CRANE Database - Data Dictionary: February 2024

KEY: * 'Notification only' data items / fields I.e. Patient consent = No/DK. ** 'Patient registration short' Export fields. ¥ Data items / fields that constitute the minimum CRANE dataset.

Section / Data item	Field name	Response values / labels	Description These descriptions are available through information (i) buttons found next to each data item.	Guidance & Notes	Minimum Dataset¥
Patient Registration					Yes
Patient Consent					Yes
Consent status*	consent**	1 = No 2 = Yes 3 = Unknown, awaiting verification 4 = Not possible to verify	As indicated on consent form.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #1 of 17
Consent status: Please give further details	consent_details	Text	Reason why if choose 3 or 4 for 'consent'. "*Please give further details:" (Field name: consent_details).		No
Linkage of CRANE data to Health data*	consent_health	1 = No 2 = Yes 3 = Unknown, awaiting verification 4 = Not possible to verify	As indicated on consent form. This field may also capture future requests to NOT link patient's CRANE data to Health data.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #2 of 17
Linkage of CRANE data to Education data*	consent_education	1 = No 2 = Yes 3 = Unknown, awaiting verification 4 = Not possible to verify	As indicated on consent form. This field may also capture future requests to NOT link patient's CRANE data to Education data.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #3 of 17
Cleft team details					No
Administrative unit name*	unit_id**	Administrative unit name (shown in text format).	Administrative unit name. More than one unit name may be available for selection from a drop-down menu; based on unit/region permissions. *[This takes a 4-digit numeric value in data exports. E.g. 9011 = Royal Victoria Infirmary (Newcastle)]*	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
Administrative unit number*	unit_no**	Number or alpha-numeric value (e.g. AB12345).	Patient number used in regional administrative ("hub") hospital. This may be a number or an alpha-numeric value (e.g. AB12345).	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
Hospital name	hospital_id	Hospital name (shown in text format).	Hospital name. Local ("spoke") hospitals will be available for selection from a drop-down menu. Your local ("spoke") hospital may be the same as your administrative unit. *[This takes a 6-digit numeric value in data exports. E.g. 901100 = Royal Victoria Infirmary (Newcastle) and 901101 = Sunderland Royal Hospital.]*		No
Hospital number	hospital_no	Number or alpha-numeric value (e.g. A123456).	Patient number used in local hospital. This may be a number or an alpha-numeric value (e.g. A123456).		No
Patient details					Yes
CRANE ID*	crane_id**	Number	Unique patient identifier automatically generated when a new patient is added.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
Patient's NHS/CHI Number*	nhs**	Either: *Valid NHS/CHI Number = Valid 10 digit number. *Valid non NHS/CHI Number (unavailable/unapplicable) = 10 zeros. *Blank/null	NHS/CHI Number	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #4 of 17
Reason patient's NHS/CHI Number not available*	nhs_na	1=Patient from the Channel Islands 3=Private UK patient 4=Non-UK resident 5=Other	Where NHS/CHI Number is not available, please provide a reason.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
Reason patient's NHS/CHI Number not available - other reason*	nhs_na_oth	Text			No
Date of birth*	dob**	DD / MM / YYYY	Where consent has not been provided, only year of birth is available to the Database team (CRANE Administrators)	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #5 of 17
Date deceased*	dod**	DD / MM / YYYY	Only complete where applicable.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
Present surname	surname**	Text			No
First names	forenames**	Text	Forenames		No
Sex*	sex	1 = Female 2 = Male	Patient sex	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #6 of 17

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Ethnic group*	ethnicity	White 1 = White British 2 = White Irish 3 = Any other White background Mixed/ Multiple ethnic groups 4 = White and Black Caribbean 5 = White and Black African 6 = White and Asian 7 = Any other Mixed/ Multiple ethnic background Asian/ Asian British 8 = Indian 9 = Pakistani 10 = Bangladeshi 11 = Chinese 12 = Any other Asian background Black/ African/ Caribbean/ Black British 13 = African 14 = Caribbean 15 = Any other Black/ African/ Caribbean background Other ethnic group 16 = Arab 17 = Any other ethnic group	**Collected from the 1 April 2021** What is the patient's ethnic group? Chose one option that best describes the ethnic group or background.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #7 of 17
Postcode	pcode	8-character, alpha-numeric field	Postcode of current residence		No
Postcode History	pcode_history	Previous postcodes in 8-character, alpha-numeric format. Plus associated date at which each previous postcode was originally set.			No
Surname at birth (if different)	surname_birth	Text			No
First contact information					Yes
Hospital of birth/referral*	hosp_refer	Text	Hospital of birth or referral if home birth	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #8 of 17
