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**Suppl. material 1.** Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement

No.	Item	Guide and description	Location in this review
1	Aim	State the research question the synthesis addresses.	Methods
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	Methods
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	Methods
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	Methods
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	Methods
6	Electronic search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	Methods, suppl. material 2
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	Methods
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	Results; see Table 1 & 2.
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	Results; Figure 1.
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	Methods, Suppl
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	Methods; results, Suppl. material 3.
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	Methods
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	Methods
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	Methods
15	Software	State the computer software used, if any.	Methods
16	Number of reviewers	Identify who was involved in coding and analysis.	Methods
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	Methods

18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	Methods, Figure 3.
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	Methods
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	Results, see Suppl. Material 4.
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	Results; Figure 2

**Reference: Tong A. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Medical Research Methodology ;12(1):181 182.**

## Suppl. material 2. Search strategy (10/10/2024)

Database searched	Platform	Years of coverage	Records	Records after duplicates removed
Medline ALL	Ovid	1946 - Present	501	497
Embase	Embase.com	1971 - Present	577	292
Web of Science Core Collection*	Web of Knowledge	1975 - Present	368	154
Cochrane Central Register of Controlled Trials	Wiley	1992 - Present	73	51
CINAHL Plus	EBSCO	1982 - Present	270	117
PsycINFO	Ovid	1806 - Present	124	88
Additional Search Engines: Google Scholar**			100	92
Total			2013	1291

\*Science Citation Index Expanded (1975-present) ; Social Sciences Citation Index (1975-present) ; Arts & Humanities Citation Index (1975-present) ; Conference Proceedings Citation Index- Science (1990-present) ; Conference Proceedings Citation Index- Social Science & Humanities (1990-present) ; Emerging Sources Citation Index (2005-present)

\*\*Google Scholar was searched via "Publish or Perish" to download the results in EndNote.

No other database limits were used than those specified in the search strategies

### MEDLINE

(exp Craniofacial Abnormalities / OR \* Jaw Abnormalities / OR Goldenhar Syndrome/ OR Facial Asymmetry/co OR Mandibulofacial Dysostosis/ OR Pierre Robin Syndrome/ OR (((craniofacial\* OR facial\* OR orofacial\* OR cranio-facial\* OR maxill\* OR skull\* OR cranial\* OR cranio\* OR mandib\* OR jaw OR acrofacial\* OR hemifacial\*) ADJ3 (malform\* OR abnormal\* OR anomal\* OR synost\* OR dysostosis\* OR dysplas\* OR cleft\* OR microsomia\* OR disfigure\* OR syndrome\* OR congenital\* OR severe\* OR handicap\*)) OR (rare\* ADJ3 (craniofacial\* OR cranio-facial\*) ADJ3 conditio\*) OR ((unicoronal\* OR coronal\* OR metopic\* OR sagittal\*) ADJ3 synost\*) OR cranioclinoid\* OR treacher-collin\* OR (robin\* ADJ3 sequence\*) OR oculo-auriculo-vertebral\* OR goldenhar OR Plagiocephal\* OR Adams-Oliver OR Antley-Bixler OR Baller-Gerold OR basilar-impression OR brachycephal\* OR Crouzon OR dyscephal\* OR exencephal\* OR frontal-bossing OR Hallermann-Streiff OR Hypertelorism\* OR Hypotelorism\* OR Marshall OR Opitz OR plagiocephal\* OR trigonocephal\* OR Oxycephal\* OR scaphocephal\* OR Acrocephalosyndactyl\* OR Apert OR Oxycephal\* OR Nager OR Franceschetti\* OR (pfeiffer\* ADJ3 syndrome\*) OR muenke\* OR saethre-hotzen\* OR burn-mckeown\* OR plagiocephal\* OR brachycephal\* OR dyscephal\* OR exencephal\* OR hypertelorism\* OR hypotelorism\* OR ((Opitz OR Marshall) ADJ3 syndrome\*)),ab,ti,kw. OR ((craniofacial\* OR cranio-facial\*) ADJ3 difference\*).ti.) AND (Life Change Events/ OR Health Services Accessibility/ OR Patient Satisfaction/ OR Patient Preference/ OR Caregiver Burden/ OR Stress, Psychological/ OR Adverse Childhood Experiences/ OR Adaptation, Psychological/ OR Emotional Adjustment/ OR Coping Skills/ OR exp \* Emotions / OR exp Parent-Child Relations/ OR Social Adjustment/ OR Homeostasis/ OR Social Support/ OR Holistic Health / OR (holistic\* OR wholistic\* OR Whole-Person\* OR (life ADJ3 event\*) OR ((human OR patient\* OR personal\* OR basic\* OR service\* OR healthcare\* OR health-care\* OR caregiver\* OR parent\* OR father\* OR paternal\* OR mother\* OR maternal\* OR child\* OR family\* OR families\*) ADJ3 (need OR needs OR Accessibilit\* OR access\* OR satisf\* OR preferen\* OR attitud\* OR burden\* OR stress\* OR Perspective\* OR expectation OR view\* OR experience\* OR emotion\* OR psycholog\* OR mental\* OR opinion\* OR acceptan\* OR perception\* OR value\* OR priorit\* OR relation\* OR reflection\*)) OR ((emotion\* OR psycholog\* OR mental\* OR social\* OR psychosocial\* OR early-life) ADJ3 (stress\* OR burden\* OR adjust\* OR function\* OR assess\* OR wellbeing OR well-being OR adapti\* OR interaction\* OR strateg\* OR support\* OR skill\*)) OR (adapti\* ADJ3 behav\*) OR (support\* ADJ3 need\*) OR coping\* OR autoregulat\* OR self-regulat\*).ab,ti,kw. OR (accessibilit\* OR stress\* OR emotion\* OR mood OR wellbeing OR well-being OR adaptation\*).ti.) AND (Qualitative Research/ OR Health Care Surveys/ OR Health Surveys/ OR Interviews as Topic/ OR Interview / OR Observational Study / OR Observational Studies as Topic/ OR Grounded Theory/ OR Observation/ OR "Surveys and Questionnaires"/ OR Focus Groups/ OR (((qualitative OR observation\* OR phenomenon\* OR thematic\* OR grounded\*) ADJ3 (research\* OR stud\* OR analy\* OR validit\* OR method\* OR theor\* OR data)) OR (health ADJ3 survey\*) OR (open-end\* ADJ3 questionnaire\*) OR interview\* OR focusgroup\* OR focus-group\* OR hermeneutic\* OR mixed-method\*).ab,ti,kw. OR (qualitative\* OR survey\* OR open-end\* OR questionnaire\* OR observation\* OR phenomenolog\*).ti.) NOT (exp \* Health Personnel / OR exp \*

