Cerebral Palsy Integrated Pathway, Scotland.
CPIPS

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Cerebral Palsy Integrated Pathway Scotland – the story so far

Background

What CPIPS is

Current status

Future

1. Background

UPPFÖLJNINGSPROGRAM
FÖR CEREBRAL PARES

Professor Gunnar Hägglund, Lund, Sweden

CPUP Sweden

Surveillance Programme began in Southern Sweden in 1994

Since 2005 CPUP has been designated as a National Quality Register in Sweden

All the regions and county councils in Sweden participate in CPUP

What can we learn from CPUP?

Since the introduction of CPUP the number of children with a dislocated hip fell from 7.7% to 0.8% of the CP population in Southern Sweden

Prevention of dislocation of the hip in children with cerebral palsy, The first ten years of a population based prevention programme. Hagglund G et al. J Bone Joint Surg 2005;87B:95-101

What can we learn from CPUP?

The proportion of children treated with orthopaedic surgery for contracture or skeletal torsion deformity decreased from 40 to 15%

Prevention of severe contractures might replace multilevel surgery in cerebral palsy: results of a population-based health care programme and new techniques to reduce spasticity. Hagglund G et al. J Pediatr Orthop B 2005;14:269-73.

What can we learn from CPUP?

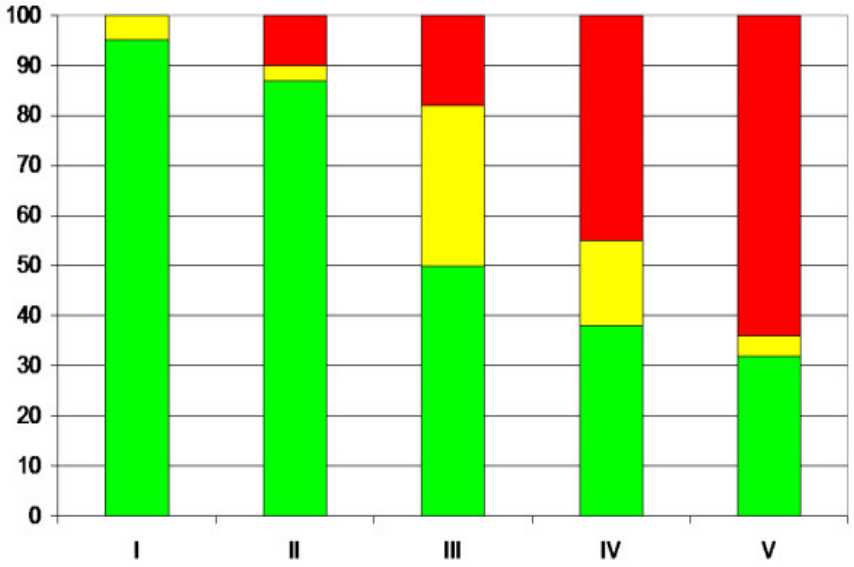
Hip dislocation

Norway	Sweden
before CPUP	with CPUP
15%	1%

Prevalence of hip dislocation among children with cerebral palsy in regions with and without a surveillance programme: a cross sectional study in Sweden and Norway. Elkamil A I et al. Musculoskelet Disord 2011;12:284

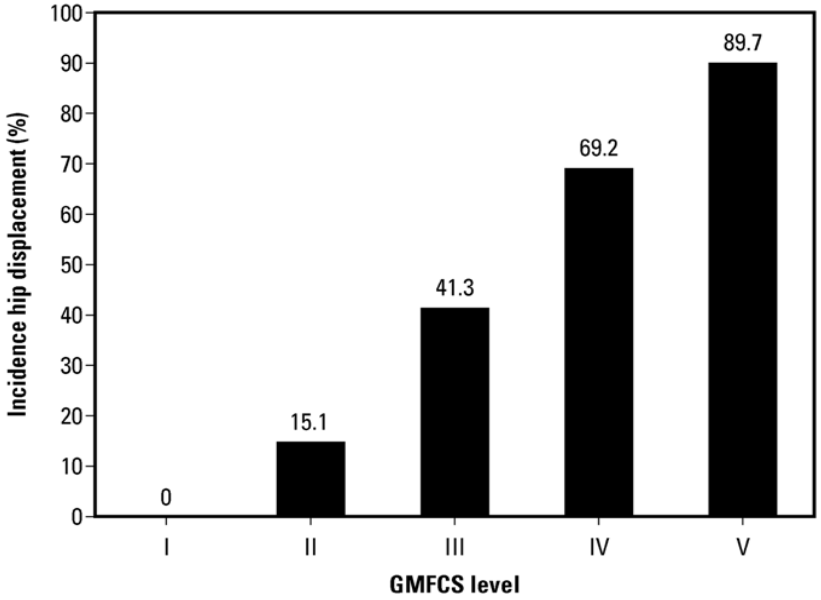
What can we learn from CPUP?