Timing of diagnosis*	diag_time	1 = Antenatal 2 = At birth (within 24 hours of birth) 22 = Within 72 hours 3 = Within 1 week 4 = Within 1 month 5 = Within 6 months 6 = Later than 6 months	Time when cleft diagnosis was made for the first time	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #9 of 17
For antenatal, date and time cleft team informed of **antenatal** diagnosis*	an_team_inf	DD / MM / YYYY HH:MM	Date and time when cleft team was informed of antenatal cleft diagnosis	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
For antenatal, date and time of first contact with cleft team following **antenatal** diagnosis*	an_team_con	DD / MM / YYYY HH:MM	Date and time when cleft team made first contact with baby's family following antenatal diagnosis (contact does not imply a face-to-face visit, it can be by letter, text, phone, Skype).	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
Was contact made within 24 hours of receiving the antenatal referral by a Clinical Nurse Specialist?*	an_cns_con	1 = No 2 = Yes	Whether or not contact was made within 24 hours of receiving the antenatal referral by a Clinical Nurse Specialist (contact does not imply a face-to-face visit, it can be by letter, text, phone, Skype).	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
Reason contact NOT made within 24 hours of receiving the antenatal referral?*	an_cns_reason	1 = No answer to phone calls. 2 = Incorrect contact details. 3 = Interpreter required (and not possible to arrange within 24 hours). 9 = Other reason.			No
Other reason contact NOT made within 24 hours of receiving the antenatal referral details*	an_cns_spec	Text	Details of other reason for not making contact within 24 hours of receiving the antenatal referral		No

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Section / Data item	Field name	Response values / labels	Description These descriptions are available through information (i) buttons found next to each data item.	Guidance & Notes	Minimum Dataset¥
For all births					Yes
For all births, date and time cleft team informed following birth*	team_inf	DD / MM / YYYY HH:MM	Date and time when cleft team was informed of cleft diagnosis following birth	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #10 of 17
Date and time of first contact with cleft team following birth*	team_con	DD / MM / YYYY HH:MM	Date and time when cleft team made first contact with baby's family following birth (contact does not imply a face-to-face visit, it can be by letter, text, phone, Skype).	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #11 of 17
Date and time of first visit by a member of the cleft team following birth*	team_vis	DD / MM / YYYY HH:MM	Date and time when a member of the cleft team first visited baby's family following birth	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #12 of 17
Was a visit made within 24 hours of receiving the postnatal referral by a Clinical Nurse Specialist?*	cns_con	1 = No 2 = Yes	Whether or not visit was made within 24 hours of receiving the postnatal referral by a Clinical Nurse Specialist	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #13 of 17
Reason visit NOT made within 24 hours of receiving the postnatal referral?*	cns_con_reason	1 = No CNS available. 2 = Travel distance from unit (not possible to complete journey within 24 hours). 3 = Clinical decision - feeding well and no concerns. 4 = Clinical decision - other comorbidities, advised by NICU not to attend. 9 = Other reason.			No
Other reason visit NOT made within 24 hours of receiving the postnatal referral details*	cns_con_spec	Text	Details of other reason for not visiting within 24 hours of receiving the postnatal referral		No
Cleft Details*			This form is used to describe the cleft. It is required for each new patient.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	No
Is this a submucous cleft*	submucous	1 = No 2 = Yes	Presence of submucous cleft palate (SMCP). If applicable, users should record the presence of a submucous cleft palate by: 1. Responding 'yes' to this question ('Is this a submucous cleft?'). 2. Then users should record LAHSAL code to allow a cleft type category of CP, UCLP or BCLP to be assigned to this patient / derived from the items below.	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #14 of 17
Pierre Robin Sequence present*	pierrerobin	1 = No 2 = Yes	Birth defect where micrognathia and glossoptosis appear together with cleft palate. Recording of a PR sequence being present will automatically reduce cleft description options below. Only hard palate and soft palate will be available for completion		Yes - Item #15 of 17
Forme Fruste present*	formefruste	1 = No 2 = Yes	Presence of a "Forme Fruste" or microform cleft lip, exhibited as a depression or indentation in the lip and slight alteration of the nostril floor or alar shape. Users should record a LAHSAL code indicating an incomplete cleft of the lip on the affected side. These patients will be assigned to the CL cleft type group for the purposes of analysis.		Yes - Item #16 of 17
Cleft description					Yes
Simonart's Bands - Patient's right*	cd1_band_right	0 = Not present/No (.) 2 = Yes (Y)	Cleft description element 1 - Presence of Simonart's Bands on right hand side	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17a of 17 (to calculate l_code)