Attitude of Health Personnel / OR \* Cleft Palate / OR \* Cleft Lip / OR \* Urinary Incontinence, Stress / OR \* Oxidative Stress / OR (personnel\* OR doctor\* OR nurse\* OR (position\* ADJ3 deformit\*) OR trauma\* OR cleft-lip\* OR cleft-palate\* OR (stress ADJ3 (incontinen\* OR oxidative\*)))ti.) NOT (case reports/ OR (case-report\*)):ti.) AND english.la. NOT (exp animals/ NOT humans/)

EMBASE

('skull malformation'/exp OR 'face malformation'/mj OR 'cleft face'/de OR 'jaw malformation'/mj OR 'Goldenhar syndrome'/de OR 'hemifacial microsomia'/de OR 'mandibulofacial dysostosis'/de OR 'Nager acrofacial dysostosis'/de OR 'Pierre Robin syndrome'/de OR (((craniofacial\* OR facial\* OR orofacial\* OR cranio-facial\* OR maxill\* OR skull\* OR cranial\* OR cranio\* OR mandib\* OR jaw OR acrofacial\* OR hemifacial\*) NEAR/3 (malform\* OR abnormal\* OR anomal\* OR synost\* OR dysostos\* OR dysplas\* OR cleft\* OR microsomia\* OR disfigure\* OR syndrome\* OR congenital\* OR severe\* OR handicap\*)) OR (rare\* NEAR/3 (craniofacial\* OR cranio-facial\*) NEAR/3 conditio\*) OR ((unicoronal\* OR coronal\* OR metopic\* OR sagittal\*) NEAR/3 synost\*) OR craniosynostos\* OR treacher-collin\* OR (robin\* NEAR/3 sequence\*) OR oculo-auriculo-vertebral\* OR goldenhar OR Plagiocephal\* OR Adams-Oliver OR Antley-Bixler OR Baller-Gerold OR basilar-impression OR brachycephal\* OR Crouzon OR dyscephal\* OR exencephal\* OR frontal-bossing OR Hallermann-Streiff OR Hypertelorism\* OR Hypotelorism\* OR Marshall OR Opitz OR plagiocephal\* OR trigonocephal\* OR Oxycephal\* OR scaphocephal\* OR Acrocephalosyndactyl\* OR Apert OR Oxycephal\* OR Nager OR Franceschetti\* OR (pfeiffer\* NEAR/3 syndrome\*) OR muenke\* OR saethre-chotzen\* OR burn-mckeown\* OR plagiocephal\* OR brachycephal\* OR dyscephal\* OR exencephal\* OR hypertelorism\* OR hypotelorism\* OR ((Opitz OR Marshall) NEAR/3 syndrome\*)):ab,ti,kw OR ((craniofacial\* OR cranio-facial\*) NEXT/1 difference\*):ti) AND ('life event'/de OR 'human needs'/exp OR 'health care access'/exp OR 'patient satisfaction'/exp OR 'patient satisfaction assessment'/de OR 'patient preference'/de OR 'patient attitude'/de OR 'caregiver burden'/de OR 'mental stress'/de OR 'emotional stress'/de OR 'parental stress'/exp OR 'early life stress'/de OR 'adaptive behavior'/de OR 'psychological adjustment'/de OR 'coping behavior'/de OR emotion/mj OR 'psychological aspect'/mj OR 'child parent relation'/de OR 'social adaptation'/de OR autoregulation/de OR 'social support'/exp OR (holistic\* OR wholistic\* OR Whole-Person\* OR (life NEAR/3 event\*) OR ((human OR patient\* OR personal\* OR basic\* OR service\* OR healthcare\* OR health-care\* OR caregiver\* OR parent\* OR father\* OR paternal\* OR mother\* OR maternal\* OR child\* OR family\* OR families\*) NEAR/3 (need OR needs OR Accessibilit\* OR access\* OR satisf\* OR preferen\* OR attitud\* OR burden\* OR stress\* OR Perspective\* OR expectation OR view\* OR experience\* OR emotion\* OR psycholog\* OR mental\* OR opinion\* OR acceptan\* OR perception\* OR value\* OR priorit\* OR relation\* OR reflection\*)) OR ((emotion\* OR psycholog\* OR mental\* OR social\* OR psychosocial\* OR early-life) NEAR/3 (stress\* OR burden\* OR adjust\* OR function\* OR assess\* OR wellbeing OR well-being OR adapti\* OR interaction\* OR strateg\* OR support\* OR skill\*)) OR (adapti\* NEAR/3 behav\*) OR (support\* NEAR/3 need\*) OR coping\* OR autoregulat\* OR self-regulat\*):ab,ti,kw OR (accessibilit\* OR stress\* OR emotion\* OR mood OR wellbeing OR well-being OR adaptation\*):ti) AND ('qualitative research'/exp OR 'qualitative analysis'/de OR 'qualitative validity'/de OR 'health care survey'/de OR 'health survey'/de OR 'open ended questionnaire'/de OR questionnaire/de OR interview/exp OR 'observational study'/de OR 'observational method'/de OR phenomenology/de OR 'thematic analysis'/de OR 'grounded theory'/de OR 'mixed method'/de OR observation/de OR questionnaire/de OR (((qualitative OR observation\* OR phenom\* OR thematic\* OR grounded\*) NEAR/3 (research\* OR stud\* OR analy\* OR validit\* OR method\* OR theor\* OR data)) OR (health NEAR/3 survey\*) OR (open-end\* NEAR/3 questionnaire\*) OR interview\* OR focusgroup\* OR focus-group\* OR hermeneutic\* OR mixed-method\*):Ab,ti,kw OR (qualitative\* OR survey\* OR open-end\* OR questionnaire\* OR observation\* OR phenomenolog\*):ti) NOT ('health care personnel'/exp/mj OR 'health personnel attitude'/mj/exp OR 'cleft palate'/mj OR 'cleft lip'/mj OR 'cleft lip palate'/mj OR 'stress incontinence'/mj OR 'oxidative stress'/mj OR (personnel\* OR doctor\* OR nurse\* OR (position\* NEAR/3 deformit\*) OR trauma\* OR cleft-lip\* OR cleft-palate\* OR (stress NEAR/3 (incontinen\* OR oxidative\*)))ti) NOT ('case report'/de OR (case-report\*)):ti) NOT [conference abstract]/lim AND [english]/lim NOT ([animals]/lim NOT [humans]/lim)

