

CONNECTING  
SCIENCE

SOCIETY+  
ETHICS  
RESEARCH



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Society and Ethics Research Group

Wellcome Genome Campus (inc Sanger Institute)

Cambridge, UK

# Premise

- Data sharing endeavors rely on people willing for their donated data to be shared (i.e. 'data donors')
- Even if we aren't personally donating, we'll be related to someone who is, i.e. the ethical issues linked to data sharing are relevant to global publics
- Exemplary practice involves listening to what potential donors want, believe and fear and consider policy implications
- This work is part of GA4GH strategic roadmap

# Overview of presentation

- Brief background to the social sciences research
- Public attitudes from 37,000 publics, 22 countries in 14 languages
- Evidence based recommendations for supporting good practice and potentially increasing uptake of genomic data donation

Building a bridge to public audiences, to orientate and engage and then involve



# Your DNA, Your SAY

[reset answers and start again](#)



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- Welcome
  - Online footprint
  - Data access by others
  - Access by medical doctors
  - Access by non-profit researchers
  - Access by for-profit researchers
  - Perceived harms
  - Expectations of information
  - Trust
  - Last few questions about you
  - Submit your response

## Welcome

This is a survey about your online health data and how it might be used by others.

# Global public survey

Sample size: 37,000 completed samples, 'representative' public recruited via Dynata (global market research company)

## あなたのDNA、あなたの意見



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### ようこそ

このアンケートでは、オンライン上にあるみなさんの健康情報や、他の人によるその情報の利用について質問します。

動画を見ていくつかの質問に答えるという簡単な形式です。回答に必要な情報は動画に含まれています。下線が引かれた単語の上にマウスを置くと、その用語の解説をみることができます。

このアンケートは誰でも入力できますので気軽にご参加ください。みなさんの回答は、英国ケンブリッジにあるWellcome Genome Campusにおいて匿名化された状態で安全に保管されます。

質問への回答開始をもって、アンケートへの参加に同意したものとみなされます。このアンケートで得られる匿名化されたデータは、将来の研究のために他の社会学者と共有する可能性があります。

どの時点でも、このページをブックマークすれば後で戻ってこれることができます。

この研究は、利益のためではなく、ひとびとのために行います。

次 »

الحمض النووي الخاص بك

العربية

Ihre DNA, Ihre Entscheidung

Deutsch

Your DNA, Your Say

English

Tu DNA, Tu Decisión

Español

Votre ADN, Votre Avis

Français

Pitt erfðæfni, þín ákvörðun

Íslenska

É il tuo DNA, Decidi Tu

Italiano

Twoje DNA, Twoje zdanie

Polski

O seu ADN, a sua voz

Português

Ваши гены - Вам решать

Русский

## آپ کا ڈی این اے، آپ کا کہنا



### خوش آمدید

یہ ایک سروے ہے جو آپ کے آن لائن صحت کے ڈیٹا کے بارے میں ہے اور اسے دوسرے کیسے استعمال کر سکتے ہیں۔

یہ بہت آسان ہے۔ فلوں کو دیکھنے اور چند

سوالات کا جواب دیجئے۔ فلیں آپ کو سب جان کاری ونگلی۔ اپنے ماڈس سے ان الفاظ کو دیکھیے جن کے نیچے لائن ہے اور آپ کو ایک فہرست نظر

آئے گی۔

سروے کوئی بھی اور سمجھی بھر سکتے ہیں، لہذا آگے بڑھیں۔ آپ کی شرکت مکمل طور پر کرنا م ہے اور ہم دیکھ کر چیونٹہ نہیں، کیونکہ برطانیہ میں تمام جو ایات محفوظ رکھیں گے۔

اگر آپ سوالات کے جواب شروع کرتے ہیں تو یہ اپ کی رضامندی کا اظہار ہے اس کا گنا م ڈیٹا مستقبل میں سماہی سائنس دانوں کے ساتھ تحقیق کے لئے کام آسکتا ہے۔

کسی بھی وقت، آپ اس صفحہ کو بک مارک کر سکتے ہیں اور بعد میں واپس آسکتے ہیں۔

یہ تحقیق منافع کے لئے نہیں بلکہ انسانوں کی خدمت کے لیے ہے۔

اگلا »

### الحمض النووي الخاص بك

reset answers and start again

- ✓ أهلاً وسهلاً
- ✓ الیصمة الإلكترونية
- ✓ إمكانية الوصول للبيانات من قبل آخرین
- ✓ إمكانية الوصول من قبل الأطباء المختصين
- ✓ إمكانية الوصول من قبل الباحثين غير هادفي الربح
- ✓ إمكانية الوصول من قبل الباحثين الهادفين للربح
- الأضرار المتوقعة
  - المتوقع من المعلومات
  - الثقة
  - آخر الأسئلة المتعلقة بك
  - إرسال إجاباتك



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### الأضرار المتوقعة

لننقرض أنه قد أصعبت الخيار للتبرع بالحمض النووي الخاص بك و بمعلوماتك الطبية بحيث تكون مجهول الهوية وذلك من أجل أن تستخدم من قبل أيا مما يلي:

- الأطباء المختصين (مثال: من أجل مساعدتهم في تشخيص الحالات المرضية والقيام بنشر الأبحاث الطبية)
- الباحثين الغير هادفي الربح (مثال: من أجل القيام بأبحاث طبية و أيضا للحصول على تمويل جديد)
- للشركات الهادفة للربح (مثال: من أجل تطوير الأدوية والحصول على مال من وراء ذلك)

ضمن السيناريوهات الثلاثة المذكورة أعلاه لننقرض أيضا أن هناك فرصة بأن يتم التعرف عليك شخصيا من قبل أحد الباحثين القادرين على الوصول الي قاعدة بياناتك. نريد معرفة ماذا تعتقد ...

● إن أقوم بالتبرع بمعلومات عن الحمض النووي الخاص بي و معلوماتي الطبية.

● سوف أقوم بالتبرع بمعلومات عن الحمض النووي الخاص بي و معلوماتي الطبية لئتم استخدامها من قبل ... (اختر من الاجابات التالية بالضغظ على المربع)

#### الأطباء المختصين

إن أقوم بالتبرع	سأقبل بنسبة 1% أن يتم التعرف علي	سأقبل بنسبة 10% أن يتم التعرف علي	سأقبل بنسبة 50% أن يتم التعرف علي	سأقبل بنسبة 90% أن يتم التعرف علي	لا اظن
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#### الباحثون الغير هادفي الربح

إن أقوم بالتبرع	سأقبل بنسبة 1% أن يتم التعرف علي	سأقبل بنسبة 10% أن يتم التعرف علي	سأقبل بنسبة 50% أن يتم التعرف علي	سأقبل بنسبة 90% أن يتم التعرف علي	لا اظن
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#### الباحثون الهادفون للربح

إن أقوم بالتبرع	سأقبل بنسبة 1% أن يتم التعرف علي	سأقبل بنسبة 10% أن يتم التعرف علي	سأقبل بنسبة 50% أن يتم التعرف علي	سأقبل بنسبة 90% أن يتم التعرف علي	لا اظن
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تطبيقات

«التالي»

«السابق»





# We've been thorough!

Statisticians from RAND Europe have done the modelling, not going to show loads of forest plots, but present the statistically significant associations

New data plus peer reviewed and  
published data

What we are focusing on....

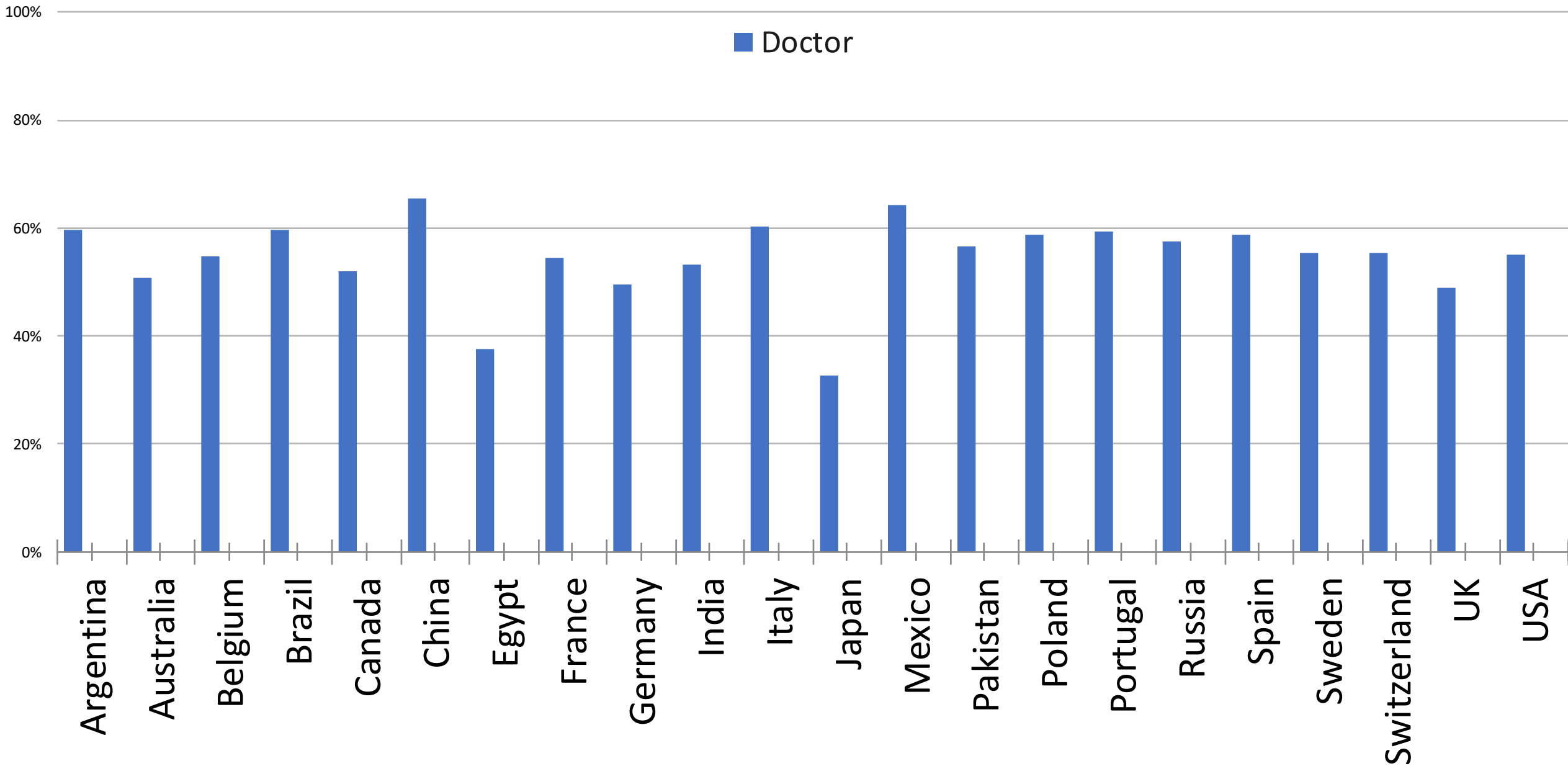
Willingness to donate one's  
genomic data