Lip - Patient's right*	cd2_lip_right	0 = Not present (.) 1 = Incomplete (I) 2 = Complete (C)	Cleft description element 2 - Presence of cleft lip on right hand side	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17b of 17 (to calculate l_code)
Alveolus - Patient's right*	cd3_alv_right	0 = Not present (.) 1 = Incomplete (I) 2 = Complete (C)	Cleft description element 3 - Presence of cleft alveolus on right hand side	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17c of 17 (to calculate l_code)
Hard Palate*	cd4_hard	0 = Not present (.) 1 = Incomplete (I) 2 = Complete (C)	Cleft description element 4 - Presence of cleft hard palate	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17d of 17 (to calculate l_code)
Soft Palate*	cd5_soft	0 = Not present (.) 1 = Incomplete (I) 2 = Complete (C)	Cleft description element 5 - Presence of cleft soft palate	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17e of 17 (to calculate l_code)
Alveolus - Patient's left*	cd6_alv_left	0 = Not present (.) 1 = Incomplete (I) 2 = Complete (C)	Cleft description element 6 - Presence of cleft alveolus on left hand side left hand side	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17f of 17 (to calculate l_code)
Lip - Patient's left*	cd7_lip_left	0 = Not present (.) 1 = Incomplete (I) 2 = Complete (C)	Cleft description element 7 - Presence of cleft lip on left hand side	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17g of 17 (to calculate l_code)
Simonart's Bands - Patient's left*	cd8_band_left	0 = Not present/No (.) 2 = Yes (Y)	Cleft description element 8 - Presence of Simonart's Bands on left hand side	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17h of 17 (to calculate l_code)
LAHSAL code*	l_code	Text 6-characters	Cleft description displayed in LAHSAL code format automatically generated from elements (2-7) of cleft description	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Item #17 of 17

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Cleft type category (derived from LAHSAL code)*	cleft_type	1 = Isolated cleft lip (CL) 2 = Isolated cleft palate (CP) 3 = Unilateral cleft lip and palate (UCLP) 4 = Bilateral cleft lip and palate (BCLP)	Cleft type category automatically generated from elements (2-7) of cleft description	* Notification fields I.e. Should always be completed - even if patient consent = No (1) / DK (3) / Not verified (4)	Yes - Calculated by CRANE from l_code (above)
Cleft type category in the absence of LAHSAL code (CRANE office use only)*	cleft_type_without_lahsal	1 = Isolated cleft lip (CL) 2 = Isolated cleft palate (CP) 3 = Unilateral cleft lip and palate (UCLP) 4 = Bilateral cleft lip and palate (BCLP)	Cleft category in absence of completed LAHSAL code manually assigned by CRANE Database Administrator at centre's request		No
Record created date	date_created	DD / MM / YYYY HH:MM	The date/time that the record for this crane_id was first added to the database (applies from 27/09/2001) - automatically generated.		No
Notes					No
Notes	notes		Additional notes for this patient. This is for units' / hospitals' own use.		No
Surgical procedures					No
To be added in future			**New data collection fields for surgical procedures to be added in future.**		No
Syndromes			**Note: Please do not record Pierre Robin Sequence (PRS) (or any PRS features) as a syndrome. PRS information is entered under the 'Cleft Details' tab.**		No
Confirmed syndromic diagnosis present	syndrome	1 = No 2 = Yes, named 3 = Yes, unknown name	Does the child have a confirmed syndromic diagnosis? The confirmed diagnosis can be either a named syndrome or an unknown syndrome	If "syndrome" = "2 = Yes, named" then the system will ask that you complete "Syndrome_1" (plus "syndrome_1_oth" if relevant) and "Syndrome_2" (plus "syndrome_2_oth" if relevant). If "syndrome" = "3 = Yes, unknown" then the system will ask that you complete "syndrome_unk_desc_1" to "_8" (plus "syndrome_unk_oth" if relevant).	No
1. Main syndrome or additional diagnoses	syndrome_1	1 = CHARGE syndrome 2 = Chromosome or gene abnormalities not elsewhere specified (e.g. trisomy, deletion, duplication) 3 = Congenital malformations of the circulatory system (arteries, veins or heart) 4 = Congenital malformations of the nervous system (e.g. microcephaly, spina bifida) 5 = Di George syndrome / 22q11.2 Deletion syndrome / Velocardiofacial syndrome 6 = Fetal alcohol syndrome 7 = Goldenhar syndrome / Hemi-facial microsomia 8 = Stickler syndrome 9 = Van der Woude syndrome 10 = Other, please specify	Does the child have a main confirmed named syndromic diagnosis? Please select the main named syndrome or choose 'Other' and enter a brief description.	Do not include developmental delay or autism here, as these are not syndromes.	No
If 'Other' main syndrome, please specify:	syndrome_1_oth	Text	If syndrome_1 = Other (10)		No
2. Secondary syndrome or additional diagnoses	syndrome_2	1 = CHARGE syndrome 2 = Chromosome or gene abnormalities not elsewhere specified (e.g. trisomy, deletion, duplication) 3 = Congenital malformations of the circulatory system (arteries, veins or heart) 4 = Congenital malformations of the nervous system (e.g. microcephaly, spina bifida) 5 = Di George syndrome / 22q11.2 Deletion syndrome / Velocardiofacial syndrome 6 = Fetal alcohol syndrome 7 = Goldenhar syndrome / Hemi-facial microsomia 8 = Stickler syndrome 9 = Van der Woude syndrome 10 = Other, please specify	Does the child have a secondary confirmed named syndromic diagnosis? Please select the secondary named syndrome or choose 'Other' and enter a brief description.	Do not include developmental delay or autism here, as these are not syndromes.	No