Hip displacement and GMFCS



% of children with MP < 33% (green), 33–39% (yellow), > 40% (red)

Hagglund et al. BMC Musculoskeletal Disorders 2007, 8:101



Incidence of hip displacement (MP>30%) and GMFCS level

Soo et al. J Bone Joint Surg Am 2006;88:121-129

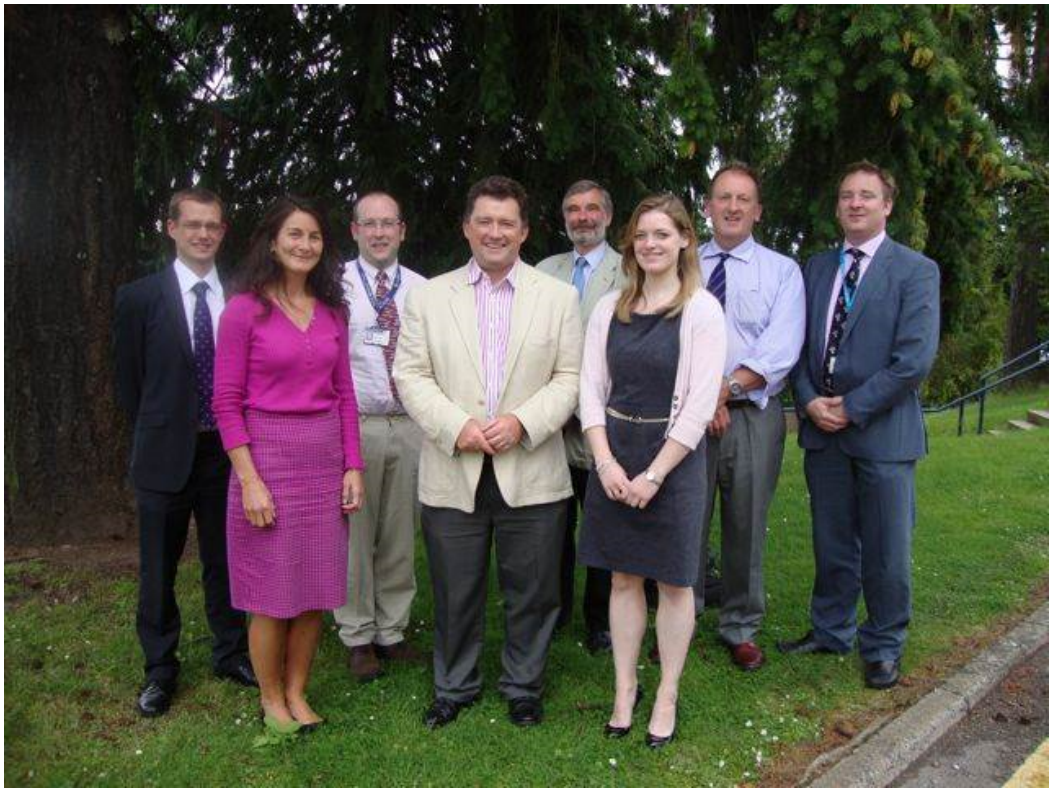
How CPIPS started

2009 Joint Swedish Paediatric Orthopaedic Society and Scottish Paediatric Orthopaedic Club meeting

2010 Liverpool CP hip consensus meeting

After this a group of Scottish children's orthopaedic surgeons met to consider introducing a hip surveillance programme based on CPUP