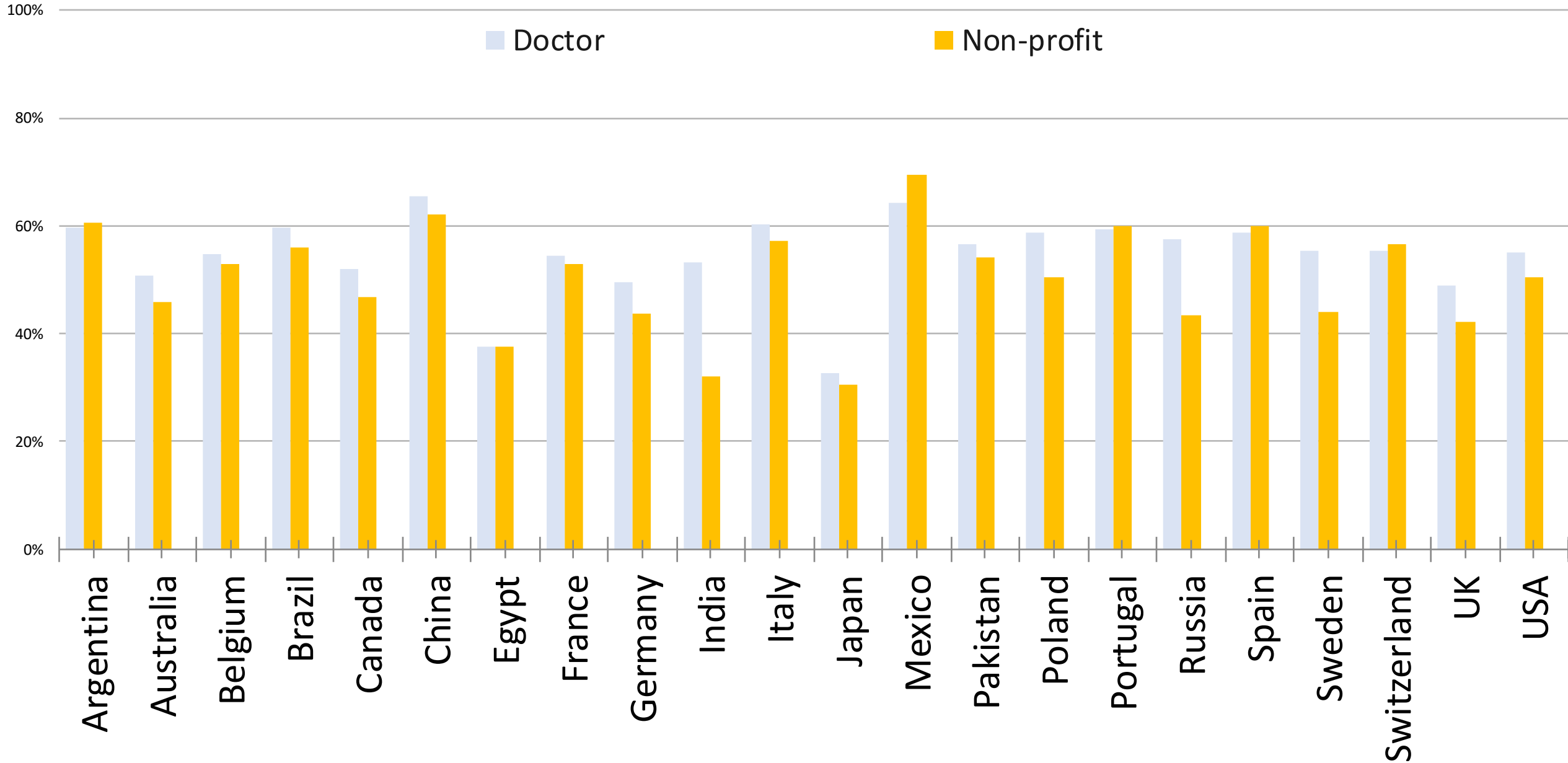
Would you donate your anonymous DNA information and medical information for use by:

- Medical doctors
- Non-profit researchers
- For-profit researchers

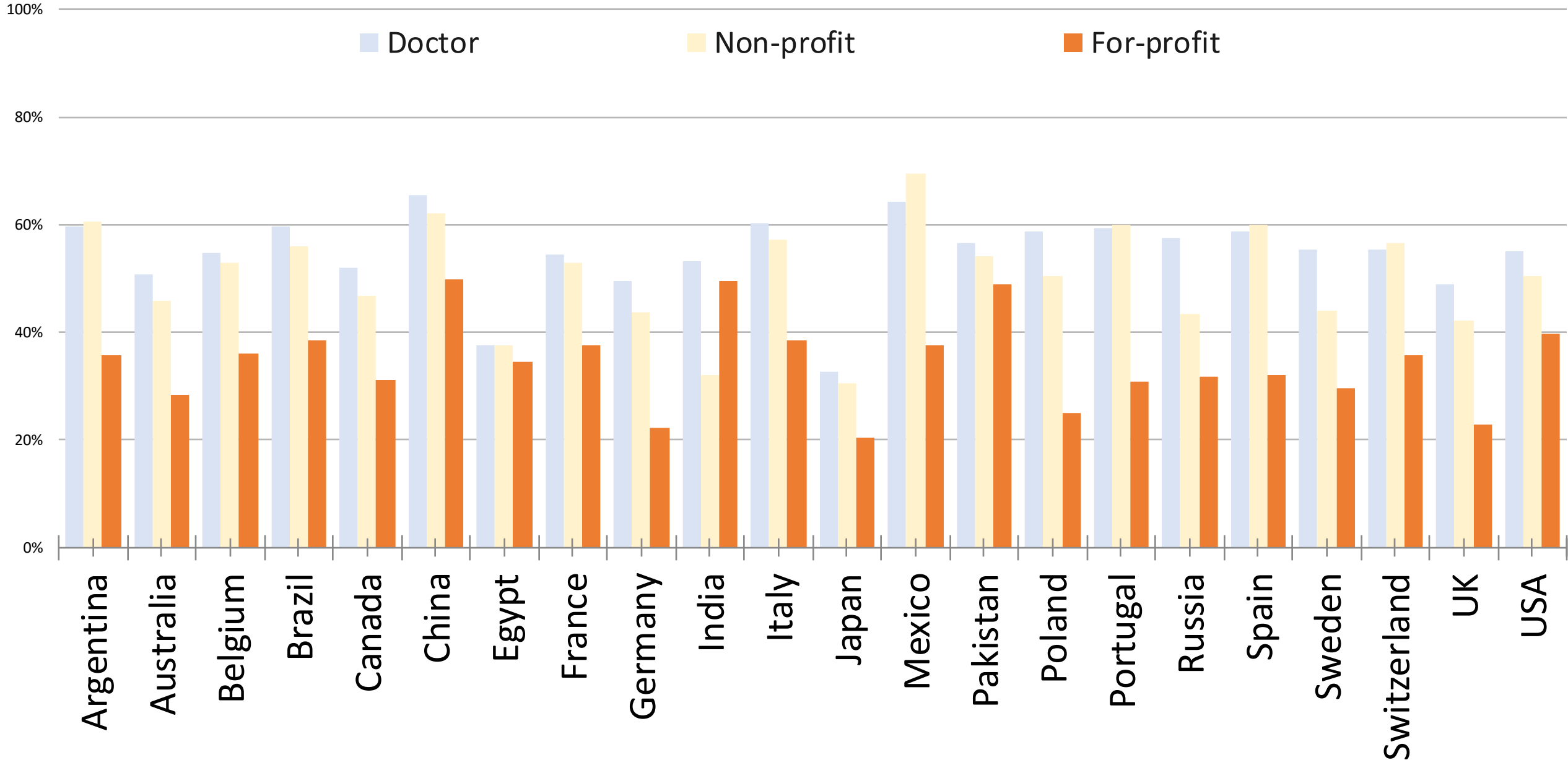
# Willingness to donate DNA and health information