If 'Other' secondary syndrome, please specify:	syndrome_2_oth	Text	If syndrome_2 = Other (10)		No
If syndrome is 'Yes, unknown name' please specify affected system(s):	syndrome_unk_desc_1 to syndrome_unk_desc_8	1 = Circulatory/cardiovascular system 2 = Digestive/excretory system 3 = Endocrine system 4 = Nervous system 5 = Renal system 6 = Respiratory system 7 = Skeletal system 8 = Other, please specify	Tick all that apply.	If 'Circulatory/cardiovascular system' is ticked syndrome_unk_desc_1 = 1. If 'Digestive/excretory system' is ticked syndrome_unk_desc_2 = 1. If 'Endocrine system' is ticked syndrome_unk_desc_3 = 1. If 'Nervous system' is ticked syndrome_unk_desc_4 = 1, and so on. This is reflected in Exports of the data.	No
Description of affected systems	syndrome_unk_oth	Text	If syndrome_unk_desc_8 = 1 (i.e. 'Other')		No

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Outcomes		**All Outcomes: Outcome information is collected according to age of patients and cleft type**	For all types of outcomes and age ranges we capture reasons why the record is excluded or is not available for that patient.	A field to identify the age timepoint is automatically generated by the system and specifies outcome(s) relevant for data collection (i.e. At birth, at 1 year, 5 years, 10 years, etc).	No
Outcome at Birth					No
Child Growth (at birth)					No
Gestational age	gest_age	Integer	Baby's gestational age at birth (weeks)		No
Weight at birth	weight_g0	Number (up to 2 decimal places)	Body weight at birth (kg). (NOT to be adjusted for gestational age)		No
Date weight at birth record taken	Weight_g0_date	DD / MM / YYYY			No
Child Growth (at birth): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_g0	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason			No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_g0	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_g0	Text	Details of other reason outcome not collected		No
Psychology (at birth)					No
Date of 1st psychology consultation	date_scr1_p5	DD / MM / YYYY	Note: Suffix for this field name remains "_p5" as previously collected at 5 years.		No
Psychology (at birth): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_p0	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason	Bespoke code for Psychology - at birth: 10 = No consultation before 5 year appointment		No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_p0	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_p0	Text	Details of other reason outcome not collected		No
Outcome at 1 year					No
Child Growth					No
Weight at 1 year	weight_g1	Number (up to 2 decimal places)	Body weight at 1 year (kg)		No
Date weight at 1 year record taken	Weight_g1_date	DD / MM / YYYY			No
Height at 1 year	height_g1	Number (up to 1 decimal place)	Height at 1 year (cm)		No
Date height at 1 year record taken	height_g1_date	DD / MM / YYYY			No
Child Growth (at 1 year): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_g1	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason			No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_g1	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_g1	Text	Details of other reason outcome not collected		No

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Outcome at 5 years					No
Child Growth (at 5 years): Reasons Outcomes not collected					No
Weight at 5 years	weight_g5	Number (up to 2 decimal places)	Body weight at 5 years (kg)		No
Date weight at 5 years record taken	Weight_g5_date	DD / MM / YYYY			No
Height at 5 years	height_g5	Number (up to 1 decimal place)	Height at 5 years (cm)		No
Date height at 5 years record taken	height_g5_date	DD / MM / YYYY			No
Child Growth (at 5 years): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_g5	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason			No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_g5	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_g5	Text	Details of other reason outcome not collected		No
Orthodontics			**Complete UCLP cases only (i.e. 'LAHS..' or '..HSAL')**		No
Date study model taken	study_model_o5	DD / MM / YYYY			No
Date photos taken	photos_taken_o5	DD / MM / YYYY			No
Five Year Old Index (internal)	five_year_internal_o5	Score 1-5	Five Year Old Index internally validated score	Externally validated score preferred, provide internal score only if external score not available	No
Five Year Old Index (external)	five_year_external_o5	Score 1-5	Five Year Old Index externally validated score		No
Orthodontics (at 5 years): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_o5	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason			No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_o5	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_o5	Text	Details of other reason outcome not collected		No
Dentistry - decayed, missing or filled teeth in primary dentition (dmft)					No
