

ACHIEVING HIGH LEVELS OF DATA COMPLETENESS IN SOUTH WALES

HELEN EXTENCE

CLINICAL DIRECTOR AND LEAD SPEECH AND LANGUAGE THERAPIST

22ND JANUARY 2024



Y Ganolfan Gymraeg i
Wefus a Thafod Hollt
The Welsh Centre for
Cleft Lip & Palate



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Bae Abertawe
Swansea Bay University
Health Board

OUR SERVICE IS A POSITIVE OUTLIER FOR REPORTING:

- Gestational age
- Birthweight
- 5 year old height and weight
- DMFT scores
- Speech and psychology data completeness



Y Ganolfan Gymraeg i
Wefus a Thafnod Holt
The Welsh Centre for
Cleft Lip & Palate

POSITIVE ALERT FOR RECORDING REFERRAL TIME AND CONSENT VERIFICATION



Y Ganolfan Cymraeg i
Wefus a Thafnod Hollt
The Welsh Centre for
Cleft Lip & Palate

WHY? – OUR TEAM'S REFLECTIONS



ALL ROUND TEAM EFFORT!





Y Ganolfan Cymraeg i
Wefus a Thafod Holtt
The Welsh Centre for
Cleft Lip & Palate

GOOD PRO FORMAS

- Gestational age
- Birthweight



Y Ganolfan Cymraeg i
Wefus a Thaflod Holt
The Welsh Centre for
Cleft Lip & Palate

 Bwrdd Iechyd Prifysgol Bae Abertawe Swansea Bay University Health Board		Hospital No:	CRANE Identifier:	Surgeon:
 Canolfan Cymru ar gyfer Gwefus a Thafod Holt The Welsh Centre for Cleft Lip & Palate		New Baby Registration Form		
Surname:	Date and time of birth:			
Surname at birth:	Sex:			
First names:	E.D.D:			
Address including postcode:				
Home Phone Number:				
G.P Name and Address:				
Community Midwife:				
Health Visitor: contact number & email address				
Social Worker/ other professionals:				
Mothers Name, Mobile & email address:		Fathers Name, Mobile & email address:		
(Address if different)		(Address if different)		
Next of Kin:				
Correspondence letters to be sent to both parents if addresses differ? Yes/No				
Ethnic group: (2001 Census classification)				
1. Asian/Asian British- Indian	2. Asian/Asian British- Pakistani	3. Asian/Asian British- Bangladeshi	4. Other Asian	5. White- British
6. Other Ethnic group	7. Black/Black British- Caribbean	8. Black/Black British- African	9. Other Black	10. Chinese
11. White- Irish	12. Mixed- white& Black Caribbean	13. Mixed- White & Black African	14. Mixed- White & Asian	15. Other Mixed
16. White- other	Any other essential information (eg. Interpreter required)		Yes	No

Cleft Description:					
Diagnosed by whom:					
Date and time of Referral:	Referring Professional & Hospital:				
Paediatrician:					
Date and time first seen:	Geneticist? Y/N		Name of Geneticist		
Prenatal diagnosis of cleft? Y/N		Home Birth? Y/N			
Delivery: (natural, cesarean, forceps, ventouse, breach)		Reason if not natural delivery:			
1. Single <input type="checkbox"/> 2. Identical twin <input type="checkbox"/> 3. Non-identical Twin <input type="checkbox"/> 4. More <input type="checkbox"/>					
If Twins, Other twin affected? Yes/No					
Gestation: /40		Weight (kg):		Head Circumference (cm):	
Timing of Diagnosis:					
Antenatal		Pierre Robin Sequence?			
At birth (within 24 hours of birth)		PRS (micrognathia + Glossoptosis + cleft palate)			
Within 72 hours		PRS severity:			
Within 1 week		Sub mucous cleft:			
Within 1 month		Other Syndrome:			
Within 6 months					
Later than 6 months					
Family Cleft History? Y/N		Describe- (e.g. mother cleft lip)			
Family Medical History? Y/N		Describe:			
Older Siblings					
Child Name	1	2	3	4	5
DOB					
Sex					