# Willingness to donate DNA and health information



# Willingness to donate DNA and health information



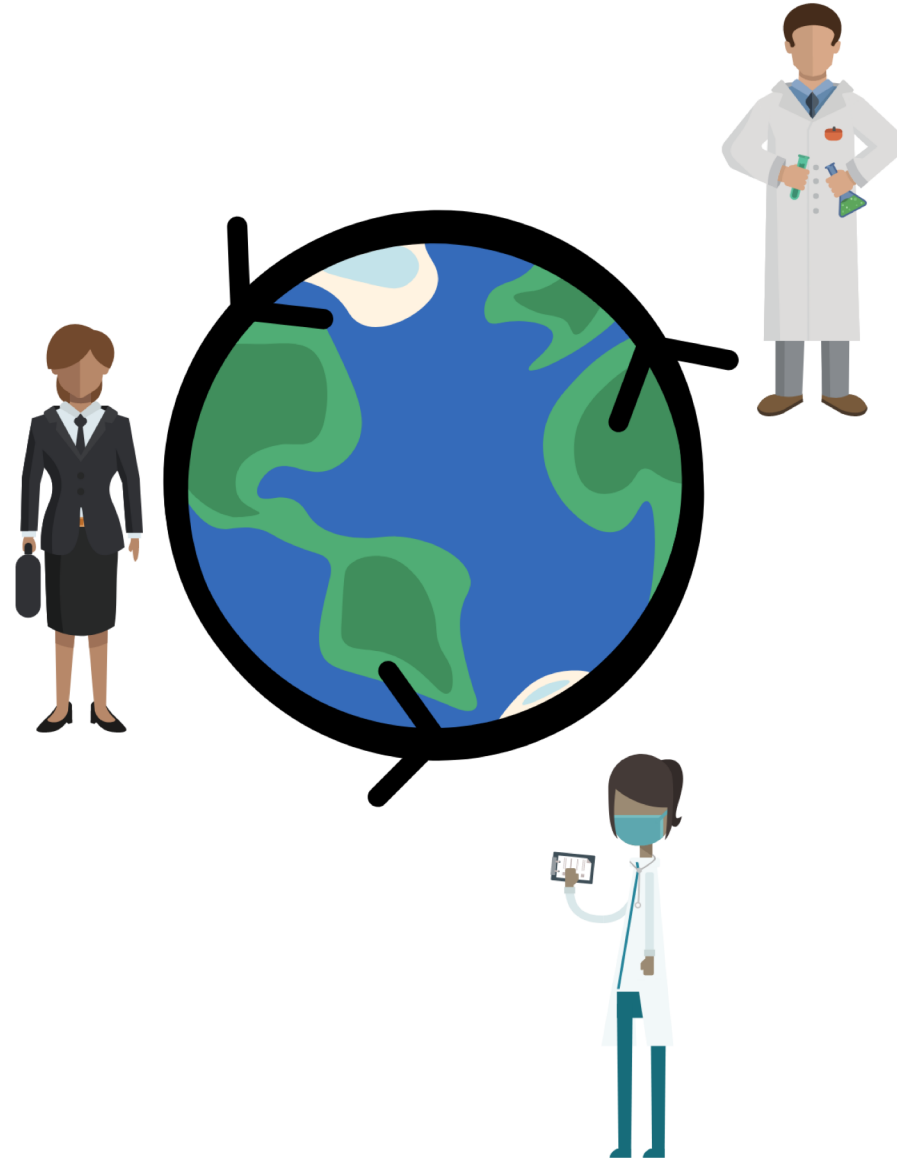
Across 22 countries, **global publics** are more comfortable with their data being used by **doctors** than **for-profit companies**



Willingness to donate genomic data globally may be **increased** if **engagement & information** focusses on:



**Why genomic data sharing requires a partnership between medicine, non-profit & for-profit researchers and industries**



What affects willingness?

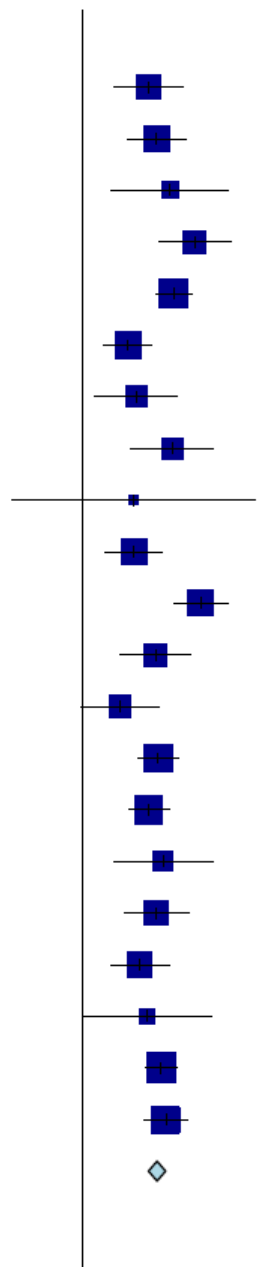
- Who the recipient is
- Familiarity with genomics
- Perception that there is something special about genomic data that warrants donation
- Trust in the recipient
- Perceived harms from re-identification
- Ability to receive raw data back
- Reassurance of legal protections in place



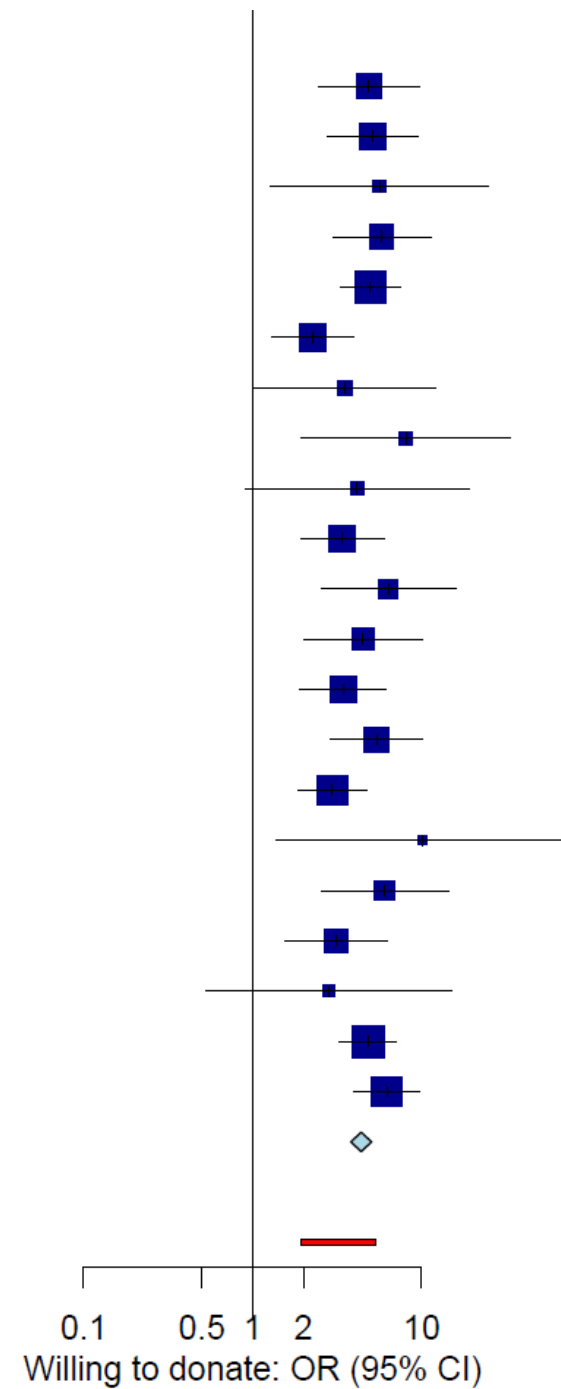
Familiarity with the subject  
matter

Source	OR (95% CI)
<b>Genetics knowledge = Familiar</b>	
Argentina	2.42 [1.53; 3.81]
Australia	2.69 [1.82; 3.97]
Belgium	3.20 [1.46; 6.99]
Brazil	4.45 [2.74; 7.22]
Canada	3.36 [2.64; 4.27]
Egypt	1.84 [1.34; 2.52]
France	2.04 [1.17; 3.54]
Germany	3.29 [1.91; 5.67]
India	1.96 [0.39; 9.88]
Italy	1.99 [1.36; 2.89]
Japan	4.81 [3.37; 6.87]
Mexico	2.65 [1.65; 4.24]
Pakistan	1.65 [0.98; 2.78]
Poland	2.74 [2.11; 3.56]
Portugal	2.42 [1.84; 3.18]
Russian Federation	2.93 [1.53; 5.63]
Spain	2.67 [1.74; 4.09]
Sweden	2.15 [1.46; 3.16]
Switzerland	2.37 [1.01; 5.57]
United Kingdom	2.85 [2.31; 3.53]
United States	3.03 [2.25; 4.09]
Total	2.70 [2.41; 3.02]