Date record taken	record_taken_d5	DD / MM / YYYY	Date dmft record taken		No
Total number of decayed teeth in primary dentition (dt)	dt_d5	Integer	Total number of decayed teeth (dt) in the primary dentition at age 5 years (If none, specify 0)		No
Total number of missing teeth in primary dentition (mt)	mt_d5	Integer	Total number of missing teeth (mt) in the primary dentition at age 5 years(If none, specify 0)		No
Total number of filled teeth in primary dentition (ft)	ft_d5	Integer	Total number of filled teeth (ft) in the primary dentition at age 5 years (If none, specify 0)		No
Total number of decayed, missing or filled teeth in primary dentition (dmft)	dmft_d5	Integer	Total number of decayed, missing or filled teeth (dmft) in the primary dentition at age 5 years automatically generated	Calculation of a value for this field requires the dt, mt and ft fields to be specified	No
Care Index	care_index_d5	Number between 0 and 1 (up to 3 decimal places)	Care Index (ft/dmft) automatically generated	Calculation of a value for this field requires the ft and dmft fields to be specified	No
Treatment Index	treat_index_d5	Number between 0 and 1 (up to 3 decimal places)	Treatment Index ((mt+ft)/dmft) automatically generated	Calculation of a value for this field requires the mt, ft and dmft fields to be specified	No

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Section / Data item	Field name	Response values / labels	Description These descriptions are available through information (i) buttons found next to each data item.	Guidance & Notes	Minimum Dataset¥
Dentistry - Developmental Defects of Enamel (DDE)			**Collected since May 2022**		No
SN (Right): Supernumerary - Patient's right	dde_snr_d5	0= Normal 1= Hypomineralisation (Localised or diffuse opacities) 2= Hypoplasia 3= Abnormal shape/size 4= Congenitally missing 91= Restored 92= Carious 93= Extracted 94= Exfoliated 99= Not present - for supernumerary (SN) only	Normal: Normal shape size colour and enamel surface [score subtotal 1]. Abnormalities [score subtotal 1] - Hypomineralisation: Reduced mineralization of enamel surface evidenced by white yellow or brown patched, localised or diffuse. - Hypoplastic: Areas on the tooth where enamel is reduced in thickness or formed with an uneven surface. - Abnormal shape or size: Teeth smaller than average (microdont), larger than average (macrodont), geminated, fused , tapered/ conical, trituberculate, extra cusp/cusps, dens in dente. - Congenitally missing. Reasons not recorded [no score subtotal recorded]: - Unable - restored: A restoration covers the surface so makes it not possible to assess the surface. - Unable - carious: Decay has destroyed enamel so unable to assess the surface. - Unable - extracted: Not present to assess because has been removed. - Unable - exfoliated: Only relevant in 5 year olds - natural loss prior to eruption of adult tooth. - Not present: For SN (Right) / SN (left) only – these are not expected to be present, but they may be. Which is why there is the option to add data on 'Normal' or 'Abnormalities'.		No
URB: Upper Right incisor B - Patient's right	dde_urb_d5	0= Normal 1= Hypomineralisation (Localised or diffuse opacities) 2= Hypoplasia 3= Abnormal shape/size 4= Congenitally missing 91= Restored 92= Carious 93= Extracted 94= Exfoliated 99= Not present - for supernumerary (SN) only	Normal: Normal shape size colour and enamel surface [score subtotal 0]. Abnormalities [score subtotal 1] - Hypomineralisation: Reduced mineralization of enamel surface evidenced by white yellow or brown patched, localised or diffuse. - Hypoplastic: Areas on the tooth where enamel is reduced in thickness or formed with an uneven surface. - Abnormal shape or size: Teeth smaller than average (microdont), larger than average (macrodont), geminated, fused , tapered/ conical, trituberculate, extra cusp/cusps, dens in dente. - Congenitally missing. Reasons not recorded [no score subtotal recorded]: - Unable - restored: A restoration covers the surface so makes it not possible to assess the surface. - Unable - carious: Decay has destroyed enamel so unable to assess the surface. - Unable - extracted: Not present to assess because has been removed. - Unable - exfoliated: Only relevant in 5 year olds - natural loss prior to eruption of adult tooth. - Not present: For SN (Right) / SN (left) only – these are not expected to be present, but they may be. Which is why there is the option to add data on 'Normal' or 'Abnormalities'.		No
URA: Upper Right incisor A - Patient's right	dde_ura_d5	As for 'dde_urb_d5' above	As for 'dde_urb_d5' above (same description as for 'URB: Upper Right incisor B - Patient's right')		No
ULA: Upper Left incisor A - Patient's left	dde_ula_d5	As for 'dde_urb_d5' above	As for 'dde_urb_d5' above (same description as for 'URB: Upper Right incisor B - Patient's right')		No
ULB: Upper Left incisor B - Patient's left	dde_ulb_d5	As for 'dde_urb_d5' above	As for 'dde_urb_d5' above (same description as for 'URB: Upper Right incisor B - Patient's right')		No
SN (Left): Supernumerary - Patient's left	dde_snl_d5	As for 'dde_snr_d5' above	As for 'dde_snr_d5' above (same description as for 'SN (Right): Supernumerary - Patient's right')		No
DDE score subtotal for SN (Right)	dde_tot_snr_d5	1= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 1]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_snr_d5 field to be specified	No
