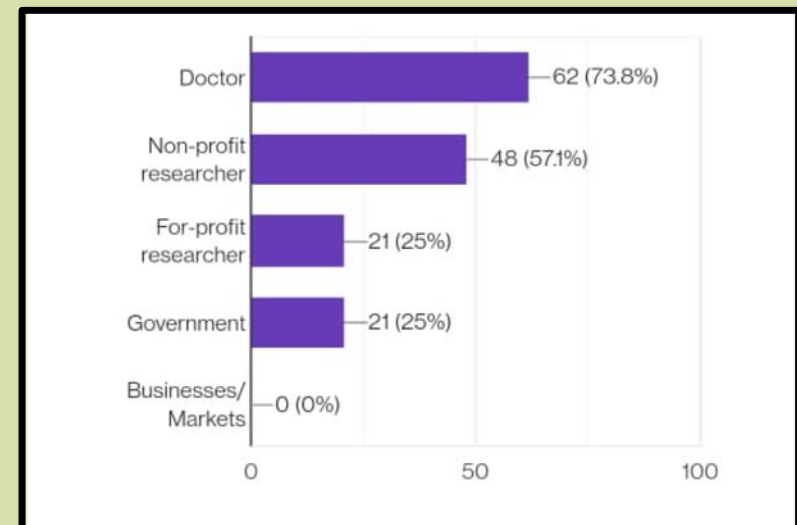


Results from FGD -

- 57.3% were willing to donate their data for the larger good. Prominence of an altruistic pursuit
- A law in place would motivate the participants to donate their DNA or medical information as people had questions about who has access to their data and how is their data being used.
- Most of the participants were comfortable sharing their DNA data with the doctor and non-profit research and none of them were willing to share it with businesses/markets.



Willingness to donate if there was a law in place to protect DNA data from getting exploited



Willingness to donate your DNA to different stakeholders

“...what is **DNA**? Where is it? Does everyone have it?”

“I will only donate my **DNA** if one of my family member requires it”

“How is it even possible to donate **DNA**? I don't even know where my DNA is!”

“How do I have access to my **DNA**?”



Awareness and Trust

- People need to be aware of what they possess before they bestow their trust on a third party to secure their DNA without their privacy being breached.
- The Indian data showed that people could not relate to the idea of DNA even though the YDYS questionnaire had videos to ensure easy translation of knowledge.
- The sample had to be explained about what DNA is and how DNA donation works before the survey was administered.
- This occurrence was a testimony to the information asymmetry, lack of awareness and privilege that certain groups possess.



What does the YDYS Data for India say?

Familiarity with DNA

- The odds of being unfamiliar with DNA increases with increasing age.
(OR at 95% CI: 2.25 for the age group 41 to 60 & 3.8 for the age group of 61+)
- The odds of Indian women being unfamiliar are higher compared to Indian men
(OR: 0.73 at 95% CI for Indian Men)
- Indian population who have completed or are pursuing studies in tertiary educational institutions have higher odds of being familiar with DNA (OR at 95% CI) is 0.33 compared to 0.44 for people who have completed or are pursuing secondary school



What does the YDYS Data for India say?

Do Indians see DNA and Medical Data differently?

- Older people are less likely to see DNA data different to medical Data.
 - OR is 0.13 for cohort of 61+ of the sample compared to 0.79 for people belonging to 41-60 age cohort at 95% CI.
- Also, people who have completed or are pursuing education in tertiary institutions are more likely to see DNA data different to medical data.
 - OR of people who have completed or are pursuing tertiary education is 2.6
 - OR of people who have completed or are pursuing secondary education is 1.77
 - Both at 95% confidence interval



What does YDYS Data for India Say?

Would Indians be comfortable sharing their DNA data if there was a law in place?

- Older people are less likely to be reassured by law in place.
 - This might stem from the indifference due to the higher unfamiliarity rates amongst the older population.
 - OR for 61+ cohort is 0.19 at 95% confidence interval compared to 0.66 for the 41 to 60 cohort.
- Also, women are less likely to be comfortable sharing their DNA data even with a law in place.
 - The literature suggests that women are more likely to have negative experience in the online arena which makes them skeptical with sharing data that concerns their privacy.
 - OR for females is 0.7 at 95% confidence interval.
- Educated people are more likely to be reassured by a law in place to protect their DNA data
 - OR (tertiary): 2.56 at 95% confidence interval
 - OR (secondary): 1.29 at 95% confidence interval



What more...?

- 90% of the data says that people have no data online. However, the Indian healthcare systems uses computer networks and cloud storage to save patient's data.
- As people are unaware about what DNA is and where is it found feeds into the thought of denial about having their DNA data online.
- Younger educated males are the ones who are most aware about DNA compared to old uneducated females.
- Younger educated males will be the ones who would make the policies at the center to safeguard and regulate the use of DNA data.



Focused Group Discussion-1

- Educated and Aware Group: Genetic Specialists/Practitioners and Students
- (Total sample: 100; FGD Sample: 20)
- The younger cohort was skeptical about sharing their DNA data and the older cohort was indifferent.
 - This was simulated by the affects of Indian political scenario as they were weary of the state's surveillance and privacy breaches
 - Both old and young cohort shared concerns over sharing DNA data with the market for its capitalistic pursuits
 - Both of the cohorts agreed on donating their DNA for the betterment of the society or for research.
- A law in place to regulate the usage of DNA data would mitigate their concerns



Focused Group Discussion– 2

- Educated and Unaware
- Primary and Secondary Teachers at district schools (n=15)
- Could not relate to the idea of DNA hence, could not comprehend how DNA data could be donated let alone utilized or exploited.
- Women were more skeptical in sharing their DNA compared to the men attending the FGD.
- All teachers agreed that they would donate their DNA data if it would help their family or else, not.



DNA and Big Data

- Both are sunrise industries— the market for DNA testing is currently growing in leaps and bounds.
- Holds a lot of possibilities—
 - Potential health hazards, genetic predispositions to different traits and conditions
 - All-knowing medical health service
 - Ease in fighting epidemics and shield us from cancer, heart diseases etc.
- Coupling DNA and Big Data
 - Will humans remain autonomous or will they become a part of a huge global network ?
 - Is our society and polity prepared for the discourse?



Are Markets Corrupt?

- Both the quantitative and the qualitative studies underlined the fact that Indian population is very skeptical of sharing their DNA data with the market.
- They believed that the inherent capitalistic tendencies of the markets make them corrupt— you never know how your data is being used without you knowing it.
- Concerns over how markets access individual's DNA information, how it uses it and it capitalizes on it.
- Example: *23andme* by Google



Grounds for an Effective Regulatory Public Policy

- Bottom-up approach to understand the ground level problems.
- Major concern: young educated males designing the policies that widens the intersectional gaps.
- The agenda setting should be founded on the premise of how aware Indian population is towards DNA and DNA data sharing.
- The envisaged policy should regulate how the data is collected, used and protected.
- The coupling of biotech and infotech are global phenomena– should the policy be global or local?



Summary

- Obtaining health/ genomic data is central to understanding the role of genetic factors in health and disease.
- Successful data sharing relies on public support, which depends on willingness of people to donate their data which can be shared with others for research.
- To maximize societal benefits from genomic data sharing - factors that effect decision to donate DNA across social, cultural, and legal contexts need to be addressed
- Those who were familiar with genetics/DNA were more likely to be willing to donate
- In India creating Public awareness is essential for the success of projects involving genomic and medical data collection
- Urgent steps need to be taken to address this.

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