How CPIPS started

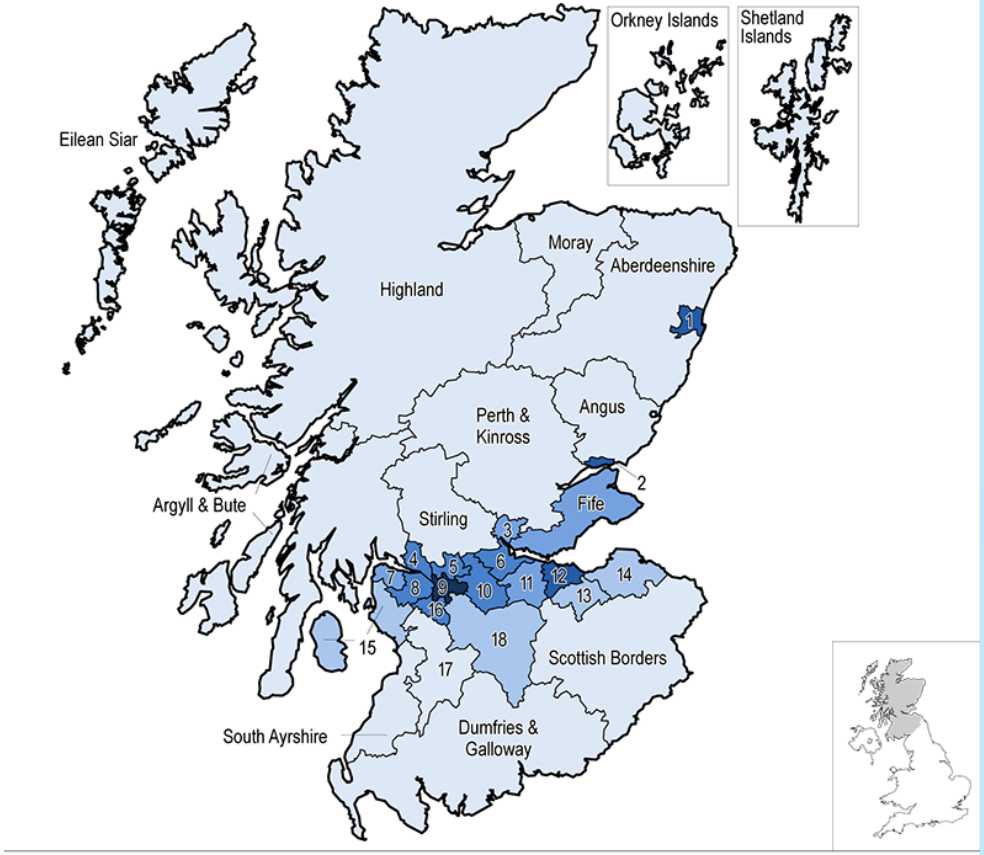


Shared demographics

	Scotland	Sweden
Population	5.3 million	9.5 million
Birth rate (raw)	11/1000	12/1000
Incidence of CP	2-3/1000	2-3/1000

Both have socialised health care effectively free at the point of delivery

Population densities



But we didn't know

1. How many children with CP lived in Scotland
2. How they accessed an orthopaedic surgeon
3. If referral pathways were similar
4. If clinicians had a hip surveillance protocol
5. If standard positioning for hip x-rays was used