DDE score subtotal for URB	dde_tot_urb_d5	0= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 0]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_urb_d5 field to be specified	No

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DDE score subtotal for URA	dde_tot_ura_d5	0= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 0]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_ura_d5 field to be specified	No
DDE score subtotal for ULA	dde_tot_ula_d5	0= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 0]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_ula_d5 field to be specified	No
DDE score subtotal for ULB	dde_tot_ulb_d5	0= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 0]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_ulb_d5 field to be specified	No
DDE score subtotal for SN (Left)	dde_tot_snl_d5	1= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 1]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_snl_d5 field to be specified	No
Total 5 year DDE score	dde_tot_d5	Values of 0 to 6 Plus X= All reason not recorded	Total number of developmental defects of enamel (DDE) - up to a maximum of 6. Note: 'X = All reasons not recorded' will be calculated only if all sub-scores are not recorded.	Calculation of a value for this field requires the dde_snr_d5, dde_urb_d5, dde_ura_d5, dde_ula_d5, dde_ulb_d5, and dde_snl_d5 fields to be specified	No
Date record taken	dde_date_d5	DD / MM / YYYY	Date DDE record taken		No
Dentistry (dmft and DDE, at 5 years): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_d5	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason	These reasons apply to the collection of both dmft and DDE scores, as it is anticipated these would be collected at the same appointment/clinic.		No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_d5	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_d5	Text	Details of other reason outcome not collected		No
Psychology					No
4a. Psychology (SDQ) > Strengths & Difficulties Questionnaire			**CRANE will collect SDQ scores for children born up to 31 December 2017 only**		No
Date of psychosocial screen using SDQ at age 5	date_scr_p5	DD / MM / YYYY		Collected for children born <2018 only	No
Parent SDQ Total	sdq_total_p5	Integer / Number between 0 and 40	Total number score for parent Strengths & Difficulties Questionnaire (ranging between 0-40). Sum of scores from all scales except 'Prosocial'.	Collected for children born <2018 only	No
Parent SDQ Emotional	sdq_emotion_p5	Integer / Number between 0 and 10	Number score for parent Strengths & Difficulties Questionnaire - Emotional score (ranging between 0-10).	Collected for children born <2018 only	No
Parent SDQ Conduct	sdq_conduct_p5	Integer / Number between 0 and 10	Number score for parent Strengths & Difficulties Questionnaire - Conduct score (ranging between 0-10).	Collected for children born <2018 only	No
Parent SDQ Hyperactivity [0-10]	sdq_hyper_p5	Integer / Number between 0 and 10	Number score for parent Strengths & Difficulties Questionnaire - Hyperactivity score (ranging between 0-10).	Collected for children born <2018 only	No
Parent SDQ Peer Problems	sdq_peer_p5	Integer / Number between 0 and 10	Number score for parent Strengths & Difficulties Questionnaire - Peer Problems score (ranging between 0-10).	Collected for children born <2018 only	No
Parent SDQ Prosocial	sdq_prosocial_p5	Integer / Number between 0 and 10	Number score for parent Strengths & Difficulties Questionnaire - Prosocial score (ranging between 0-10).	Collected for children born <2018 only	No
Psychology (SDQ, at 5 years): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_p5	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason	Bespoke codes for Psychology (SDQ) - at 5 years: 11 = Screen only partially completed 12= Not completed due to language barriers 13 = Parents declined to complete		No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_p5	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_p5	Text	Details of other reason outcome not collected		No

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4b. Psychology (TIM) > Tiers of Involvement Measure					No
Date of psychosocial screen using TIM at age 5	date_tim_p5	DD / MM / YYYY			No
TIM score	tim_total_p5	0a 0b 0c 0d 0e 1 2 3 4 5 6 (Enter as scored)	0a: Psychologist with another patient. 0b: Psychologist on annual leave. 0c: Psychologist off sick. 0d: Psychologist not present. 0e: Psychology declined by patient. 1: Patient seen/screened by MDT. No psychological input required. 2: Psychological input provided during the clinic. 3: Further action required by psychologist but appointment not offered. 4: A Clinical Psychology appointment is offered & the appointment will be arranged in a clinically appropriate timescale. 5: A Clinical Psychology appointment is needed and offered and the patient/family will be seen as soon as the resource becomes available. 6: The patient is already actively seeing a member of the Clinical Psychology team OR the need for Clinical Psychology input becomes apparent in the MDT clinic & input provided immediately.		No