Heterogeneity:  $\chi^2_{20} = 33.97$  ( $P = .03$ ),  $I^2 = 41\%$



<b>Genetics knowledge = Personal</b>	
Argentina	4.88 [2.46; 9.72]
Australia	5.15 [2.77; 9.57]
Belgium	5.63 [1.26; 25.12]
Brazil	5.83 [2.98; 11.39]
Canada	4.99 [3.34; 7.47]
Egypt	2.28 [1.31; 3.98]
France	3.53 [1.02; 12.22]
Germany	8.06 [1.93; 33.74]
India	4.16 [0.90; 19.21]
Italy	3.41 [1.93; 6.00]
Japan	6.37 [2.54; 15.94]
Mexico	4.51 [2.01; 10.11]
Pakistan	3.44 [1.91; 6.17]
Poland	5.45 [2.90; 10.22]
Portugal	2.97 [1.87; 4.71]
Russian Federation	10.15 [1.37; 75.16]
Spain	6.06 [2.55; 14.41]
Sweden	3.15 [1.57; 6.32]
Switzerland	2.83 [0.53; 15.00]
United Kingdom	4.83 [3.28; 7.13]
United States	6.22 [3.97; 9.73]
Total	4.39 [3.81; 5.06]
Heterogeneity: $\chi^2_{20} = 17.85$ ( $P = .60$ ), $I^2 = 0\%$	
Pred. Int.	[1.94; 5.32]



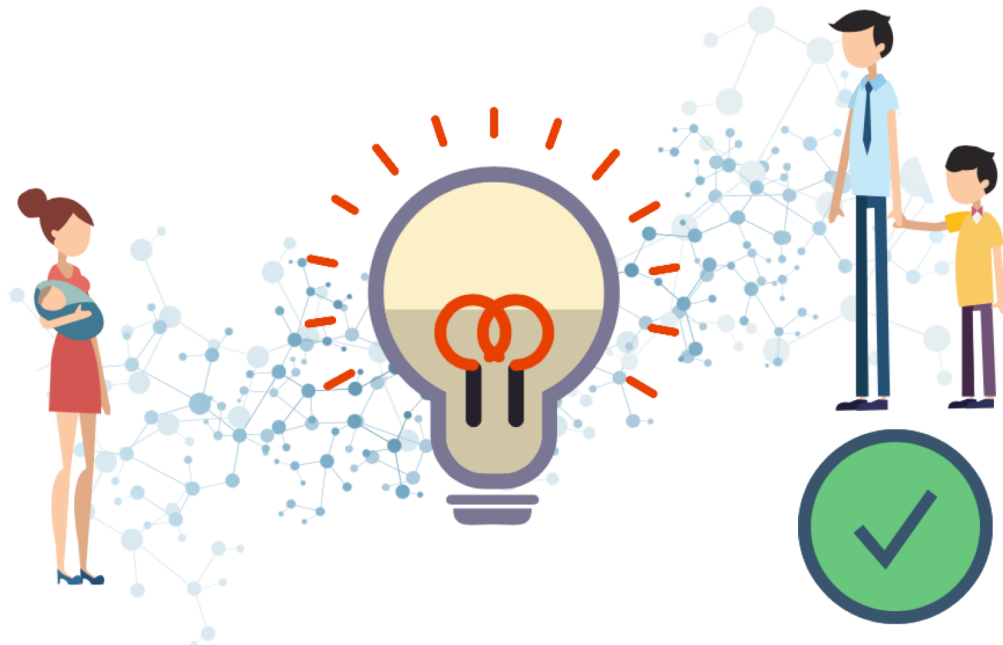
Willingness to donate genomic data globally may be **increased** if **engagement & information** focusses on:



Willingness to donate genomic data globally may be **increased if engagement & information focusses on:**

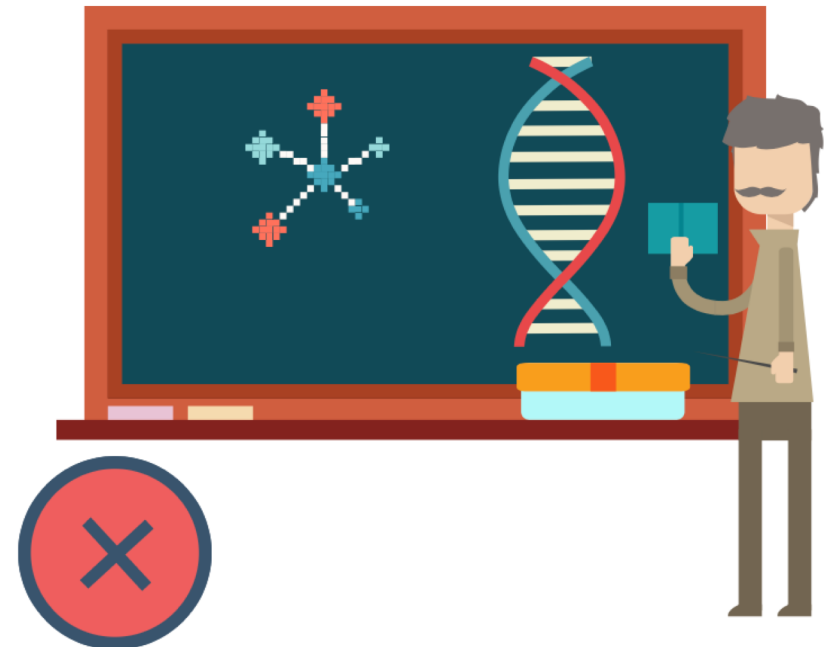


Increasing **familiarity** about genomics.  
*This means helping people **shift** from 'unaware' to 'aware' so that they understand 'What does this mean to me? Why is donating my data relevant?'*



Familiar is good,  
**personal familiarity** is better

But **don't** confuse this with increasing knowledge and literacy,

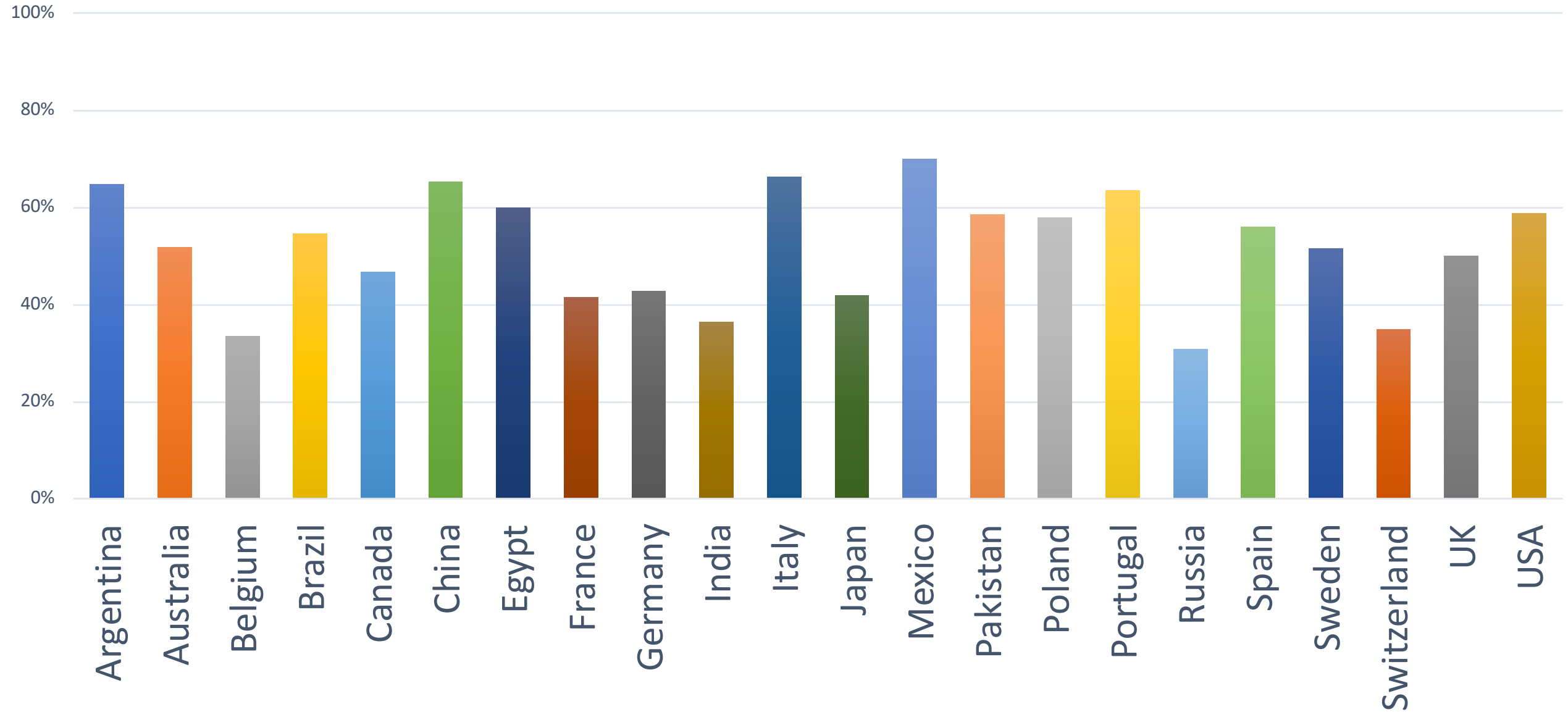


*People don't need to know the four bases of DNA or how genome sequencing is done*