5 YEAR OLD CLINICS PRO FORMA

- DMFT scores
- 5 year old height and weight



Y Ganolfan Gymraeg i
Wefus a Thafod Hollt
The Welsh Centre for
Cleft Lip & Palate

CLINIC DATE -	Patient Details (place sticker here)
Diagnosis:	
Age:	
GDP:	
GMP:	
Clinicians Present:	
Patient attending with:	

HEIGHT: cm WEIGHT: Kgs BMI:

SPEECH

PAEDIATRIC DENTISTRY

SURGERY

PRS Yes/No
SYNDROME 1=No, 2=Yes and named, 3=Yes but unknown name. (Do not include PRS as a syndrome)
 Yes and named- please circle
 Main syndrome: 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 macroomia, 8 = Stickler syndrome, 9 = Van der Woude syndrome, 10 = Other- please specify: _____
 Yes but un named- circle all the systems that apply
 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: _____

ORTHODONTICS

STUDY MODELS TAKEN Yes / No No TAKEN BY Print Name:

IF NO, REASON NOT TAKEN

OVERJET MEASUREMENT SENT FOR PHOTOGRAPHS Yes / No No

FIVE-YEAR-OLD INDEX (Internally validated score – 1 to 5)

PSYCHOLOGY

ENT/AUDIOLOGY

Audit-
Exam -
XRAY -
Audio -

OUTCOME

DATA COLLECTION SHEET

DMFT DATA

Date decayed, missing and filled teeth (dmft) record taken – / /

Patient Details (place sticker here)

Total number of decayed, missing or filled teeth in primary dentition (dmft)

Total number of decayed teeth in primary dentition (dt)

Total number of missing teeth in primary dentition (mt)

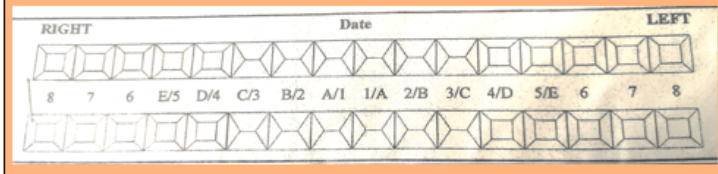
Total number of filled teeth in primary dentition (ft)

Developmental Defects of Enamel (DDE)

	SN (Right)	URB	URA	ULA	ULB	SN (Left)
Normal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypomineralisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypoplasia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Abnormal shape/size	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Congenitally missing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unable – restored	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unable – carious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unable – extracted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unable – exfoliated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not present	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

DDE Score Sub-Totals

Total DDE score



GOOD ADMINISTRATION AND ORGANISATION

- Admin support
- List from our own hospital data base of all 5 year olds and cross checked with CRANE
- “Was Not Brought” policy helps patients to attend MDT appointments
- Designated 5-year and 10 year old audit clinics



Y Ganolfan Gymraeg i
Wefus a Thafod Hollt
The Welsh Centre for
Cleft Lip & Palate

“DATA INPUTTING STARS”



SPEECH COMPLETENESS

SLT Assistant :

- Fills in the consensus listening forms at the time of consensus listening
- Inputs data
- Checks for any missing data

PSYCHOLOGY COMPLETENESS

- A Clinical Psychologist (CP) and an Assistant Psychologist (AP) attend our clinics
- Data is inputted by the AP
- Missing data checked by the AP

POSITIVE ALERT FOR RECORDING REFERRAL TIME AND CONSENT VERIFICATION

- Referral time is recorded on the new birth registration pro forma
- Consent at baby clinic around 6-8 weeks old
- Put on the database when secretary types the clinic



THE KEY TO OUR SUCCESS



- Good Pro formas
- Good administration- designated staff who know what they are doing
- Good organisation of clinics
- Good team commitment



Y Ganolfan Cymraeg i
Wefus a Thafnod Hollt
The Welsh Centre for
Cleft Lip & Palate

THANK YOU FOR LISTENING



Y Ganolfan Cymraeg i
Wefus a Thafod Hollt
The Welsh Centre for
Cleft Lip & Palate