Psychology (TIM, at 5 years): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_pb5	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason	Bespoke codes for Psychology (TIM) - at 5 years: 11 = Screen only partially completed 12= Not completed due to language barriers 13 = Parents declined to complete		No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_pb5	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_pb5	Text	Details of other reason outcome not collected		No
Outcomes at 5 and 10 years					No
Speech and Language Therapy: CAPS-A			**CP / UCLP / BCLP cases only**		No
Date of Speech Assessment Recording	speech_assess_date_s5 (and _10)	DD / MM / YYYY			No
VP surgery / Fistula repair before assessment	vp_fist_s5 (and _10)	1 = No 2 = Yes			No
Context of evaluation	context_eval_s5 (and _10)	1 = Consensus listened (includes an external CAPS-A trained listener) 2 = Consensus listened (internal listeners with a minimum of 2 CAPS-A trained listeners) 3 = Other			No
Hypernasality	hyper_s5 (and _10)	0 1 2 3 4 8			No
Hyponasality	hypo_s5 (and _10)	0 1 2 8			No
Audible Nasal Emission	audible_s5 (and _10)	0 1 2 8			No
Nasal Turbulence	nasal_s5 (and _10)	0 1 2 8			No

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Anterior Cleft Speech Characteristics (CSCs)					No
Dentalisation / interdentalisation	ant_dent_s5 (and _10)	0 = A 2 = B		Definitions: A Dark Green on CAPS-A B Light Green on CAPS-A C Amber on CAPS-A D Red on CAPS-A	No
Lateralisation / lateral	ant_lat_s5 (and _10)	0 = A 1 = B 2 = C		As above	No
Palatalisation / Palatal	ant_pal_s5 (and _10)	0 = A 1 = B 2 = C		As above	No
Posterior CSCs					No
Double articulation (posterior)	post_double_s5 (and _10)	0 = A 1 = B 2 = C		As above	No
Backed to velar / uvular	post_velar_s5 (and _10)	0 = A 1 = C 2 = D		As above	No
Non Oral CSCs					No
Pharyngeal articulation	non_oral_phar_s5 (and _10)	0 = A 1 = C 2 = D		As above	No
Glottal Articulation	non_oral_glot_s5 (and _10)	0 = A 1 = C 2 = D		As above	No
Active Nasal Fricatives	non_oral_fric_s5 (and _10)	0 = A 1 = C 2 = D		As above	No
Double articulation (non-oral)	non_oral_artic_s5 (and _10)	0 = A 1 = C 2 = D		As above	No
Passive CSCs					No
Weak and or nasalised consonants	pass_weak_s5 (and _10)	0 = A 1 = C 2 = D		As above	No
Nasal realisation of plosives	pass_nasal_s5 (and _10)	0 = A 1 = C 2 = D		As above	No
Gliding of fricatives	pass_glide_s5 (and _10)	0 = A 1 = C 2 = D		As above	No
Speech and Language Therapy (CAPS-A, at 5 and 10 years): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_s5 (and _10)	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason	Bespoke codes for Speech - at 5 years: 14 = Not appointed before 6 years Bespoke codes for Speech - at 10 years: 15 = Not appointed before 11 years		No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_s5 (and _10)	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_s5 (and _10)	Text	Details of other reason outcome not collected		No

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Outcome at 10 years					No
Dentistry - decayed, missing or filled teeth in permanent dentition (DMFT) at 10 years					No
Date record taken	record_taken_d10	DD / MM / YYYY	Date DMFT record taken		No
Total number of decayed teeth in permanent dentition (DT)	dt_d10	Integer	Total number of decayed teeth (DT) at age 10 years (If none, specify 0)		No
Total number of missing teeth in permanent dentition (MT)	mt_d10	Integer	Total number of missing teeth (MT) at age 10 years (If none, specify 0)		No
Total number of filled teeth in permanent dentition (FT)	ft_d10	Integer	Total number of filled teeth (FT) at age 10 years (If none, specify 0)		No
Total number of decayed, missing or filled teeth in permanent dentition (DMFT)	dmft_d10	Integer	Total number of decayed, missing or filled teeth (DMFT) at age 10 years automatically generated	Calculation of a value for this field requires the DT, MT and FT fields to be specified	No
Care Index	care_index_d10	Number between 0 and 1 (up to 3 decimal places)	Care Index (FT/DMFT) automatically generated	Calculation of a value for this field requires the FT and DMFT fields to be specified	No
Treatment Index	treat_index_d10	Number between 0 and 1 (up to 3 decimal places)	Treatment Index ((MT+FT)/DMFT) automatically generated	Calculation of a value for this field requires the MT, FT and DMFT fields to be specified	No
Dentistry - Developmental Defects of Enamel (DDE) at 10 years			**Collected since May 2022**		No
SN (Right): Supernumerary - Patient's right	dde_snr_d10	0= Normal 1= Hypomineralisation (Localised or diffuse opacities) 2= Hypoplasia 3= Abnormal shape/size 4= Congenitally missing 91= Restored 92= Carious 93= Extracted 94= Exfoliated 99= Not present - for supernumerary (SN) only	Normal: Normal shape size colour and enamel surface [score subtotal 1]. Abnormalities [score subtotal 1] - Hypomineralisation: Reduced mineralization of enamel surface evidenced by white yellow or brown patched, localised or diffuse. - Hypoplastic: Areas on the tooth where enamel is reduced in thickness or formed with an uneven surface. - Abnormal shape or size: Teeth smaller than average (microdont), larger than average (macrodont), geminated, fused , tapered/ conical, trituberculate, extra cusp/cusps, dens in dente. - Congenitally missing. Reasons not recorded [no score subtotal recorded]: - Unable - restored: A restoration covers the surface so makes it not possible to assess the surface. - Unable - carious: Decay has destroyed enamel so unable to assess the surface. - Unable - extracted: Not present to assess because has been removed. - Unable - exfoliated: Only relevant in 5 year olds - natural loss prior to eruption of adult tooth. - Not present: For SN (Right) / SN (left) only – these are not expected to be present, but they may be. Which is why there is the option to add data on 'Normal' or 'Abnormalities'.		No