# Exceptionalism

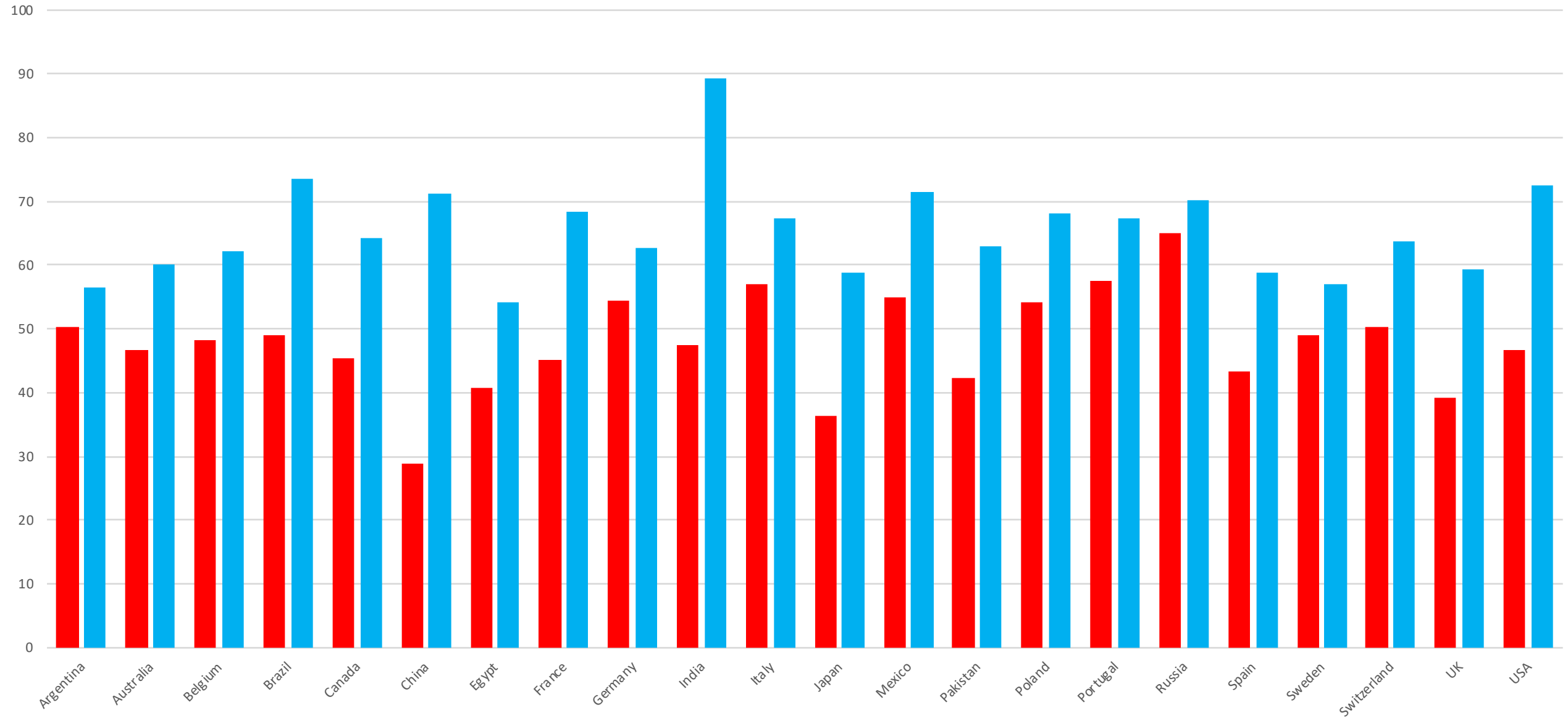
Perception that there is something different special about genomic data, compared to medical data

# "For me DNA Information is different to other medical information"



# % of those who see DNA information as same/different to other medical information who are willing to donate DNA data

■ Same/unsure ■ Different



Policy makers argue from **both** positions – that genomic data **should or shouldn't be treated as exceptional**.



Willingness to donate genomic data globally may be **increased** if **engagement & information** focusses on:

Explaining how genomic data is **different** to medical data

*e.g. it is **shared** between us, it can tell us about our **past, present & future health**, it offers information about our **biological relatives**, etc*



Perceiving that genomic data is **special** or **different** to other medical data is **linked to willingness to donate** it for research



# Trust and Data Sharing are thought to go hand in hand

Trinidad et al, 2010; Eckstein et al 2018; Lawler et al 2018; Shabani et al 2014,  
Nuffield Council on Bioethics, 2015

# Trust is thought to shape attitudes towards genomics and intention to participate in research

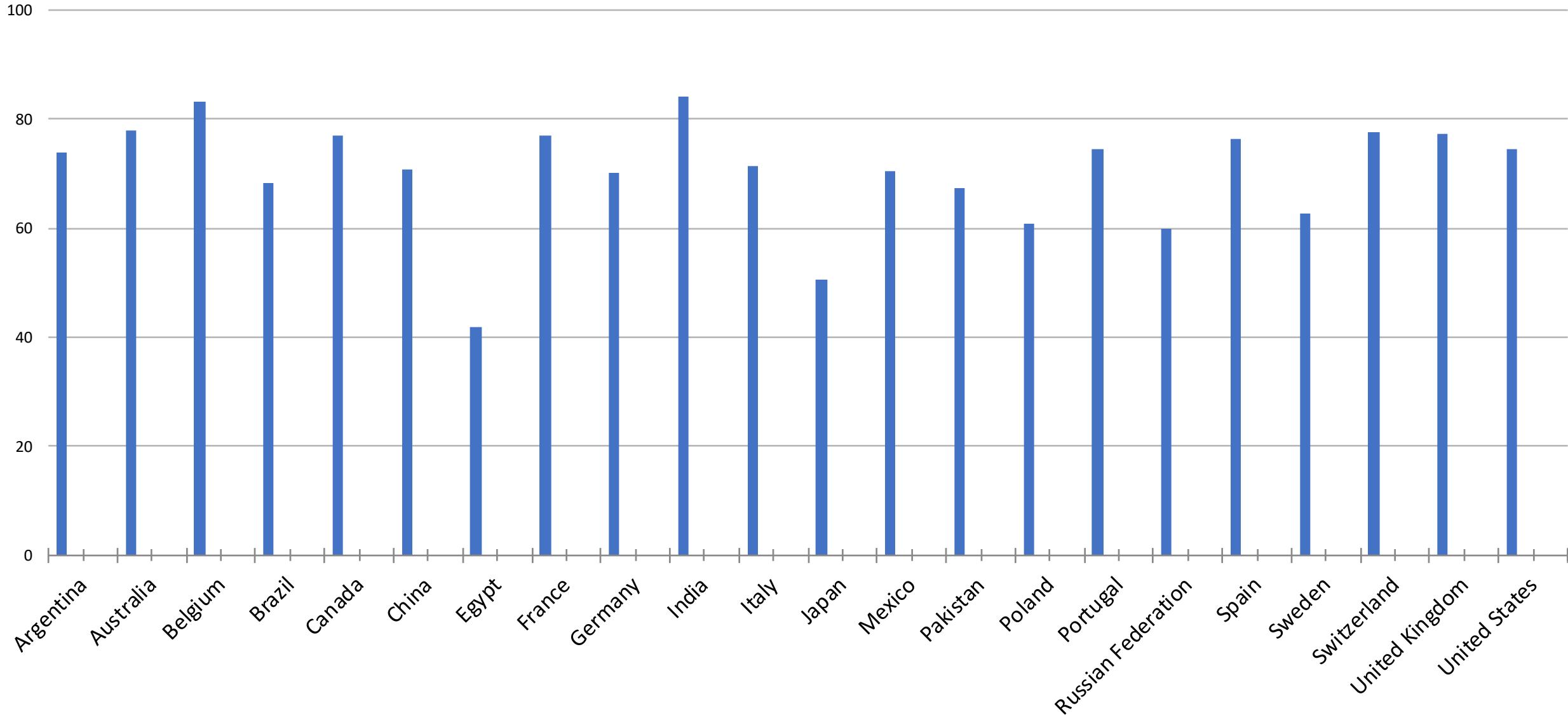
(Lipworth, et al 200; Critchley et al 2015; Nicol et al 2016; Lawler et al 2018)

# Where trust is absent, the social license and mandate of researchers and clinicians to obtain and distribute data may be lost

(Carter et al 2015)

