

Parents' perspectives on the use of children's facial images for research and diagnosis: a survey

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Online Resource 1

Facial analysis research survey

Information and consent

We would like to invite you to take part in a research survey aimed at investigating people's views on the collection, storage, usage and publication of facial photos for research and diagnosis. This survey forms part of an MSc research project at the University of Pretoria. In this quick 15 minute survey we will ask you a few questions about yourself and your views. Your participation in this study is entirely voluntary. You may choose not to answer certain questions and you can refuse to participate or stop at any time during the study without giving any reason. If you decide not to be in this research study or if you decide to stop at a later date, there will be no penalty or loss of benefits to which you are entitled. You can access your data by contacting the researcher below. All information that you give will be kept strictly confidential. Research reports, presentations and articles in scientific journals will not include any information that may identify you. This study has received written approval from Research Ethics Committees of the Faculty of Natural and Agricultural Sciences and the Faculty of Health Sciences at the University of Pretoria, telephone numbers 012 420 4356 and 012 356 3085. If you have any questions or concerns, please contact Lize Schoeman (MSc student; email: u17105316@tuks.co.za) or Prof. Vinet Coetzee (research supervisor; vinet.coetzee@up.ac.za) Do you agree to take part in the survey?

Yes

No

Skip To: End of Survey If We would like to invite you to take part in a research survey aimed at investigating people's vie... = No

Section A: Demographic information

Q1 How old are you?

Q2 What is your gender?

- Male
- Female
- Other
- Prefer not to say

Q3.1 What country are you from?

Q3.2 What is your ethnicity?

- Asian
- Coloured
- Indian
- Ndebele
- Pedi
- South Sotho
- Swazi
- Tsonga
- Tswana
- Venda
- White
- Xhosa
- Zulu
- Foreign
- Other
- Prefer not to say

Q4 Highest completed level of education

- No formal education
- Grade 1
- Grade 2
- Grade 3
- Grade 4
- Grade 5
- Grade 6
- Grade 7
- Grade 8
- Grade 9
- Grade 10
- Grade 11
- Grade 12 (National Senior Certificate)
- Higher certificate (NQF level 5)
- Diploma (NQF level 6)
- Bachelor's degree, Advanced Diploma (NQF level 7)
- Bachelor Honours degree, Post Graduate Diploma (NQF level 8)
- Master's degree (NQF level 9)
- Doctor's degree (NQF level 10)
- Prefer not to say

Q5 How many children do you have?

Skip To: End of Survey If How many children do you have? = 0

Q6.1a How old is your [oldest/firstborn/second/third etc] child?

Q6.2a What is the gender of your [oldest/firstborn/second/third etc] child?

- Male
- Female
- Other
- I prefer not to say

Section B: Inborn conditions

Q7 Were any of your children born with an inborn condition?

Inborn conditions are any health conditions your child might have been born with such as Down syndrome, Fetal alcohol syndrome or a cleft lip.

- Yes
- No
- Prefer not to say

Display This Question:

*If Were any of your children born with an inborn condition? Inborn conditions are any health condit... =
Yes*

Q8 Which child/children were born with an inborn condition?
(select all the children that were born with an inborn condition)

- Oldest/firstborn child
- Second child
- Third child
- Fourth child
- Fifth child
- Sixth child
- Seventh child
- Eighth child
- Ninth child or more
- Prefer not to say

Q9.1a Which inborn condition was your [oldest/firstborn/second/third etc] child diagnosed with?

Q9.2a What tests did the doctors perform to test for this condition?

Q9.3a At what age was your [oldest/firstborn/second/third etc] child diagnosed with this condition?

Q9.4a How old were you when your [oldest/firstborn/second/third etc] child was born?

Section C: Facial analysis research

Computers can help doctors to diagnose inborn conditions at an earlier age and more effectively. For example, you can take a photo of a baby and the computer can tell the doctor if there is a good chance that this baby has an inborn condition or not. This is very useful because the doctor will then be able to refer the baby for further testing to establish an accurate diagnosis. But, to develop these tools researchers need to collect a database of

facial photos of people with and without these conditions. We would like to understand your views about the collection, storage, usage and publication of facial photos.

Q10 Collection of facial photos:

We want to understand your views about researchers taking facial photos for research and diagnostics. If researchers invited you to take part in a research study that you think is a worthy cause:

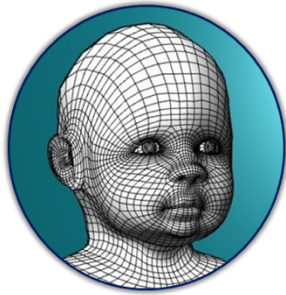
Do you think you would allow researchers to take facial photos of your child/children?