URB: Upper Right incisor B - Patient's right	dde_ur2_d10	0= Normal 1= Hypomineralisation (Localised or diffuse opacities) 2= Hypoplasia 3= Abnormal shape/size 4= Congenitally missing 91= Restored 92= Carious 93= Extracted 94= Exfoliated 99= Not present - for supernumerary (SN) only	Normal: Normal shape size colour and enamel surface [score subtotal 0]. Abnormalities [score subtotal 1] - Hypomineralisation: Reduced mineralization of enamel surface evidenced by white yellow or brown patched, localised or diffuse. - Hypoplastic: Areas on the tooth where enamel is reduced in thickness or formed with an uneven surface. - Abnormal shape or size: Teeth smaller than average (microdont), larger than average (macrodont), geminated, fused , tapered/ conical, trituberculate, extra cusp/cusps, dens in dente. - Congenitally missing. Reasons not recorded [no score subtotal recorded]: - Unable - restored: A restoration covers the surface so makes it not possible to assess the surface. - Unable - carious: Decay has destroyed enamel so unable to assess the surface. - Unable - extracted: Not present to assess because has been removed. - Unable - exfoliated: Only relevant in 5 year olds - natural loss prior to eruption of adult tooth. - Not present: For SN (Right) / SN (left) only – these are not expected to be present, but they may be. Which is why there is the option to add data on 'Normal' or 'Abnormalities'.		No

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URA: Upper Right incisor A - Patient's right	dde_ur1_d10	As for 'dde_ur2_d10 ' above	As for 'dde_ur2_d10 ' above (same description as for 'URB: Upper Right incisor B - Patient's right')		No
ULA: Upper Left incisor A - Patient's left	dde_ul1_d10	As for 'dde_ur2_d10 ' above	As for 'dde_ur2_d10 ' above (same description as for 'URB: Upper Right incisor B - Patient's right')		No
ULB: Upper Left incisor B - Patient's left	dde_ul2_d10	As for 'dde_ur2_d10 ' above	As for 'dde_ur2_d10 ' above (same description as for 'URB: Upper Right incisor B - Patient's right')		No
SN (Left): Supernumerary - Patient's left	dde_snl_d10	As for 'dde_snr_d10 ' above	As for 'dde_snr_d10' above (same description as for 'SN (Right): Supernumerary - Patient's right')		No
DDE score subtotal for SN (Right)	dde_tot_snr_d10	1= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 1]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_snr_d10 field to be specified	No
DDE score subtotal for URB	dde_tot_ur2_d10	0= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 0]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_ur2_d10 field to be specified	No
DDE score subtotal for URA	dde_tot_ur1_d10	0= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 0]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_ur1_d10 field to be specified	No
DDE score subtotal for ULA	dde_tot_ul1_d10	0= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 0]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_ul1_d10 field to be specified	No
DDE score subtotal for ULB	dde_tot_ul2_d10	0= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 0]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_ul2_d10 field to be specified	No
DDE score subtotal for SN (Left)	dde_tot_snl_d10	1= Normal 1= Abnormality X= Reason not recorded	Normal [score subtotal 1]. Abnormalities [score subtotal 1] Reasons not recorded [X]	Calculation of a value for this field requires the dde_snl_d10 field to be specified	No
Total 10 year DDE score	dde_tot_d10	Values of 0 to 6 Plus X= All reason not recorded	Total number of developmental defects of enamel (DDE) - up to a maximum of 6. Note: 'X = All reasons not recorded' will be calculated only if all sub-scores are not recorded.	Calculation of a value for this field requires the dde_snr_d10, dde_urb_d10, dde_ura_d10, dde_ula_d10, dde_ulb_d10 and dde_snl_d10 fields to be specified	No
Date record taken	dde_date_d10	DD / MM / YYYY	Date DDE record taken		No
Dentistry (DMFT and DDE, at 10 years): Reasons Outcomes not collected					No
Reason outcome not collected	outcome_notcoll_reason_d10	1= Patient deceased or emigrated 2= Patient transferred in or out of area 3= Syndromic Diagnosis 4= Clinically contraindicated (other than syndromic) - this record type for this patient 5= Lack of staff / facilities / equipment 6= Patient DNA / cancelled / did not consent / cooperate 9= Other reason	These reasons apply to the collection of both DMFT and DDE scores, as it is anticipated these would be collected at the same appointment/clinic.		No
Clinically contraindicated (other than syndromic) reason - details	clincon_nonsyndr_specify_d10	Text	Details of clinically contraindicated (other than syndromic) reason outcome not collected		No
Other reason - details	outcome_notcoll_specify_d10	Text	Details of other reason outcome not collected		No