Web of Science

(TS=(((craniofacial\* OR facial\* OR orofacial\* OR cranio-facial\* OR maxill\* OR skull\* OR cranial\* OR cranio\* OR mandib\* OR jaw OR acrofacial\* OR hemifacial\*) NEAR/2 (malform\* OR abnormal\* OR anomal\* OR synost\* OR dysostos\* OR dysplas\* OR cleft\* OR microsomia\* OR disfigure\* OR syndrome\* OR congenital\* OR severe\* OR handicap\*)) OR (rare\* NEAR/2 (craniofacial\* OR cranio-facial\*) NEAR/2 conditio\*) OR ((unicoronal\* OR coronal\* OR metopic\* OR sagittal\*) NEAR/2 synost\*) OR craniosynostos\* OR treacher-collin\* OR (robin\* NEAR/2 sequence\*) OR oculo-auriculo-vertebral\* OR goldenhar OR Plagiocephal\* OR Adams-Oliver OR Antley-Bixler OR Baller-Gerold OR basilar-impression OR brachycephal\* OR Crouzon OR dyscephal\* OR exencephal\* OR frontal-bossing OR Hallermann-Streiff OR Hypertelorism\* OR Hypotelorism\* OR Marshall OR Opitz OR plagiocephal\* OR trigonocephal\* OR Oxycephal\* OR scaphocephal\* OR Acrocephalosyndactyl\* OR Apert OR Oxycephal\* OR Nager OR Franceschetti\* OR (pfeiffer\* NEAR/2 syndrome\*) OR muenke\* OR saethre-chotzen\* OR burn-mckeown\* OR plagiocephal\* OR brachycephal\* OR dyscephal\* OR exencephal\* OR hypertelorism\* OR hypotelorism\* OR ((Opitz OR Marshall) NEAR/2 syndrome\*)) OR TI=(((craniofacial\* OR cranio-facial\*) NEAR/1 difference\*)) AND (TS=(holistic\* OR wholistic\* OR Whole-Person\* OR (life NEAR/2 event\*) OR ((human OR patient\* OR personal\* OR basic\* OR service\* OR healthcare\* OR health-care\* OR caregiver\* OR parent\* OR father\* OR paternal\* OR mother\* OR maternal\* OR child\* OR family\* OR families\*) NEAR/2 (need OR needs OR Accessibilit\* OR access\* OR satisf\* OR preferen\* OR attitud\* OR burden\* OR stress\* OR Perspective\* OR expectation OR view\* OR experience\* OR emotion\* OR psycholog\* OR mental\* OR opinion\* OR acceptan\* OR perception\* OR value\* OR priorit\* OR relation\* OR reflection\*)) OR ((emotion\* OR psycholog\* OR mental\* OR social\* OR psychosocial\* OR early-life) NEAR/2 (stress\* OR burden\* OR adjust\* OR function\* OR assess\* OR wellbeing OR well-being OR adapti\* OR

interaction\* OR strateg\* OR support\* OR skill\*) OR (adapti\* NEAR/2 behav\*) OR (support\* NEAR/2 need\*) OR coping\* OR autoregulat\* OR self-regulat\*) OR TI=(accessibilit\* OR stress\* OR emotion\* OR mood OR wellbeing OR well-being OR adaptation\*) AND (TS=((qualitative OR observation\* OR phenomem\* OR thematic\* OR grounded\*) NEAR/3 (research\* OR stud\* OR analy\* OR validit\* OR method\* OR theor\* OR data)) OR (health NEAR/3 survey\*) OR (open-end\* NEAR/3 questionnaire\*) OR interview\* OR focusgroup\* OR focus-group\* OR hermeneutic\* OR mixed-method\*) OR TI=(qualitative\* OR survey\* OR open-end\* OR questionnaire\* OR observation\* OR phenomenolog\*) NOT TI=((personnel\* OR doctor\* OR nurse\* OR (position\* NEAR/2 deformat\*) OR trauma\* OR cleft-lip\* OR cleft-palate\* OR (stress NEAR/2 (incontinen\* OR oxidative\*)))) NOT TI=((case-report\*)) NOT DT=(Meeting Abstract OR Meeting Summary)

Cochrane

(((((craniofacial\* OR facial\* OR orofacial\* OR cranio-facial\* OR maxill\* OR skull\* OR cranial\* OR cranio\* OR mandib\* OR jaw OR acrofacial\* OR hemifacial\*) NEAR/3 (malform\* OR abnormal\* OR anomal\* OR synost\* OR dysostos\* OR dysplas\* OR cleft\* OR microsomia\* OR disfigure\* OR syndrome\* OR congenital\* OR severe\* OR handicap\*) OR (rare\* NEAR/3 (craniofacial\* OR cranio-facial\*) NEAR/3 conditio\*) OR ((unicoronal\* OR coronal\* OR metopic\* OR sagittal\*) NEAR/3 synost\*) OR craniostenosis\* OR treacher-collin\* OR (robin\* NEAR/3 sequence\*) OR oculo-auriculo-vertebral\* OR goldenhar OR Plagiocephal\* OR Adams-Oliver OR Antley-Bixler OR Baller-Gerold OR basilar-impression OR brachycephal\* OR Crouzon OR dyscephal\* OR exencephal\* OR frontal-bossing OR Hallermann-Streiff OR Hypertelorism\* OR Hypotelorism\* OR Marshall OR Opitz OR plagiocephal\* OR trigonocephal\* OR Oxycephal\* OR scaphocephal\* OR Acrocephalosyndactyl\* OR Apert OR Oxycephal\* OR Nager OR Franceschetti\* OR (pfeiffer\* NEAR/3 syndrome\*) OR muenke\* OR saethre-chotzen\* OR burn-mckeown\* OR plagiocephal\* OR brachycephal\* OR dyscephal\* OR exencephal\* OR hypertelorism\* OR hypotelorism\* OR ((Opitz OR Marshall) NEAR/3 syndrome\*)):ab,ti,kw OR ((craniofacial\* OR cranio-facial\*) NEXT/1 difference\*):ti) AND ((holistic\* OR wholistic\* OR Whole-Person\* OR (life NEAR/3 event\*) OR ((human OR patient\* OR personal\* OR basic\* OR service\* OR healthcare\* OR health-care\* OR caregiver\* OR parent\* OR father\* OR paternal\* OR mother\* OR maternal\* OR child\* OR family\* OR families\*) NEAR/3 (need OR needs OR Accessibilit\* OR access\* OR satisf\* OR preferen\* OR attitud\* OR burden\* OR stress\* OR Perspective\* OR expectation OR view\* OR experience\* OR emotion\* OR psycholog\* OR mental\* OR opinion\* OR acceptan\* OR perception\* OR value\* OR priorit\* OR relation\* OR reflection\*)) OR ((emotion\* OR psycholog\* OR mental\* OR social\* OR psychosocial\* OR early-life) NEAR/3 (stress\* OR burden\* OR adjust\* OR function\* OR assess\* OR wellbeing OR well-being OR adapti\* OR interaction\* OR strateg\* OR support\* OR skill\*)) OR (adapti\* NEAR/3 behav\*) OR (support\* NEAR/3 need\*) OR coping\* OR autoregulat\* OR self-regulat\*):ab,ti,kw OR (accessibilit\* OR stress\* OR emotion\* OR mood OR wellbeing OR well-being OR adaptation\*):ti) AND (((qualitative OR observation\* OR phenomem\* OR thematic\* OR grounded\*) NEAR/3 (research\* OR stud\* OR analy\* OR validit\* OR method\* OR theor\* OR data)) OR (health NEAR/3 survey\*) OR (open-end\* NEAR/3 questionnaire\*) OR interview\* OR focusgroup\* OR focus-group\* OR hermeneutic\* OR mixed-method\*):Ab,ti,kw OR (qualitative\* OR survey\* OR open-end\* OR questionnaire\* OR observation\* OR phenomenolog\*):ti)

