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

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## Journal of Community Genetics

## Online Resource 3

Full thematic analysis: How should the rules be different for children compared to adults?

- 1. <u>Ability to consent:</u> Adults can consent and make decisions for themselves, but children require an adult to consent on behalf of the child.
- 2. **Protection of children:** Adults can protect themselves and children cannot. Respondents indicated that children are more vulnerable than adults and thus need more protection of their facial images, privacy and identity.
- 3. **Consent from guardians:** Consent is required form the children's parents or guardians before using the facial images for research or publishing.

Full thematic analysis: How should the rules be different for children with and without congenital conditions?

- 1. <u>Better protection:</u> Respondents described that children with CDs and their identities should be better protected, with their images being more private. One respondent indicated that the images of children with CDs should have their eyes blocked out.
- 2. <u>Increased sensitivity:</u> Respondents indicated that they way facial images of children with CDs are handled should be handled more sensitively and with respect.
- 3. <u>Stringency of rules:</u> There were different views on the stringency of rules for children with and without CDs. Some respondents indicated that the rules around handling and using facial images of children with CDs should be more strict, and one respondent indicated the opposite.

Full thematic analysis: Why do you think the use of baby photos is better than using photos of older children?

1. <u>Baby photos can aid in earlier diagnosis</u>: Using baby facial photos for facial analysis research can help in the earlier diagnosis and identification of CDs.

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- 2. <u>Early diagnosis is advantageous:</u> Respondents felt that in turn, if baby facial photos can allow for earlier diagnosis, it's beneficial for the well-being of children and families.
- 3. <u>Recognition later in life:</u> Using baby facial photos for research and diagnosis purposes may make identification of the person later in life more difficult, as babies change over time. This may protect the individual's privacy.