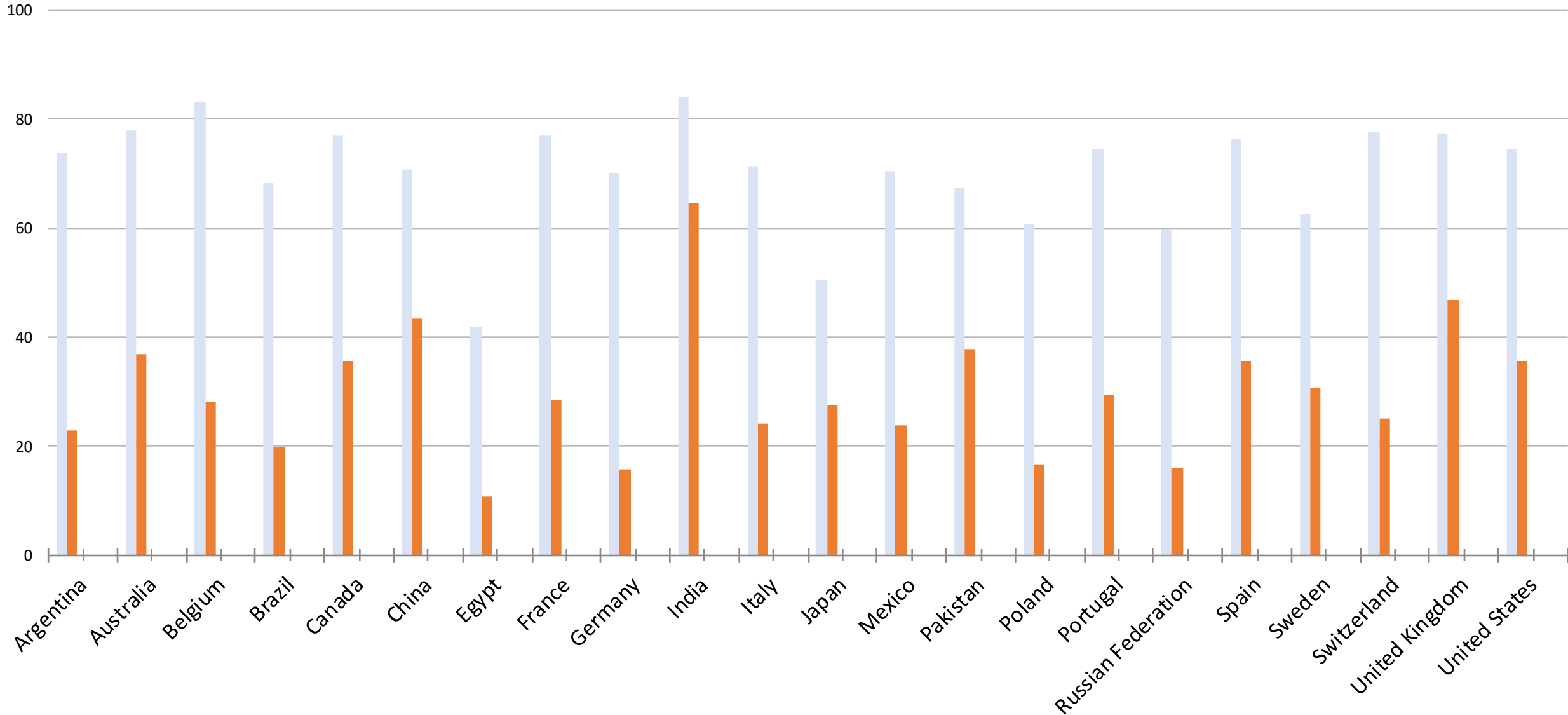
# Total percentage trusting each organisation or individual with DNA and health information (global meta-analysis)

■ Own doctor



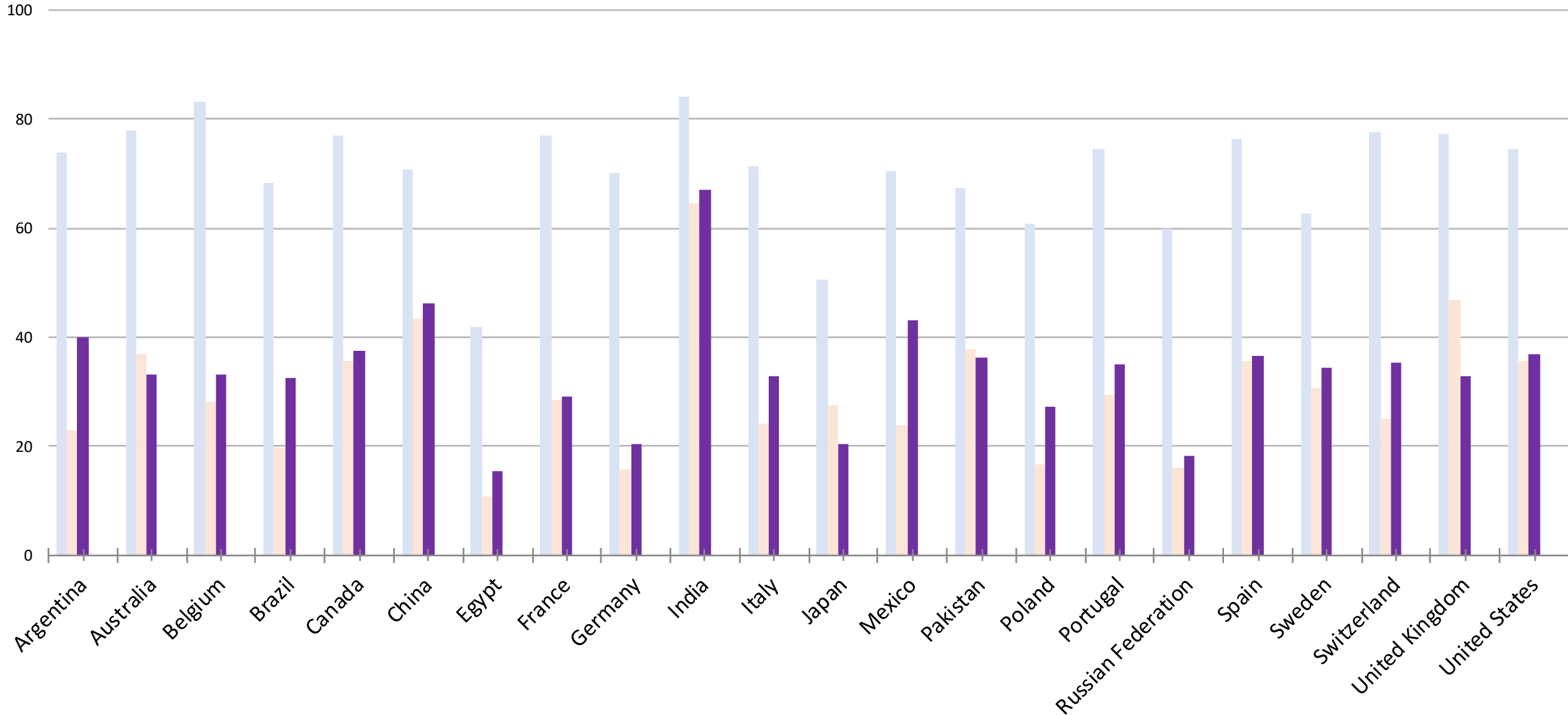
# Total percentage trusting each organisation or individual with DNA and health information (global meta-analysis)

Own doctor    Any doctor in country



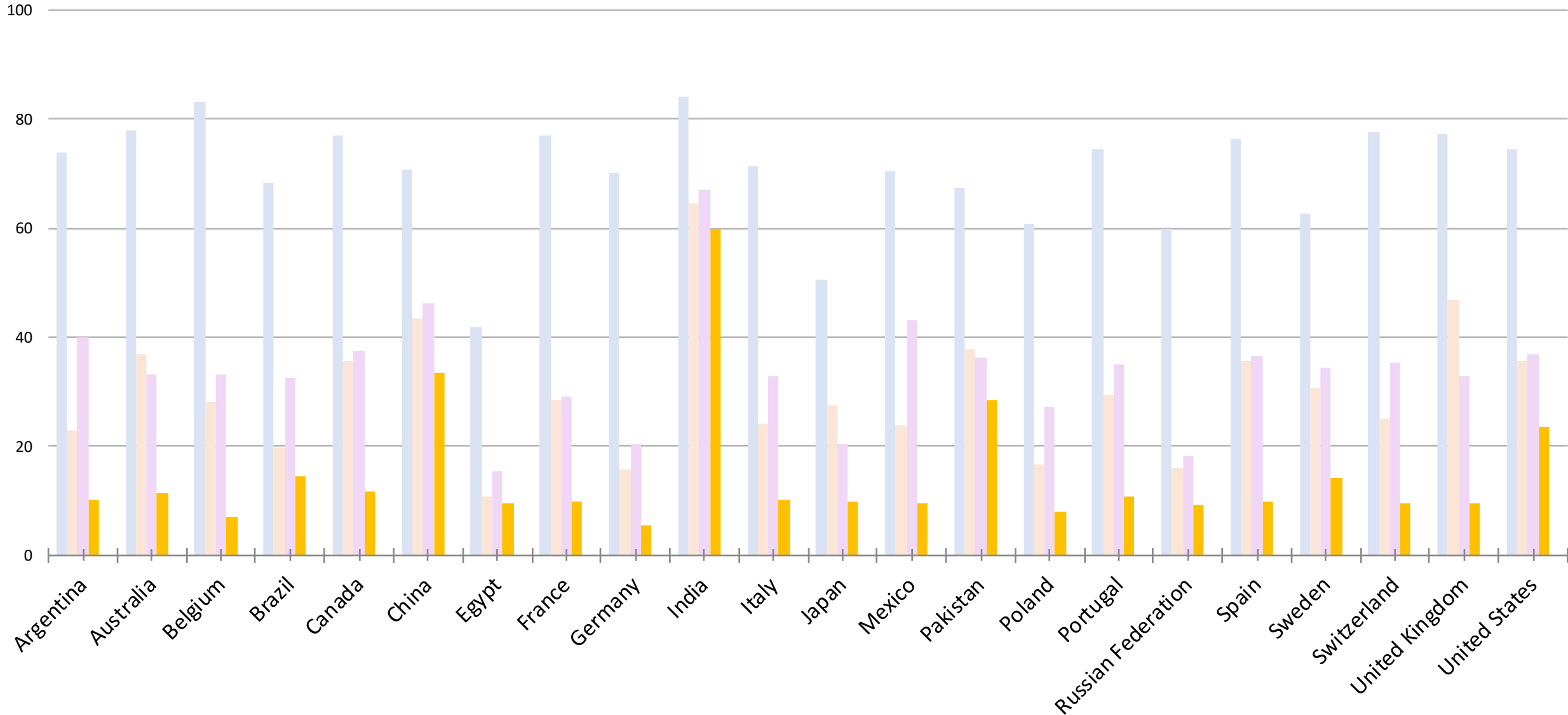
# Total percentage trusting each organisation or individual with DNA and health information (global meta-analysis)