((personnel\* OR doctor\* OR nurse\* OR (position\* NEAR/3 deformat\*) OR trauma\* OR cleft-lip\* OR cleft-palate\* OR (stress NEAR/3 (incontinen\* OR oxidative\*)))):ti)

("conference abstract":kw OR Trial registry record:pt)

#1 NOT #2 NOT #3

psycINFO

(exp Craniofacial Abnormalities / OR \* Jaw Abnormalities / OR Goldenhar Syndrome/ OR Facial Asymmetry/ OR Mandibulofacial Dysostosis/ OR Pierre Robin Syndrome/ OR (((craniofacial\* OR facial\* OR orofacial\* OR cranio-facial\* OR maxill\* OR skull\* OR cranial\* OR cranio\* OR mandib\* OR jaw OR acrofacial\* OR hemifacial\*) ADJ3 (malform\* OR abnormal\* OR anomal\* OR synost\* OR dysostos\* OR dysplas\* OR cleft\* OR microsomia\* OR disfigure\* OR syndrome\* OR congenital\* OR severe\* OR handicap\*)) OR (rare\* ADJ3 (craniofacial\* OR cranio-facial\*) ADJ3 conditio\*) OR ((unicoronal\* OR coronal\* OR metopic\* OR sagittal\*) ADJ3 synost\*) OR craniostenosis\* OR treacher-collin\* OR (robin\* ADJ3 sequence\*) OR oculo-auriculo-vertebral\* OR goldenhar OR Plagiocephal\* OR Adams-Oliver OR Antley-Bixler OR Baller-Gerold OR basilar-impression OR brachycephal\* OR Crouzon OR dyscephal\* OR exencephal\* OR frontal-bossing OR Hallermann-Streiff OR Hypertelorism\* OR Hypotelorism\* OR Marshall OR Opitz OR plagiocephal\* OR trigonocephal\* OR Oxycephal\* OR scaphocephal\* OR Acrocephalosyndactyl\* OR Apert OR Oxycephal\* OR Nager OR Franceschetti\* OR (pfeiffer\* ADJ3 syndrome\*) OR muenke\* OR saethre-chotzen\* OR burn-mckeown\* OR plagiocephal\* OR brachycephal\* OR dyscephal\* OR exencephal\* OR hypertelorism\* OR hypotelorism\* OR ((Opitz OR Marshall) ADJ3 syndrome\*)):ab,ti. OR ((craniofacial\* OR cranio-facial\*) ADJ difference\*):ti.) AND (Life Change Events/ OR Health Services Accessibility/ OR Patient Satisfaction/ OR Patient Preference/ OR Caregiver Burden/ OR Stress, Psychological/ OR Adverse Childhood Experiences/ OR Adaptation, Psychological/ OR Emotional Adjustment/ OR Coping Skills/ OR exp \* Emotions / OR exp Parent-Child Relations/ OR Social Adjustment/ OR Homeostasis/ OR Social Support/ OR Holistic Health / OR (holistic\* OR wholistic\* OR Whole-Person\* OR (life ADJ3 event\*) OR ((human OR patient\* OR personal\* OR basic\* OR service\* OR healthcare\* OR health-care\* OR caregiver\* OR parent\* OR father\* OR paternal\* OR mother\* OR maternal\* OR child\* OR family\* OR families\*) ADJ3 (need OR needs OR Accessibilit\* OR access\* OR satisf\* OR preferen\* OR attitud\* OR burden\* OR stress\* OR Perspective\* OR expectation OR view\* OR experience\* OR emotion\* OR psycholog\* OR mental\* OR opinion\* OR acceptan\* OR

perception\* OR value\* OR priorit\* OR relation\* OR reflection\*) OR ((emotion\* OR psycholog\* OR mental\* OR social\* OR psychosocial\* OR early-life) ADJ3 (stress\* OR burden\* OR adjust\* OR function\* OR assess\* OR wellbeing OR well-being OR adapti\* OR interaction\* OR strateg\* OR support\* OR skill\*)) OR (adapti\* ADJ3 behav\*) OR (support\* ADJ3 need\*) OR coping\* OR autoregulat\* OR self-regulat\*).ab,ti. OR (accessibilit\* OR stress\* OR emotion\* OR mood OR wellbeing OR well-being OR adaptation\*).ti.) AND (Qualitative Methods/ OR Surveys/ OR Interviews / OR Observation Methods / OR Grounded Theory/ OR Focus Group/ OR (((qualitative OR observation\* OR phenom\* OR thematic\* OR grounded\*) ADJ3 (research\* OR stud\* OR analy\* OR validit\* OR method\* OR theor\* OR data)) OR (health ADJ3 survey\*) OR (open-end\* ADJ3 questionnaire\*) OR interview\* OR focusgroup\* OR focus-group\* OR hermeneutic\* OR mixed-method\*).ab,ti. OR (qualitative\* OR survey\* OR open-end\* OR questionnaire\* OR observation\* OR phenomenolog\*).ti.) NOT (exp \* Health Personnel / OR exp \* Attitude of Health Personnel / OR \* Cleft Palate / OR \* Cleft Lip / OR \* Urinary Incontinence, Stress / OR \* Oxidative Stress / OR (personnel\* OR doctor\* OR nurse\* OR (position\* ADJ3 deformit\*) OR trauma\* OR cleft-lip\* OR cleft-palate\* OR (stress ADJ3 (incontinen\* OR oxidative\*))).ti.) NOT (case reports/ OR (case-report\*).ti.) AND english.la. NOT (exp animals/ NOT humans/)