- Definitely yes
- Probably yes
- Might or might not
- Probably not
- Definitely not

Skip To: End of Survey If Collection of facial photos: We want to understand your views about researchers taking facial pho... = Probably not

Skip To: End of Survey If Collection of facial photos: We want to understand your views about researchers taking facial pho... = Definitely not

Q11 3D photos are a special kind of photo that looks like this:



While 2D photos are the normal type of photo you take with a camera.

What types of photos do you think you would allow researchers to take of your child?

- 2D photos only
- 3D photos only
- Both 2D and 3D photos

Q12 Why do you feel this way about researchers taking your child's photos? (optional)

Q13 Storage of facial photos:

We want to understand your views about the storing of your child's facial photos after they were photographed in the way you were comfortable with.

Do you think you would allow researchers to store your child's facial photos in the following types of databases?

	Definitely not	Probably not	Might or might not	Probably yes	Definitely yes
A secure database that only the original researchers can access.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A secure database that other pre-approved researchers can access.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A secure database that other researchers and/or doctors, but not the general public, can access.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A publicly available database.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q14 Why do you feel this way about the storing of your child's photos? (optional)

Q15 Use of facial photos:

We want to understand your views about how you would like researchers to use your child's

facial photos after they were photographed in the way you were comfortable with.

Do you think you would allow researchers to use your child's facial photos for the following?

	Definitely not	Probably not	Might or might not	Probably yes	Definitely yes
The original study that you signed up for.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other similar research studies also aimed at improving diagnosis that received ethical approval.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any research study that received ethical approval.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Use of facial photos: We want to understand your views about how you would like researchers to us... = Other similar research studies also aimed at improving diagnosis that received ethical approval. [Might or might not]

Or Use of facial photos: We want to understand your views about how you would like researchers to us... = Other similar research studies also aimed at improving diagnosis that received ethical approval. [Probably yes]

Or Use of facial photos: We want to understand your views about how you would like researchers to us... = Other similar research studies also aimed at improving diagnosis that received ethical approval. [Definitely yes]

Q16 Are there any conditions that you would like researchers to adhere to before they use your child's facial photos in other similar research studies?

Display This Question:

If Use of facial photos: We want to understand your views about how you would like researchers to us... = Any research study that received ethical approval. [Might or might not]

Or Use of facial photos: We want to understand your views about how you would like researchers to us... = Any research study that received ethical approval. [Probably yes]

Or Use of facial photos: We want to understand your views about how you would like researchers to us... = Any research study that received ethical approval. [Definitely yes]

Q17 Are there any conditions that you would like researchers to adhere to before they use your child's facial photos in any other research study that received ethical approval?

Q18 Publication of facial photos:

We want to understand your views about how (or if) you would like researchers to publish your child's facial photos, after they were photographed and the photos used in a way you were comfortable with.

Do you think you would allow researchers to publish your child's facial photos as individual images in academic journals without their eyes covered? Academic journals are books that contain scientific research from different researchers and are mainly meant for other researchers to read.

For example:



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- Definitely yes
- Probably yes
- Might or might not
- Probably not
- Definitely not

Q19 Do you think you would allow researchers to publish your child's facial photos as individual images in academic journals, with their eyes covered?

For example:



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- Definitely yes
- Probably yes
- Might or might not
- Probably not
- Definitely not

Q20 Do you think you would allow researchers to publish your child's facial photos as individual images in academic journals, with large parts of their face covered?

For example:



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- Definitely yes
- Probably yes
- Might or might not
- Probably not
- Definitely not

Q21 Do you think you would allow researchers to publish your child's facial photos as part of a composite image in academic journals? Composite images blend facial photos of many

different people. It looks like a person, but the individual people whose facial images were used can't be identified from the composite image.

For example:



<https://learnopencv.com/average-face-opencv-c-python-tutorial/>

- Definitely yes
- Probably yes
- Might or might not
- Probably not
- Definitely not

Q22 How do you think you would allow researchers to present your child's facial photos at scientific conferences? Scientific conferences are mostly attended by other researchers and doctors. Select all the options that you think you would allow.

- As an individual image without the eyes covered.
- As an individual image with the eyes covered.
- As an individual image with a large section of the face covered.
- As a composite image.
- I wouldn't allow them to present my child's facial photo in any form.

Q23 How do you think you would allow researchers to present your child's facial photos in newspapers and magazines? Select all the options that you think you would allow.