University of St Andrews
MRes CP projects

Madeleine Baines (2010-11) - referral pathways

Kimberley Stevenson (2011-12) - applicability of the CPUP model to Scotland

Alice Wright (2011-12) - transition from paediatric to adult services

Professor Peter Donnelly, Dr Morven Shearer, Mr James Robb

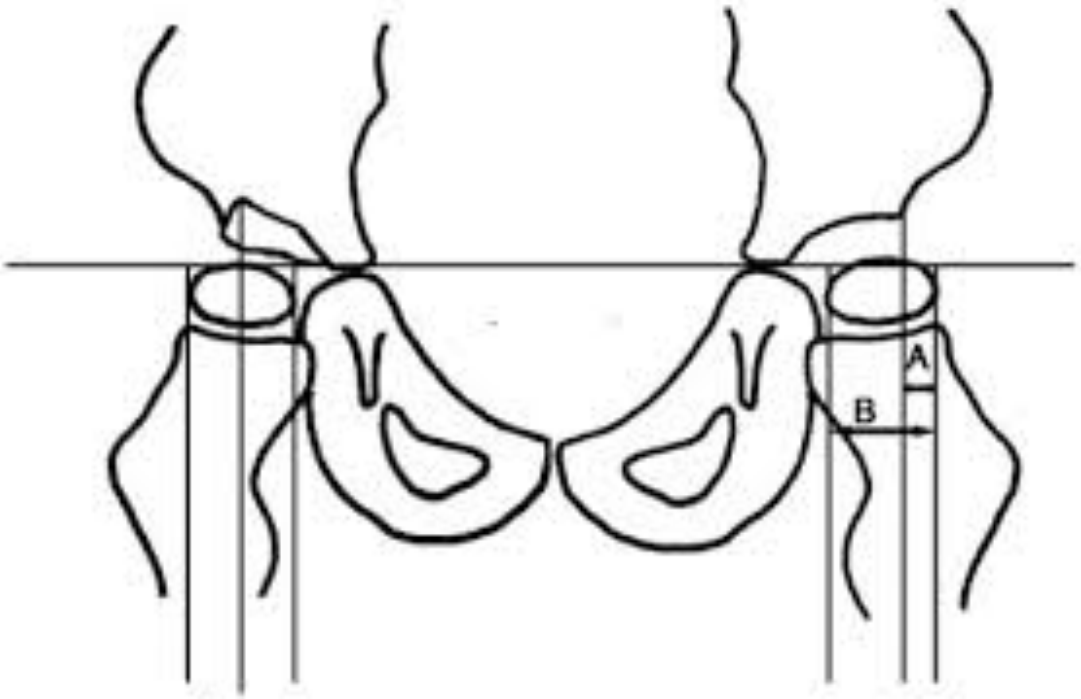
Orthopaedic surgeons

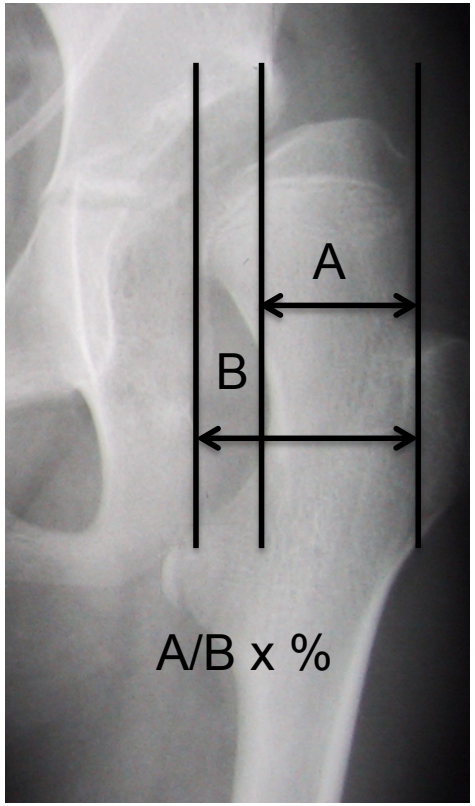
Agreed a protocol for hip radiography for children with CP at risk of hip displacement

Agreed a protocol for X-ray technique

Proposed a data set of clinical and radiological measures for hip surveillance

Migration percentage (Reimers)