## CINAHL

(MH Craniofacial Abnormalities + OR MM Jaw Abnormalities + OR MH Goldenhar Syndrome OR MH Mandibulofacial Dysostosis OR MH Pierre Robin Syndrome OR TI(((craniofacial\* OR facial\* OR orofacial\* OR cranio-facial\* OR maxill\* OR skull\* OR cranial\* OR cranio\* OR mandib\* OR jaw OR acrofacial\* OR hemifacial\*) N2 (malform\* OR abnormal\* OR anomal\* OR synost\* OR dysost\* OR dysplas\* OR cleft\* OR microsomia\* OR disfigure\* OR syndrome\* OR congenital\* OR severe\* OR handicap\*)) OR (rare\* N2 (craniofacial\* OR cranio-facial\*) N2 conditio\*) OR ((unicoronal\* OR coronal\* OR metopic\* OR sagittal\*) N2 synost\*) OR craniosynostos\* OR treacher-collin\* OR (robin\* N2 sequence\*) OR oculo-auriculo-vertebral\* OR goldenhar OR Plagiocephal\* OR Adams-Oliver OR Antley-Bixler OR Baller-Gerold OR basilar-impression OR brachycephal\* OR Crouzon OR dyscephal\* OR exencephal\* OR frontal-bossing OR Hallermann-Streiff OR Hypertelorism\* OR Hypotelorism\* OR Marshall OR Opitz OR 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Antley-Bixler OR Baller-Gerold OR basilar-impression OR brachycephal\* OR Crouzon OR dyscephal\* OR exencephal\* OR frontal-bossing OR Hallermann-Streiff OR Hypertelorism\* OR Hypotelorism\* OR Marshall OR Opitz OR plagiocephal\* OR trigonocephal\* OR Oxycephal\* OR scaphocephal\* OR Acrocephalosyndactyl\* OR Apert OR Oxycephal\* OR Nager OR Franceschetti\* OR (pfeiffer\* N2 syndrome\*) OR muenke\* OR saethre-chotzen\* OR burn-mckeown\* OR plagiocephal\* OR brachycephal\* OR dyscephal\* OR exencephal\* OR hypertelorism\* OR hypotelorism\* OR ((Opitz OR Marshall) N2 syndrome\*)) OR TI((craniofacial\* OR cranio-facial\*) N1 difference\*)) AND (MH Life Change Events OR MH Health Services Accessibility OR MH Patient Satisfaction OR MH Patient Preference OR MH Caregiver Burden OR MH Stress, Psychological OR MH Adverse Childhood Experiences OR MH Adaptation, Psychological OR MH Social Adjustment OR MM Emotions + OR MH Parent-Child Relations+ OR MH Support, Social OR MH Holistic Health OR TI(holistic\* OR wholistic\* OR Whole-Person\* OR (life N2 event\*) OR ((human OR patient\* OR personal\* OR basic\* OR service\* OR healthcare\* OR health-care\* OR caregiver\* OR parent\* OR father\* OR paternal\* OR mother\* OR maternal\* OR child\* OR family\* OR families\*) N2 (need OR needs OR Accessibilit\* OR access\* OR satisf\* OR preferen\* OR attitud\* OR burden\* OR stress\* OR Perspective\* OR expectation OR view\* OR experience\* OR emotion\* OR psycholog\* OR mental\* OR opinion\* OR acceptan\* OR perception\* OR value\* OR priorit\* OR relation\* OR reflection\*)) OR ((emotion\* OR psycholog\* OR mental\* OR social\* OR psychosocial\* OR early-life) N2 (stress\* OR burden\* OR Must\* OR function\* OR assess\* OR wellbeing OR well-being OR adapti\* OR interaction\* OR strateg\* OR support\* OR skill\*)) OR (adapti\* N2 behav\*) OR (support\* N2 need\*) OR coping\* OR autoregulat\* OR self-regulat\*) OR AB(holistic\* OR wholistic\* OR Whole-Person\* OR (life N2 event\*) OR ((human OR patient\* OR personal\* OR basic\* OR service\* OR healthcare\* OR health-care\* OR caregiver\* OR parent\* OR father\* OR paternal\* OR mother\* OR maternal\* OR child\* OR family\* OR families\*) N2 (need OR needs OR Accessibilit\* OR access\* OR satisf\* OR preferen\* OR attitud\* OR burden\* OR stress\* OR Perspective\* OR expectation OR view\* OR experience\* OR emotion\* OR psycholog\* OR mental\* OR opinion\* OR acceptan\* OR perception\* OR value\* OR priorit\* OR relation\* OR reflection\*)) OR ((emotion\* OR psycholog\* OR mental\* OR social\* OR psychosocial\* OR early-life) N2 (stress\* OR burden\* OR Must\* OR function\* OR assess\* OR wellbeing OR well-being OR adapti\* OR interaction\* OR strateg\* OR support\* OR skill\*)) OR (adapti\* N2 behav\*) OR (support\* N2 need\*) OR coping\* OR autoregulat\* OR self-regulat\*) OR TI(accessibilit\* OR stress\* OR emotion\* OR mood OR wellbeing OR well-being OR adaptation\*)) AND (MH Qualitative Studies OR MH Surveys+ OR MH Interviews + OR MH Nonexperimental Studies OR MH Grounded Theory OR MH Observational Methods OR MH Questionnaires OR MH Focus Groups OR TI(((qualitative OR observation\* OR phenom\* OR thematic\* OR grounded\*) N2 (research\* OR stud\* OR analy\* OR validit\* OR method\* OR theor\* OR data)) OR (health N2 survey\*) OR (open-end\* N2 questionnaire\*) OR interview\* OR focusgroup\* OR focus-group\* OR hermeneutic\* OR mixed-method\*) OR AB(((qualitative OR observation\* OR phenom\* OR thematic\* OR grounded\*) N2 (research\* OR stud\* OR analy\* OR validit\* OR method\* OR theor\* OR data)) OR (health N2 survey\*) OR (open-end\* N2 questionnaire\*) OR interview\* OR focusgroup\* OR focus-group\* OR hermeneutic\* OR mixed-method\*) OR TI(qualitative\* OR survey\* OR open-end\* OR questionnaire\* OR observation\* OR phenomenolog\*)) NOT (MM Health Personnel +

OR MM Attitude of Health Personnel + OR MM Cleft Palate + OR MM Cleft Lip + OR MM Urinary Incontinence, Stress + OR MM Oxidative Stress + OR TI(personnel\* OR doctor\* OR nurse\* OR (position\* N2 deformit\*) OR trauma\* OR cleft-lip\* OR cleft-palate\* OR (stress N2 (incontinen\* OR oxidative\*))).ti.) NOT (MH case reports OR TI(case-report\*)) AND LA(english) NOT (MH animals+ NOT MH humans+)

Google Scholar

'craniofacial|facial|orofacial|cranial|hemifacial malformation|abnormalalities|synostosis|dysostosis|dysplasia|microsomia' holistic|'life event'|patient|family needs|satisfaction|preference|attitude|burden|stress|Perspective|expectation|view|experience'