Own doctor    Any doctor in country    Non-profit researcher in my country

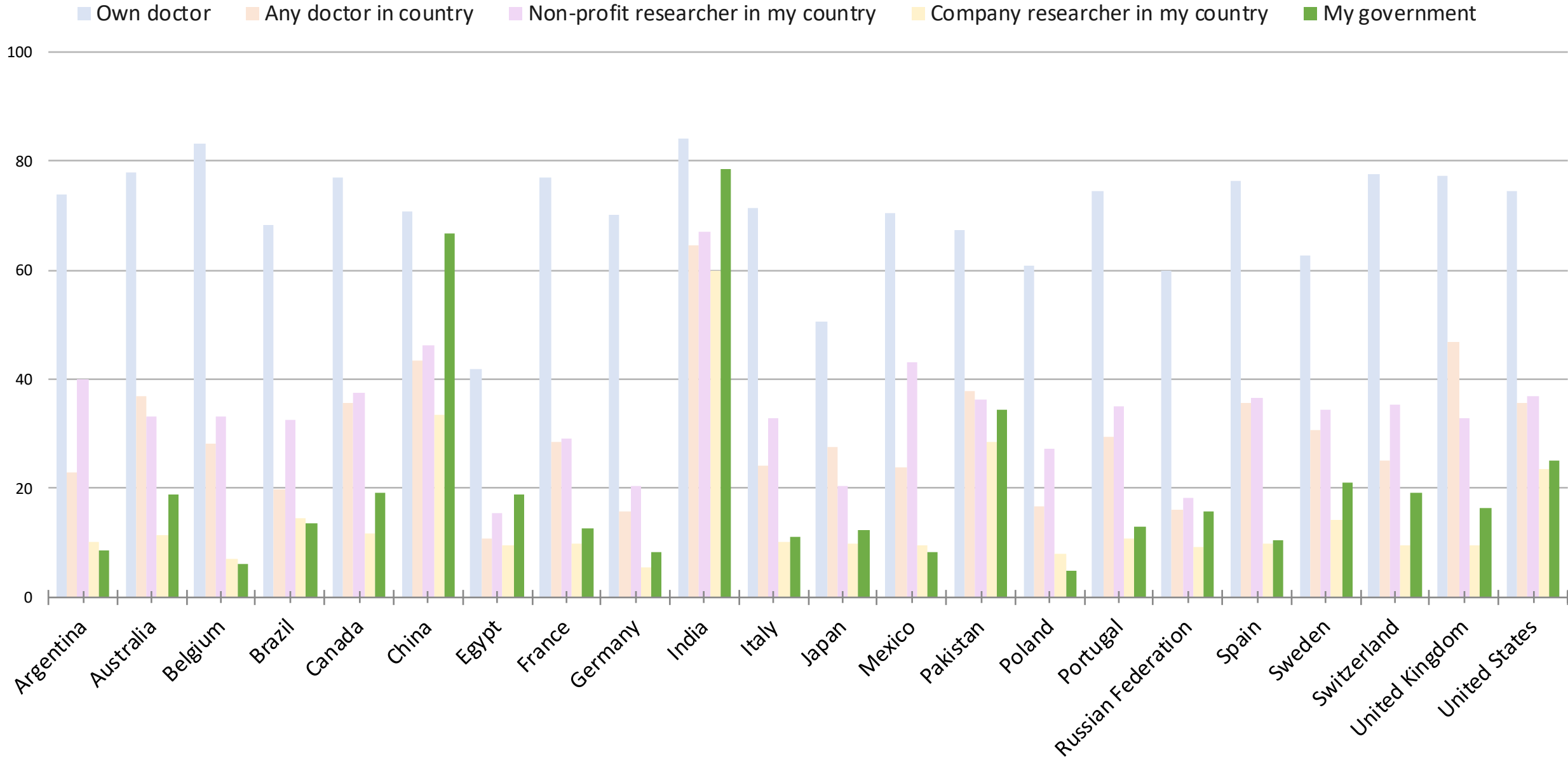


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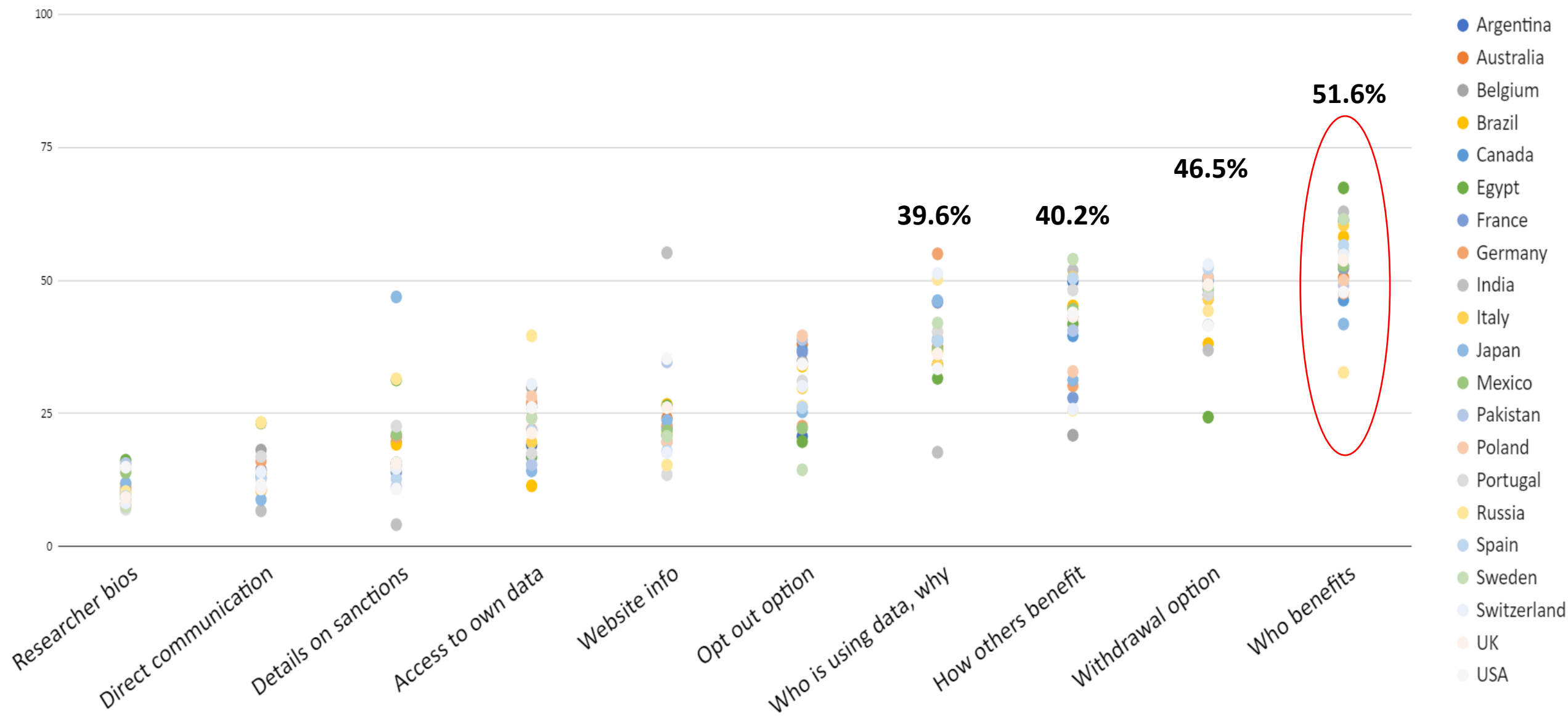
Own doctor    Any doctor in country    Non-profit researcher in my country    Company researcher in my country