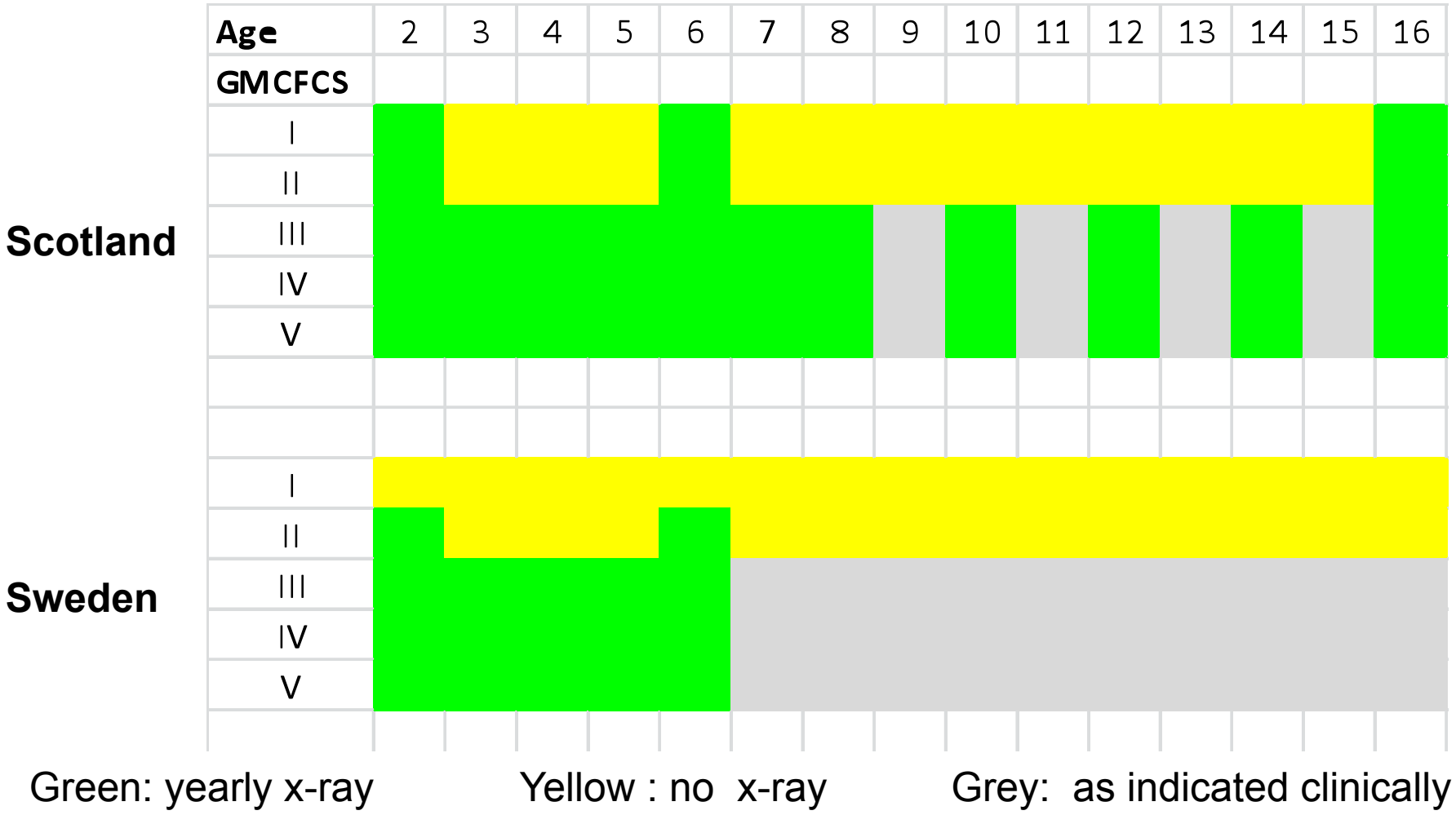




Reimers J. Acta Orthop Scand Suppl 1980;184:1-100.

Frequency of X-rays

Frequency of X-rays



Physiotherapy

Meetings with paediatric PT representatives from all 14 health boards (regions) in Scotland began in November 2011 to propose a standardised examination and reporting protocol

Very enthusiastic response

By February 2012 we had an agreed orthopaedic and physiotherapy physical examination dataset

Data set

Dominant neurological pattern

GMFCS level

Functional Mobility Scale

Lower limb range of movement

Spine - visual observation

Spasticity management, surgery, fractures

Migration Percentage

Use of aids and orthosis

Action plan

Funding

Three years' funding obtained from the Robert Barr Trust, Brooke's Dream and Scottish Government

Health Informatics Centre Dundee (CHI number)

CPIPS trialled in Lothian in Spring 2013

Went 'live' in September 2013

2. What is CPIPS?

Began as a surveillance programme

Now is a patient management system based on CPUP for children with CP aged 2 years and above

Core: electronic database accessed through NHS Scotland

Clinical examination - Physiotherapists

GMFCS, FMS, range of motion lower limbs, spine posture and postural management

Radiological examination - Orthopaedic Surgeons

Migration percentage, record of hip surgery, record of fractures

Frequency of examinations

Physical - depends on the child's age

Radiological - depends on the child's age and GMFCS level

Physical examination (PTs)

Six monthly for children between 2-6 years

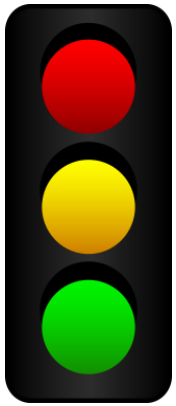
Annually for children over 6 years

More frequent if red flag signs

Traffic light system

Physical examination and radiological data values are compared with previously agreed ranges of acceptability within the database