Suppl. material 3. COREQ checklist

	References	Beaune 2004	Billaud-Feragen 2019	Billaud-Feragen 2020	Billaud-Feragen 2022	Bogart 2015	Bogart 2012	Costa 2023	Dangsonboon 2017	Hallberg 2012	Hamilton 2018	Hopper 2009	Johns 2018	Kuta 2020	Luquetti 2018	Myhre 2019	Myhre 2021	Myhre 2023	Netherton 2023	Roberts 2011	Saydam 2021	Skirko 2020	Stavropoulos 2011	Stock 2023	Umbaugh 2020	Varagur 2023	Visram 2019	Zerpe 2020	Zerpe 2022	Costa 2024	Hitchen 2024	Johns 2024	Stock 2024	
Personal characteristics	Interviewer/facilitator identified	x	x	x	x	x	x	NA	x	x	NA	x	NA	x	x	x	x	x	x	x	x	NA	NA	NA	x	x	x	x	x	x	x	x	x	
	Occupation	x	x	x	x	x	x	NA	x	x	NA	NA	x	x	x	x	x	x	x	x	x	NA	NA	NA	x	x	x					x		
	Sex	x	x	x				NA				NA	NA					x				NA	NA	NA			x	x	x			x	x	
	Experience or training in qualitative research	x	x	x							x		x	x	x	x	x	x	x					x	x			x	x	x	x		x	x
Relationship with participants	Relationship with participants established prior to study commencement	x	x	x	x	x	x		x					x		x	x	x	x		x		x	NA	NA	NA		x	x					
	Selection strategy (e.g. snowball, purposive, convenience)	x	x	x	x	x	x	x	x	x	x	x	NA	x	NA	x	x	x	x	x	x	x	x		NA	NA	NA	x		x	x	x	x	x
Participant selection	Method of approach/recruitment	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	NA	NA	x	x	x	x	x	x	x
	Sample size	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x
	Number/reasons for nonparticipation	x	x	x	x			NA					NA	NA		x	x			x			x	NA	NA	NA								
Setting	Venue of data collection	x				x	x	NA	x	x	x	NA	x	NA	x	x	x	x	x	x	x	x	x	NA	NA	NA	x	x	x		x	x		
	Presence of nonparticipants					x														x												x		
	Description of the sample Questions, prompts, or topic guide	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	NA	x	x	x	x	x	x	x	x
Data collection	Repeat interviews/observations							NA					NA	x	NA						x			NA	NA	NA								
	Audio/visual recording	x	x	x	x	x	x	NA	x	x	x	NA	x	NA	x	x				x	x	x	x	NA	NA	NA	x	x	x	x	x	x	x	x
	Field notes	x						NA	x				NA	NA										NA	NA	NA								
	Duration	x	x	x	x		x	NA	x	x	x	x	NA	NA	x	x					x	x	x	NA	NA	NA	x	x	x	x	x	x	x	x



## Suppl. material 4. Quotations from original studies illustrating the different themes.

Subtheme	Theme & illustrating quotations
<b>Physical impact of the condition</b>	
<b>Essential life function issues</b>	<p><b>Parent:</b> “He refuses to sleep alone and has since the surgeries! I’ve been trying to night wean him and it seems to finally be working /.../ They said he might have sleep regression post-surgery.” [1]</p> <p><b>Parent:</b> “I was very afraid. I was afraid to sleep in her presence I was afraid of everything and it took a long while to listen to — listen to an obstructed airway” [2]</p>
<b>Physical challenges in self-care</b>	<p><b>Parent:</b> For a number of children their CFA was associated with hand and foot malformations or reduced flexibility and some participants raised this as a significant stressor. The mother of a 12-year-old boy explained that her “son has a lot of difficulty with brushing his teeth because he hasn’t got that, he can’t bend the fingers and hasn’t got flexibility so I help him and he gets upset over that and it’s hard to make him understand that these are his, he’s not going to get any more teeth and these are the teeth we have to work with so that gets frustrating for him.” [3]</p> <p><b>Parent:</b> One mother commented on the practical aspect of her child’s new head shape (“I appreciate being able to put a hat on him now”). [4]</p>
<b>Practical hurdles in society</b>	<p><b>IRCC:</b> “I’m not allowed to play ball sport. I can play like long jump, high jump and all that. I couldn’t see properly, the ball, and normally the ball would go ker-chung, and whack me in the head, so mum says “no, we’ll just lay off the ball sports” but I can play any other that I want to so that’s cool.” [3]</p> <p><b>IRCC:</b> “When I was in the younger grades, yes. I moved here when I was in grade 3. I was in grade 3 then, but I got held back because when I was younger, I was in a signing school. So we didn’t have to learn how to pronounce words and everything. When I got to a speaking school, I didn’t pronounce or enunciate and had to stay back. In my second year of grade 3, that’s when I came to this school that I am at now.” [3]</p>
<b>Miscommunication in social life</b>	<p><b>Parent:</b> “She was almost, I would say, mute leading up to surgery. Within a week of surgery she started making sounds and now, 3 months later, has a full vocabulary’).” [4]</p> <p><b>IRCC:</b> Being misunderstood distressed and limited some. “I don’t talk much in clubs ‘cause they won’t be able to understand what I have to say, so I keep to myself.” [5]</p>
<b>Raising &amp; growing up</b>	
<b>Balancing in acceptance</b>	<p><b>IRCC:</b> “If the child is made to feel comfortable with who they are then surgery doesn’t matter because as a parent, a parent getting surgery to me is trying to correct your child when there is nothing wrong with your child. Just support them. (child)” [6]</p> <p><b>Parent:</b> “The surgery gnawed away at me. We had to decide for him that he was not pretty enough. That was really not OK, because I didn’t want to say “you look like we need to fix you.” [7]</p>
<b>Juggling between daily life and caregiving</b>	<p><b>Parent:</b> “This was a burden on the whole family. For the other kids, for me and my husband. We did not have any extra energy (. . .) to be what we were supposed to be for each other (Rosie, son aged 15).” [7]</p> <p><b>Parent:</b> “All the appointments, doctors, trainings, x-rays (...) it wasn’t like one of us did it. We were both equally engaged. And that gave an immense strength to our relationship.” [8]</p>
<b>Treating as and focusing on the ordinary</b>	<p><b>Parent:</b> Parents also underlined the unique individual appearance in an attempt to counteract a potentially negative impact of the visible difference on their child’s self-confidence, by telling the child that “we are all created differently, everyone has a different face.” [9] “You did not have hands when you were born. You went through 3 surgeries and you have 4 fingers now. What is important is what you do with these fingers; to hold a pencil, to take care of yourself. I have 5 fingers and you do all the things that I do.” [10]</p>
<b>Parents’ standing up for their child</b>	<p><b>IRCC:</b> “So, even if I tried to manage on my own, I always felt watched and I still felt very protected by the people I was with . . . um, it was often like, you know, that they never allowed me to do anything that could subject me to danger or something . . . um, they never let me try anything.” [11]</p> <p><b>IRCC/parent:</b> Social strain was common. Unwanted help from parents diminished teenagers’ sense of control and self-efficacy. One participant’s mother had pressured her to visit a doctor for her hand abnormality, although the participant didn’t perceive the need. [5]</p>
<b>Health care experiences</b>	
<b>Referral, diagnosis, and waiting for treatment</b>	<p><b>Parent:</b> “I felt very happy that my baby would be treated because another hospital said my baby couldn’t live for long not for months. It was impossible for me to just watch my baby dying. I found this place...The doctor told me that this center had treated many cases of this disease” [12]</p> <p><b>Parent:</b> “Some of the local [doctors] shouldn’t have tried to tell us they were ‘experts’ – they were kind of just interested in the condition and wanted to help, but maybe they weren’t totally qualified” (parent young child) [13]</p>
<b>IRCC-parent-clinician(s) interaction</b>	<p><b>IRCC:</b> “It’s a bit like the feeling you get when you’re at an interview . . . you don’t exactly feel like you’re on top of the world . . . but I see the point and I’d like it to be that way, instead of going from office to office, right?” (adult) [14]</p>