- As an individual image without the eyes covered.

- As an individual image with the eyes covered.
- As an individual image with a large section of the face covered.
- As a composite image.
- I wouldn't allow them to present my child's facial photo in any form.

Q24 How do you think you would allow researchers to present your child's facial photos on a website? Select all the options that you think you would allow.

- As an individual image without the eyes covered.
- As an individual image with the eyes covered.
- As an individual image with a large section of the face covered.
- As a composite image.
- I wouldn't allow them to present my child's facial photo in any form.

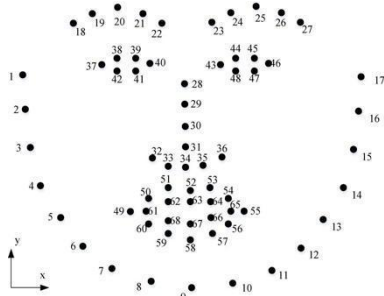
Q25 How do you think you would allow researchers to present your child's facial photos on social media, such as Facebook? Select all the options that you think you would allow.

- As an individual image without the eyes covered.
- As an individual image with the eyes covered.
- As an individual image with a large section of the face covered.
- As a composite image.
- I wouldn't allow them to present my child's facial photo in any form.

Q26 Why do you feel this way about the publication of your child's photos? (optional)

Q27 In some cases, researchers can also store information about the shape of your child's face without storing your child's actual photos. For instance, by only keeping information about 130 points on the face. However, this might limit the usefulness of the images for future studies.

For example:



Li, D., Z. Wang, Q. Gao, Y. Song, X. Yu *et al.*, 2019 Facial expression recognition based on electroencephalogram and facial landmark localization. *Technology and Health Care* 27: 373-387.

Would you feel differently about how your child's image is stored, used, and published if the information was recorded as points and not as actual photos?

- No
- Yes, I prefer the information is stored as points and not as actual photos
- Yes, I prefer the information is stored as actual photos and not as points

Display This Question:

*If In some cases, researchers can also store information about the shape of your child's face without... =
Yes, I prefer the information is stored as points and not as actual photos*

Q28a How strongly do you prefer that the information is stored as points and not as actual photos?

	Somewhat	Moderately	Strongly	Extremely strongly
I prefer the information is stored as points and not as actual photos	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If In some cases, researchers can also store information about the shape of your child's face without... != No

And In some cases, researchers can also store information about the shape of your child's face without... != Yes, I prefer the information is stored as points and not as actual photos

Q28b How strongly do you prefer that the information is stored as actual photos and not as points?

	Somewhat	Moderately	Strongly	Extremely strongly
I prefer the information is stored as actual photos and not as points.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section D: Infant photos

Q29a **The use of infant photos for facial analysis research:**

Photos of babies' faces with or without inborn conditions are especially useful as it can help doctors diagnose these conditions at a very young age. Earlier diagnosis can lead to earlier treatment and better management of the condition. People generally also cannot be recognised from their baby photos. Some people might therefore argue that it is actually better to use baby photos for research as they would not be recognised from these photos later in life. Using these photos for research can also enable earlier diagnosis. Other people

might feel differently, in that they feel babies should be more protected than older children and adults.

Do you think it is better to use baby facial photos, instead of the facial photos of older children, for facial analysis research and diagnostics?

	Definitely not	Probably not	Might or might not	Probably yes	Definitely yes
Baby photos are better than photos of older children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q29b Why do you say that? (optional)

Q30 Do you think there should be different rules for how the facial photos of children with and without inborn conditions are collected, stored, used, and published?

	Definitely not	Probably not	Might or might not	Probably yes	Definitely yes
Different rules for children with and without inborn conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Do you think there should be different rules for how the facial photos of children with and witho... = Definitely yes

Or Do you think there should be different rules for how the facial photos of children with and witho... = Might or might not

Or Do you think there should be different rules for how the facial photos of children with and witho... = Probably yes

Q31 How should the rules be different for children with and without inborn conditions?

Q32 Do you think there should be different rules for how the facial photos of children, compared to adults are collected, stored, used, and published?

	Definitely not	Probably not	Might or might not	Probably yes	Definitely yes
Different rules for children and adults.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Do you think there should be different rules for how the facial photos of children, compared to a... = Definitely yes

Or Do you think there should be different rules for how the facial photos of children, compared to a... = Probably yes

Or Do you think there should be different rules for how the facial photos of children, compared to a... = Might or might not

Q33 How should the rules be different for children compared to adults?

Q34 Is there anything else you would like to add?

THE END. Thank you for your time!