Examination data is displayed in a traffic light system

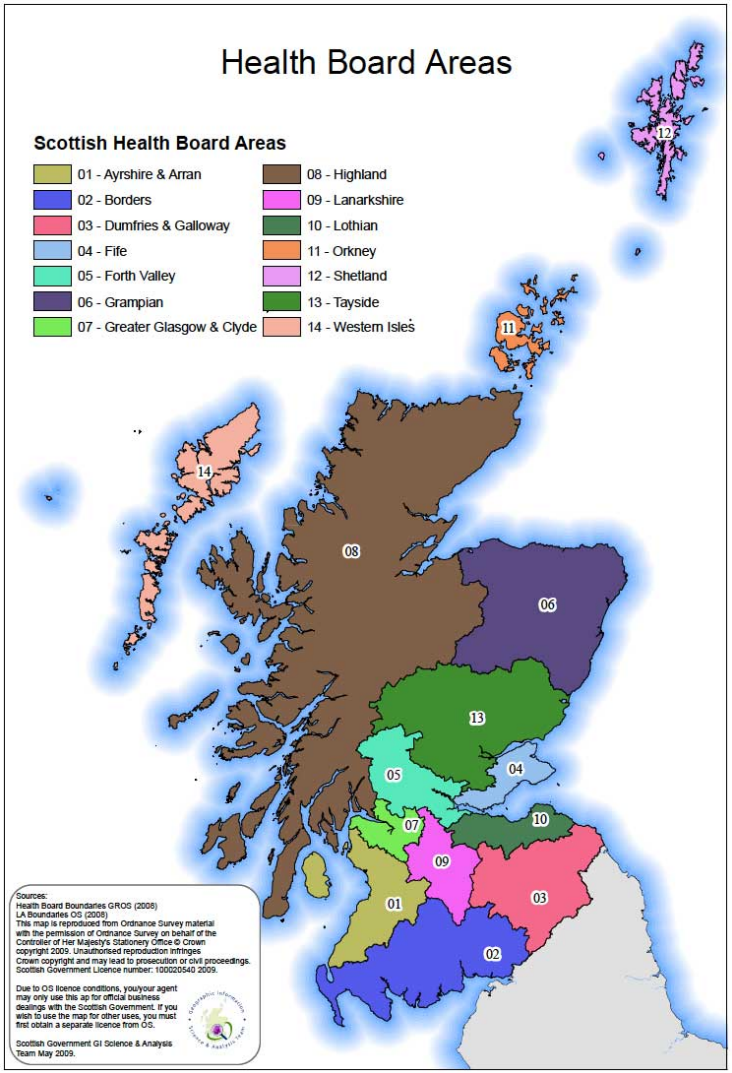


Red	further management or advice needed
Yellow	keep under observation or consider treatment
Green	values within normal ranges

Physical examination data set
GMFCS I - III

Hip Abduction	<30°	30° - 40°	>40°
Popliteal Angle	>50°	40° - 50°	<50°
Knee Extension	<0°		>0°
Dorsiflexion / Knee flexed	<0°	0° - 10°	>10°
Dorsiflexion / Knee extended	< 10° PF	10° PF - 0°	>0°
Internal Rotation	<30°	30° - 40°	>40°
External Rotation	<30°	30° - 40°	>40°
Ely test	<100°	100° >120°	>120°
Hip Extension	<10°		>10°

Physiotherapy



CPIPS is now part of the physiotherapy management of children with CP

All 14 Health Boards have at least one PT who has been trained in CPIPS evaluations

Annual competencies in physical examination have been agreed

Orthopaedic input

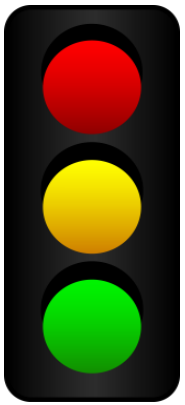
Responsibilities for orthopaedic surgeons reporting MP across Scotland have been agreed

Data on reliability of MP measurement in Scotland are now available (Kinch et al, J Pediatr Orthop. 2014 Dec.)

Anticipated that this will inform competency of MP measurements in the future

Migration percentage

Age	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
GMCFCS															
I															
II															
III															
IV															
V															