	<p><b>IRCC:</b> “A lot of doctors refer to my ‘deformities’ which is upsetting to hear” [15]</p> <p><b>Parent:</b> “[The team] said we should discuss surgical options ( . . . ), but my son doesn’t want this surgery and we don’t feel it is necessary ( . . . ). They should have discussed this with us first.” (mother, son 12) [16]</p>
<b>Appropriate information</b>	<p><b>Parent:</b> “Doctors talk to you in their language, and they say things now where I’m like “I still don’t know what you’re talking about” and we’ve been doing this for 16 years.” (mother to Kate, age 16). [17]</p> <p><b>Parent:</b> “We received written information . . . but oh, I think it’s hard to prepare yourself for what it means before you actually enter the room.” (Sandra, mother) [14]</p> <p><b>IRCC/parent:</b> [My son] sat on my lap and asked “mummy, what are they doing?” and I had to answer, “I don’t know what they are doing.” We have to be able to explain, he can’t just be a figurine ( . . . ), but sometimes it is hard to prepare the child, because we don’t know in advance what the team is going to address. (Samantha, son aged 5) [16]</p>
<b>Mental impact</b>	<p><b>Parent:</b> They said ‘Oh, he needs to go for this test on his kidneys and a test on his heart and a test here,’ and I felt like I couldn’t even catch my breath.” Some participants saw initial evaluations as reassuring: “I was fortunate that he was born at a good hospital because they knew that heart conditions are common with his syndrome, the kidneys, spinal issues, they did all of that testing before we were discharged.” [18]</p> <p><b>IRCC/parent:</b> “My son asked me “mummy, is everything wrong with me?” ( . . . ) I told him “if you have a very nice car, and you take it for a service ( . . . ), the mechanic will not talk about how nice your car is, he will talk about what needs to be repaired. That’s why you are there. This is the same.” (Olivia, son aged 12) [16]</p> <p><b>Parent:</b> Many had come mentally prepared with questions, but were then unable to recall these during the consult (Participant 1— ‘So when he said ‘do you have any questions’ I was like ‘no’ because I was just trying to take it all in’.)” [4]</p>
<b>Coming home &amp; follow-up</b>	<p><b>Parent:</b> “Everybody was nice and brought us food and all that stuff, but when he was out of the hospital, everybody kind of just disappeared.” [2]</p> <p><b>IRCC:</b> Finally, participants discussed the benefits of having their health closely monitored. A girl aged 11 described this, saying, “In case I’ve got anything wrong with me and they can fix it, it won’t be a long way without doing something. If you were just sort of normal then you would go a long way with having something wrong with you and they wouldn’t pick it up.” [3]</p>
<b>Impact condition on self</b>	
<b>Conflicts in self-acceptance</b>	<p><b>IRCC:</b> “And even this waking up with a new face after the operation, it was also a pretty big shock in itself, so it was a change, it was like you felt that you didn’t recognize yourself... That in some way ... you got a new face and you were like, you know simply unsure of who you were, and that you simply didn’t recognize yourself appearance-wise. That was a pretty big shock right there...” [19]</p> <p><b>Parent:</b> “She opened her eyes and suddenly, she looked like her father so much ( . . . ). It was a fantastic feeling.” [9]</p> <p><b>IRCC:</b> “The only way to be successful at this job was to forget that I had Moebius, and once I was able to do that, I noticed that nobody else was worried that I had Moebius. Most people didn’t care because we were serving each other and all we cared about was getting the job done. So in terms of being successful I guess I can say that I was successful in all the jobs I had.” [20]</p> <p><b>IRCC:</b> “Even though I got the surgery when I was young, I always struggled with my identity and how I looked” [1].</p>
<b>Development of character</b>	<p><b>IRCC:</b> “I’m really happy with having microtia. I would not want to be born without it. I think having it has opened my eyes to so many different aspects of life . . . It’s allowed me to be more of an open-minded person than I would be if I didn’t have microtia.” (Lynn, 22) [6]</p> <p><b>Parent:</b> “I feel it has made me a stronger advocate for (my daughter) and made me a stronger, mindful person.” [21]</p>
<b>Choices in life</b>	<p><b>IRCC:</b> “In all it [having a facial difference] has affected a lot of stuff and it makes me feel positive and I have certain ways of looking at things. When I say looking at stuff, I mean, as I said in the speech, optimism in my life; it has made me optimistic toward the future.” [22]</p> <p><b>IRCC:</b> “This year I will be her [myself] - I will wear my hair half down and half up in bun. There are ways to make your dream happen. Don’t let this syndrome stand in your way.” [23]</p>
<b>Social experiences</b>	
<b>Access to peers</b>	<p><b>IRCC:</b> “we are all helping each other out.” “We have all been going through a similar sort of journey ... we all know the ups and downs ... .. peaks and troughs of operations .....appointments ... it is nice to know ... you’ve got other families in the same boat, and you can talk .... it means a lot.” [24]</p> <p><b>Parent:</b> “I was able to connect with a group online of other children that have the same kind of diagnosis as my son and get some guidance there and it made it less scary. Just learning more and finding out that there are other children, and they live perfectly normal lives, and it’s not that big of a setback for them, so that was pretty reassuring.” [18]</p>

<b>Condition as a conversation topic</b>	<b>IRCC:</b> <i>“And the more people kind of asked me about it the more I opened up about what I’ve got and people are just understanding about it rather than judgmental.”</i> [6] <b>IRCC:</b> <i>“I don’t explain it. I just let them think what they want. I mean even my [romantic partner of 30 years] ... this is the first time we’ve ever talked about it. I know a lot of people probably won’t agree with me, but I think it’s rude when people you don’t even know ask you about it.”</i> [20]
<b>Public awareness &amp; understanding</b>	<b>Parent:</b> <i>“You are bombarded by society of images of what is perfect ... what people should look like ... it made me feel sad that my daughter has to ... make her way within a society where you have got that sort of consistent prejudice.”</i> [24] <b>IRCC:</b> <i>“You don’t want people to feel sorry for you; you want them to understand what you’re going through.”</i> [25]
<b>Participation in society</b>	<b>Parent:</b> <i>“Stares from strangers and comments that would make your blood boil! I became quite angry with society and how judgmental, rude, and ignorant people were”</i> [21] <b>IRCC:</b> <i>“I have qualifications and experience but feel I am not being employed due to my disability.”</i> [15]
<b>Role of close family and friends</b>	<b>Parent:</b> <i>“[Child’s grandmother] was learning how to tube feed. So, that was good.”</i> Participants also prepared siblings: <i>“We just showed [our child’s siblings] this book. So, they had a picture of...what a feeding tube is. So, it wasn’t such a shock when they got in there, which was great.”</i> [26] <b>IRCC:</b> <i>“Have felt disconnected from some friends as they couldn’t possibly understand and I have less patience for their minor worries.”</i> [21]

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**Suppl. material 5.** ePAG's input on findings.