# Total percentage trusting each organisation or individual with DNA and health information (global meta-analysis)

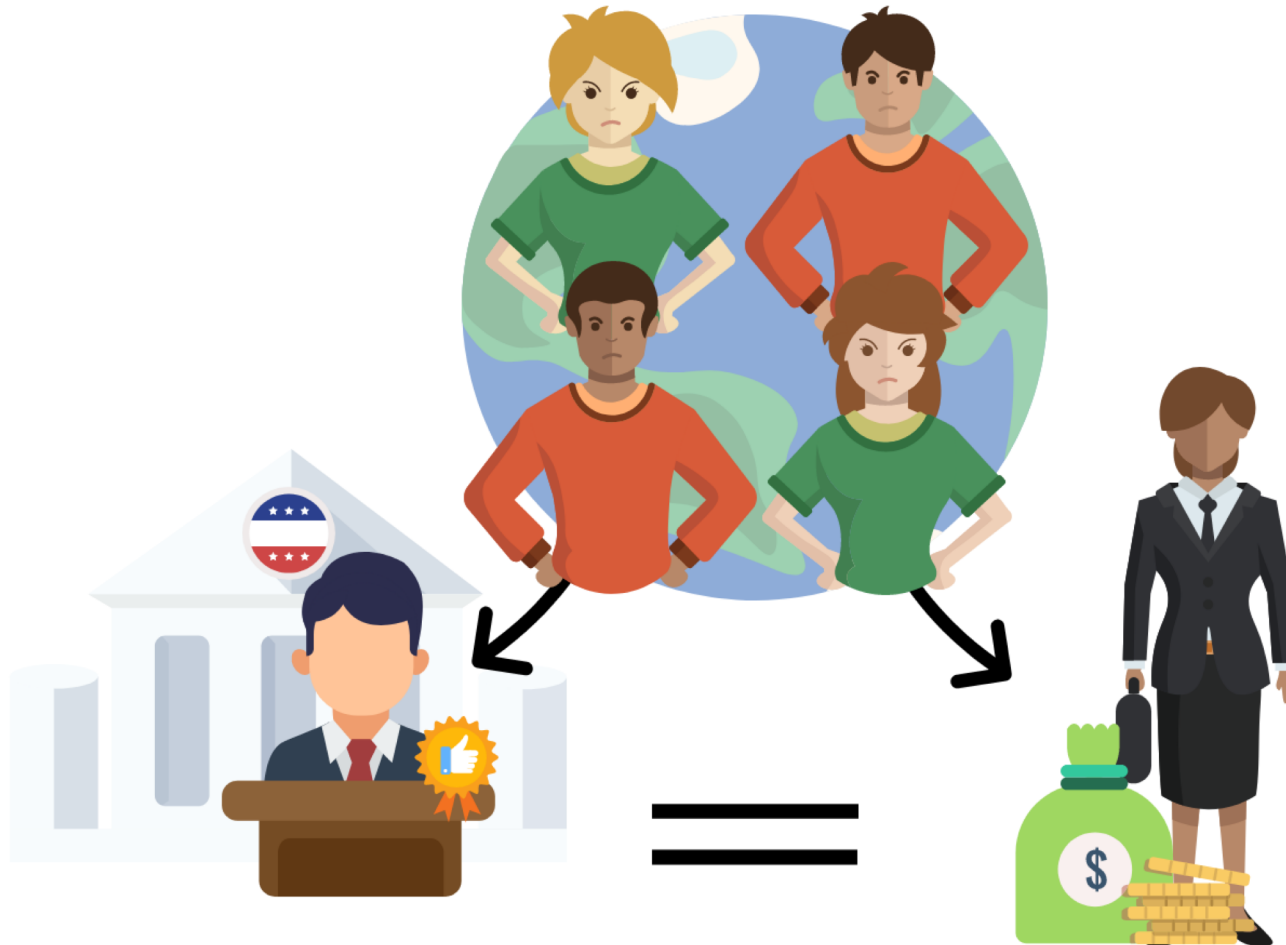


# "What information would help you to trust the people asking you to donate DNA and/or medical information?"





Across 22 countries, there's variation in who is trusted with data but the **most trusted** is a person's **own doctor**



**Doctors** play a **gatekeeping** role in supporting the **development of large-scale data sharing initiatives**

Trust may be increased by **clarity** about **who** will use the data, **for what purpose**, **who will benefit & how**

# Deeper Analysis using English speaking data only

English speakers were first to be recruited, and also each set of country data will be analysed by each collaborator

# Profile of the most 'trusting participants'

- (USA, Canada, Australia, UK only)
  - More likely to be under 50, male, with children, hold religious beliefs, have personal experience of genetics and be from the USA. This profile are the most likely to be willing to donate data for any reason
  - Milne et al 2019 Trust paper

Human Genetics  
<https://doi.org/10.1007/s00439-019-02062-0>

ORIGINAL INVESTIGATION

 Check for updates

**Trust in genomic data sharing among members of the general public in the UK, USA, Canada and Australia**

Richard Milne<sup>1,2</sup> · Katherine I. Morley<sup>3,4,5</sup> · Heidi Howard<sup>6</sup> · Emilia Niemiec<sup>6</sup> · Dianne Nicol<sup>7</sup> · Christine Critchley<sup>7,8</sup> · Barbara Prainsack<sup>9,10</sup> · Danya Vears<sup>11,12,13,14</sup> · James Smith<sup>15</sup> · Claire Steed<sup>15</sup> · Paul Bevan<sup>15</sup> · Jerome Atutornu<sup>1,16</sup> · Lauren Farley<sup>1</sup> · Peter Goodhand<sup>17</sup> · Adrian Thorogood<sup>18</sup> · Erika Kleiderman<sup>18</sup> · Anna Middleton<sup>1,19</sup>  · on behalf of the Participant Values Work Stream of the Global Alliance for Genomics and Health

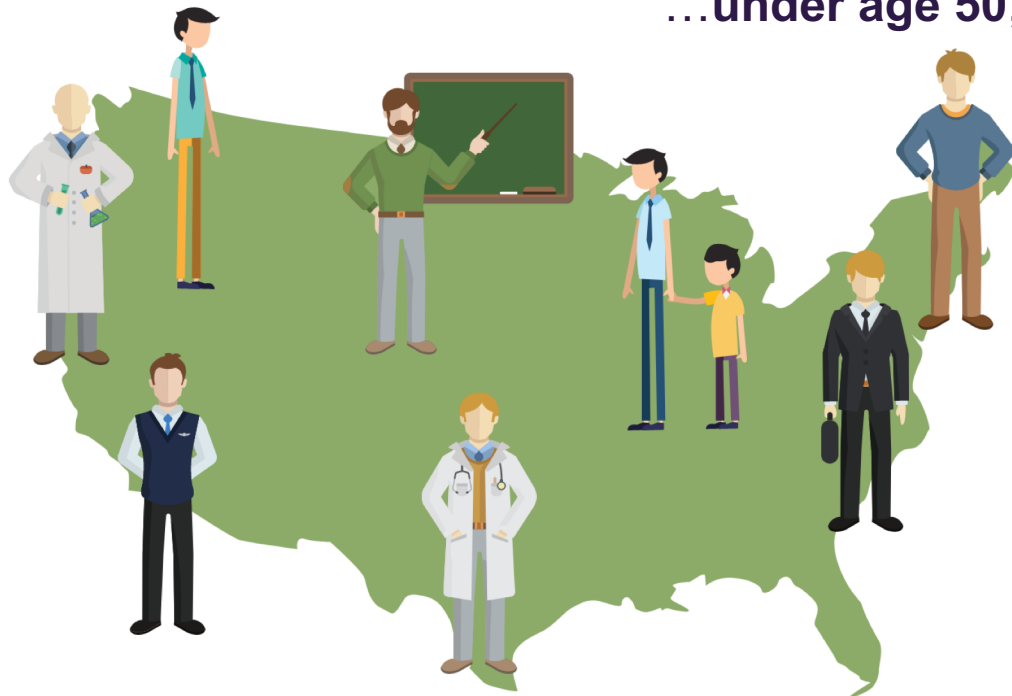
To support **responsible data sharing** practices we need to:



Ensure **diversity** amongst the professionals who **create data sharing policies, governance structures and legislation**

This is because the **profile of people** who are the most **trusting of the data sharing process** is **very similar** to the **profile of the decision makers** in genomics...

...under age 50, male, with personal **experience of genomics** and from the **USA**



# It couldn't have happened without.....

## PI

Anna Middleton

## Project Management

Lauren Robarts

## Data Analysis

Richard Milne

Kate Morley

## Sanger Web team

James Smith

Paul Bevan

Claire Stead

## Films

Tim Pope

Loudcity

## Funding

Wellcome: Audrey Duncanson

## Collaborators for Each Country/Translation

Arabic: Haytham Sheerah, Mohamed Almarri

Mandarin: Yali Cong

French: Heidi C Howard

Australian: Christine Critchley, Dianne Nicol

S. African: Shelley Macaulay, Tasha Wainstein, Amanda Krause

German: Barbara Prainsack, Torsten Heinemann

Urdu (Pakistan and India): Q Annie Hassan

Icelandic: Vígdis Stefansdottir

Italian: Deborah Mascalzoni, Virginia Romano, Maria Gnadl

Japanese: Jusaku Minari

Polish: Emilia Niemiec

Portuguese: Álvaro Mendes, Cláudia de Freitas

Russian: Vera Izhevskaya, Elena Baranova, Alena Fedotova, Nadia Kovalevskaya

Spanish: Anne West, Maria Cerezo

Swedish: Heidi C Howard, Josephine Fernow

Ghana: Jerome Atutornu

## Participant Values Task Team

Natasha Bonhomme

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Emilia Niemiec

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Elissa Levin

Christoph Schickhardt

Danya Vears

Cris Woolston

## REWS

Adrian Thorogood

Bartha Knoppers

Madeleine Murtagh

Connecting Science: Julian Rayner

GA4GH: Peter Goodhand

- Middleton et al (2019) Members of the public in the USA, UK, Canada and Australia expressing genetic exceptionalism say they are more willing to donate genomic data. *European Journal Human Genetics* (in press)
- Milne et al (2019) Trust in genomic data sharing among members of the general public in the UK, USA, Canada and Australia. *Human Genetics*
- Middleton A, et al (2019). Attitudes of publics who are unwilling to donate DNA data for research. *European Journal of Medical Genetics*. Volume 62, Issue 5, Pages 316–323.
- Middleton A et al (2018) ‘Your DNA, Your Say’: global survey gathering attitudes toward genomics: design, delivery and methods. *Personalized Medicine*, Vol. 15, issue 4, pp.311-318.
- Middleton, A (2018) Society and personal genome data. *Human Molecular Genetics*. Vol. 27, No. R1
- Middleton A(2017) Your DNA, Your Say, *The New Bioethics*, 23:1, 74-80,