**Supplementary material**

**Barber-Say/Ablepharon-Macrostomia Syndrome Semi-structured Interview**

*The questions below have been used as a guide in the interviews with the individuals with Barber-Say/Ablepharon-Macrostomia syndrome. Based on the answered further, more detailed and personalized questions have been asked to each participant.*

-How old are you?

-What do you do?/Do you study or work?

-Which kind of school are you attending?/Which kind of work do you do?

-Which kind of school would you like to attend?/Which kind of work would you like to do?

-How did you become aware of your condition for the first time?/ From family or from doctors? /Do you remember or not?

-Based on your experience, do you think the way you have been informed is correct? /Would you like to give us some advice on how to inform other patients?

-What is your relationship with your family? Do you feel accepted by them?

-What’s your relationship with other people? Partner//Friends/Working colleagues…?

-Do you feel comfortable with your physical appearance?

-Do you think your physical appearance influence your relationship with other people?

-How much importance do you give to it? Do you have an “ideal” body image? If so, how much your real body image is similar to it?

-Do you think your appearance has changed over time? If so, which part of your body has changed most?

-Have you ever undergone plastic/maxillo-facial/oral surgery?/ How many interventions?/ Do you remember in what they consisted in?

-Have you undergone any other cosmetic treatment? Laser therapy to remove excessive hair?

-Did you started to feel (more) comfortable with your appearance (only) after the surgery/other treatments or not?

-Would you advise other patients to do the same surgical/not surgical treatments or to have any treatment, or would you advise others to leave this?

-Would you like to change your body image in the future or not?

-Have you ever had any kind of psychological support/therapy or not?

-Do you think it might be helpful or not?

-Do you believe that surgery/other physical or psychological treatments increased your body satisfaction and/or your quality of life?