Seven ePAGs/patient representatives were asked the following questions to stimulate thinking:

The content of the **Results** section (starting at page 3):

- Can you **relate to the content** that is written there (why (not))?
- Does it make sense? Is the right **word choice** being used?
- What do you **notice**?
- What do you think of **Figure 1A, 2A and 2B**?

Ideas for the **Discussion** section:

- Where are **differences/similarities** between your **experiences** and those in the results section (*you can see in the references in the sentences which studies support a statement*)?
- What do you think is needed in **research and clinical practice** to **improve/change** these experiences)?
- What do you **miss**?
- What do you want to **learn more** about?

*Section continues on the next page.*

*Input derived from patient representatives based on the manuscript (introduction – results).*

Perspective	Healthcare experiences	Impact on self	Raising and growing up	Physical impact condition	Social experiences	Next steps/needs research	Clinical practice
Parent/ craniofacial	Concerns about 2 included articles in review: 1) <b>limited PRS experience</b> illustrated in 1 study (mixture of conditions) + 2) <b>influence of available/provided treatment options on personal experiences</b> in 1 study and linking generalizability issues.					See healthcare exp	
Parent/ craniofacial	<b>Go-between</b> experience between <b>local health care providers and centre of expertise</b> rather than between specialist HCPs. Moral support or information not needed as parents themselves feel to know more than HCP. <b>Therapeutic patient education</b> helped a lot from personal experiences: expectation management, repeated information, confidence in surgery, own decision and 'active member' of medical team. <b>Going back to normal after surgery</b> not considered, attention parents to make sure they feel comfortable seeking psychological help: caretaker has a toll.				Noticed that <b>some people reject the need for others</b> completely (for example, they don't feel comfortable joining our association) and <b>others who are "too identified"</b> with having a child with a syndrome (it becomes a focal point of their lives). We identify the need to communicate and share experiences with others to help.	1) Amazing steps forward on the 'technical' side of the treatments (shorter, precise, safe) -> now <b>turn needed to the side getting less attention: the patient.</b> 2) Importance to qualitatively and quantitatively <b>studying the effects (medical/financial benefits, e.g. costs, length of stay) of TPE (Therapeutic Patient Education) and similar interventions</b> delivered by HCPs aiming to empower patients to understand, be involved in the clinical decision-making process, and	<b>1) (More) sessions with a psychologist</b> before/after operations providing support. Observation of families breaking up having difficulty to handle. 2) What is happening in <b>patient associations in other countries</b> , how to better <b>structure support</b> needed for families dealing with CFC? 3) <b>Lack of knowledge creates lack of resources</b> for funding travel costs etc -> need to work on social

effectively manage their conditions. 3) Need of **other ways of communication** rather than traditional top-down doctor-to-patient model-> illustrates importance of ePAGs and communication projects. 4) How is **life as an adult** with Crouzon's syndrome?

security and awareness. 4) **Expectation management:** most attention on major and invasive surgeries what might give **feeling that patients are ready (and not being prepared for another surgery** after major procedure(s)).

Director, craniofacial	<i>Textual edits/suggestions, could <b>agree on content</b> and <b>findings</b>.</i>		
Parent, craniofacial	<i>Could relate to almost all content described.</i>	Experience that <b>90% of families facing non-syndromic craniosynostosis</b> drop off after surgery and first controls. Parents <b>do not understand</b> that during growth patients may have <b>side-pathologies linked to craniosynostosis</b> . Without the right screening and a parental association to contact, it's <b>too difficult to correlate this new disease</b> with craniosynostosis.	ERN centres should <b>keep a register of (non-)syndromic craniosynostosis patients</b> and cranio-surgery and share with parental association to create wide, consistent web.  ERN centres should guarantee an <b>annual screening from child to adulthood</b> aiming to <b>monitor side pathologies</b> patients have in common during growth and create a consistent statistical sample.

Patient, craniofacial	<p>1) Experience of living with a craniofacial condition will improve with <b>more knowledge among non-specialists</b> to have the <b>right attitude and right referral</b>.</p> <p>2) Patients expect <b>more from an HCP than just the 'things' they do with their hands</b>: function as a role model, and support. So this is not something a psychologist can fulfil but is the responsibility of every HCP. After that, society will come. 3) <b>Communication about proposed procedures</b> to IRCCs: shared-decision making, done due to pressure from society. 4) <b>MDT approach is experienced differently</b> by parents and IRCCs.</p>		Experience of psychological attack btw parents and patients in same support group: <b>different believes and expectations</b> . Also, <b>some patients don't speak to their parents</b> on that level, and that's why parents cannot be a proxy for their childrens' experiences.	<b>Problems in society are mainly caused by communication issues</b> (hearing etc) and less social exposure in IRCCs instead of the assumption that these people have a cognitive disfunction.	Experience with <b>discrimination because of condition</b> : why are there fewer doctors with a condition? How can we make sure people can fulfil their full potential?	TCS and PRS can have <b>features in common depending on the underlying condition</b> . This raises the question about diversity within conditions to put them in an isolated box and underscores the use of mixture of conditions in qualitative research that have features in common.	HCPs should consider <b>having consultation separately</b> with the parent and child.
Parent, cleft lip and palate	1) Referral, diagnosis and waiting for treatment: <b>CLP patients</b> are diagnosed easier and faster, so <b>no/less issues with getting treatment</b> .	1) Not known for CLP patients.		1) Mental impact: <b>decision of parents re surgery</b> and what to do at a young age is <b>not relevant for CLP parents</b> as cleft closure is wanted and expected to happen.	It is perhaps a perfectly logical conclusion that <b>all kinds of visible differences lead to similar experiences</b> for parents and children, regardless of the specific diagnosis.		

Patient, cleft lip and palate

Non-referrals/delay in diagnosis: issue of knowledge HCPs, **right communication of diagnosis** (with realistic/correct information), **wrong assumptions in society** ("fixed in one operation") despite that CLP is a common, 'known' condition for most people.

1) **Peer-support dilemma for people**: not wanting to identify with a group, seeing someone else with your condition is like looking in the mirror (seeing things you don't necessarily want to see). 2) **Ambivalent feelings awareness campaigns**: making a marginalised group -> can be disempowering rather than empowering (feeling standing out). 3) **Difference in experiences extended family/grandparents** (e.g. blame factors, feeling excluded from provided information). 4) **Explanation/narrative of condition is a part of acceptance** in society by creating understanding - > role parents/HCP/school.

1) **Issues/experiences** are the **same** in countries, **resources** to tackle those **different**. 2) **Need for separation of different perspectives** as they are not the same/sometimes conflict. Adults perspectives necessary.