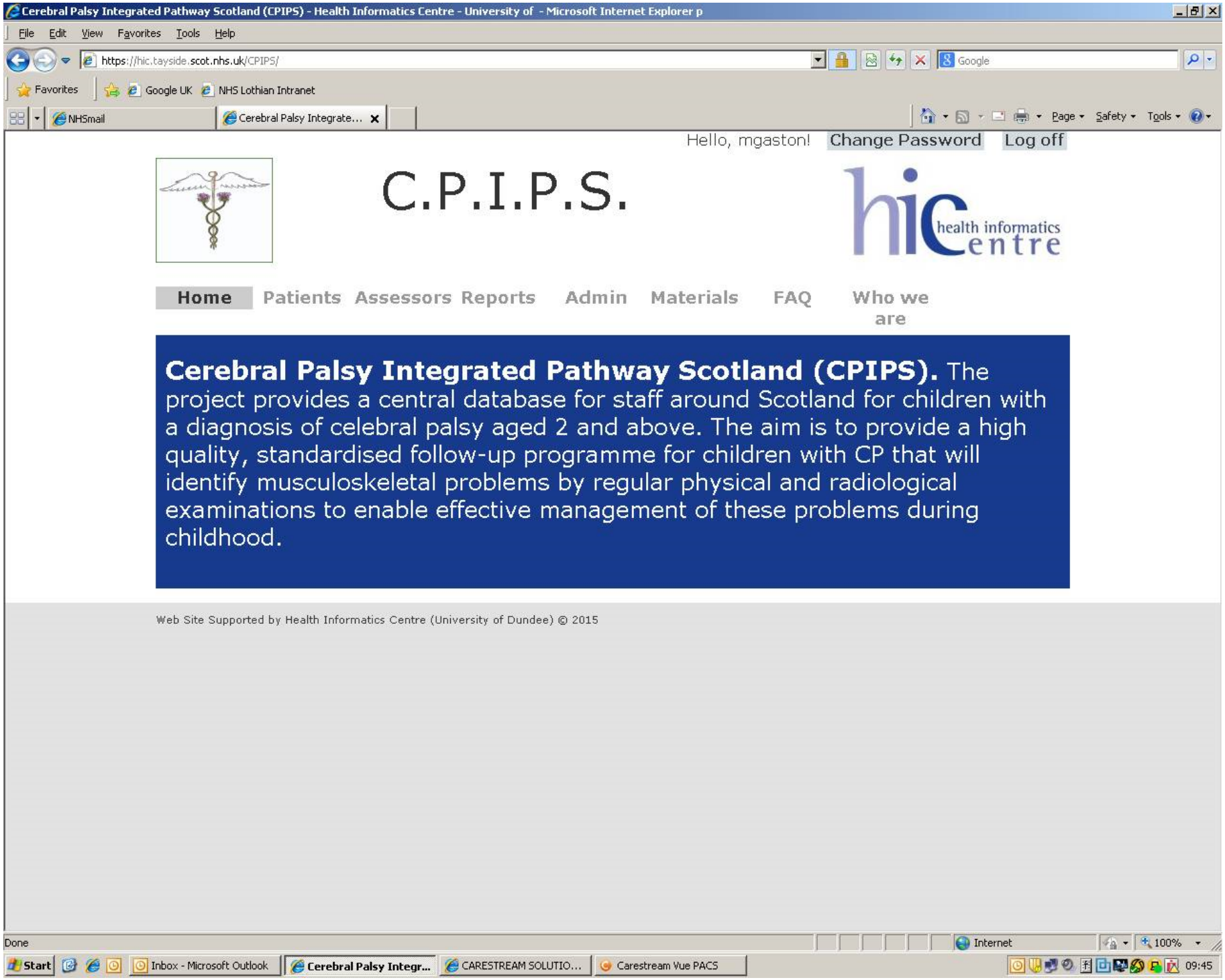


>40%

33-40%

<33%

Green annual
Grey as indicated
Yellow no X-ray


Cerebral Palsy Integrated Pathway Scotland (CPIPS) - Health Informatics Centre - University of - Microsoft Internet Explorer p
File Edit View Favorites Tools Help
https://hic.tayside.scot.nhs.uk/CPIPS/
Google
Favorites
Google UK
NHS Lothian Intranet
NHSmail
Cerebral Palsy Integrate...
Page Safety Tools
Hello, mgaston!
Change Password
Log off
C.P.I.P.S.
health informatics centre
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Who we are
Cerebral Palsy Integrated Pathway Scotland (CPIPS). The project provides a central database for staff around Scotland for children with a diagnosis of celebral palsy aged 2 and above. The aim is to provide a high quality, standardised follow-up programme for children with CP that will identify musculoskeletal problems by regular physical and radiological examinations to enable effective management of these problems during childhood.
Web Site Supported by Health Informatics Centre (University of Dundee) © 2015
Done
Internet
100%
Start
Inbox - Microsoft Outlook
Cerebral Palsy Integr...
CARESTREAM SOLUTIO...
Carestream Vue PACS
09:45

Home | Patients | Assessors | Reports | Admin | Materials | FAQ | Who we are

Patients

Create New

Show 10 entries Search:

CHI	Forename	Surname	Date of Birth	Health Board	Status	
1507041233	[redacted]	[redacted]	15/07/2004	Lothian	Discharged	Edit Assessments Delete
2904045392	[redacted]	[redacted]	29/04/2004	Greater Glasgow and Clyde	Active	Edit Assessments Delete
0502070692	[redacted]	[redacted]	05/02/2007	Lothian	Active	Edit Assessments Delete
0109078101	[redacted]	[redacted]	01/09/2007	Lothian	Unknown	Edit Assessments Delete
1004055757	[redacted]	[redacted]	10/04/2005	Lothian	Unknown	Edit Assessments Delete
0605118132	[redacted]	[redacted]	06/05/2011	Lothian	Unknown	Edit Assessments Delete
3005020592	[redacted]	[redacted]	30/05/2002	Lothian	Unknown	Edit Assessments Delete
1204055858	[redacted]	[redacted]	12/04/2005	Lothian	Suspended	Edit Assessments Delete
2101085445	[redacted]	[redacted]	21/01/2008	Greater Glasgow and Clyde	Unknown	Edit Assessments Delete
						Edit

Home Patients Assessors Reports Admin Materials FAQ Who we are

Assessments for: [redacted] - (0502070692) - Active

Create New

Show 10 entries Search:

Assessment Date	Address	Post Code	Assessor					
10/03/2014	34 Seaview Crescent	EH15 2LU	Lesley Harper	Edit Delete	Clinical Exam 4-5	Surgery Hip X-Ray	Fracture Physio	Get Pdf
29/01/2013	34 Seaview Crescent	EH15 2LU	Lesley Harper	Edit Delete	Clinical Exam 4-5	Surgery Hip X-Ray	Fracture Physio	Get Pdf
25/02/2015	34 Seaview Crescent	EH15 2LU	Lesley Harper	Edit Delete	Clinical Exam 4-5	Surgery Hip X-Ray	Fracture Physio	Get Pdf

Showing 1 to 3 of 3 entries First Previous 1 Next Last

Edit Clinical Details for 25/02/2015 Assessment

Assessor: Lesley Harper Patient: [redacted] (0502070692)

Spastic (Y/N/-)	Y
Dyskinetic (Y/N/-)	N
Dystonic (Y/N/-)	N
Ataxic (Y/N/-)	N
Mixed (Y/N/-)	N
Unclassified (Y/N/-)	N
Hemiplegia (Y/N/-)	N
Diplegia (Y/N/-)	Y
Triplegia (Y/N/-)	N
Quadriplegia (Y/N/-)	N
TotalBody (Y/N/-)	N
Other Diagnoses	none
GMFCS (1 - 5)	4
FMS 5mtr Rating (C/N/1/2/3/4/5/6)	1
FMS 50mtr Rating (C/N/1/2/3/4/5/6)	N

Last edited by lharper

Edit Examination (4-5) Details for 10/03/2014 Assessment

Assessor: Lesley Harper Patient: [redacted] - (0502070692)

Right Hip Flexion Deformity	6	Left Hip Flexion Deformity	20
Right Hip Abduction Bilateral (degrees)		Left Hip Abduction Bilateral (degrees)	
Right Hip Abduction Unilateral (degrees)	13	Left Hip Abduction Unilateral (degrees)	0
Right Hip Abduction Fast (R1) (degrees)	5	Left Hip Abduction Fast (R1) (degrees)	
Right Hip Adduction Contracture (degrees)		Left Hip Adduction Contracture (degrees)	4
Right Hip Internal Rotation (degrees)	57	Left Hip Internal Rotation (degrees)	52
Right Hip External Rotation (degrees)	74	Left Hip External Rotation (degrees)	70
Right Knee Popliteal Angle (degrees)	76	Left Knee Popliteal Angle (degrees)	56
Right Knee Popliteal Angle R1 (optional) (degrees)	92	Left Knee Popliteal Angle R1 (optional) (degrees)	70
Right Hip RoM Pain (Y/N)	N	Left Hip RoM Pain (Y/N)	N
Right Knee Fixed Flexion (degrees)	16	Left Knee Fixed Flexion (degrees)	20
Right Knee Hyperextension (degrees)		Left Knee Hyperextension (degrees)	
Right Ankle Dorsiflexion knee flexed (degrees)	0df	Left Ankle Dorsiflexion knee flexed (degrees)	4pf
Right Ankle Dorsiflexion knee extended		Left Ankle Dorsiflexion knee extended	

Last edited by mgaston

Edit Clinical Details for 25/02/2015 Assessment

Assessor: Lesley Harper Patient: [redacted] - (0502070692)

Hip Surgery since last assessment (Y/N)	N
Hip Surgery Adductor (L/R/B/N)	N
Hip Surgery Psoas (L/R/B/N)	N
Hip Surgery Femoral (L/R/B/N)	N
Hip Surgery Pelvic (L/R/B/N)	N
Hip Surgery Open (L/R/B/N)	N
Hip Surgery Other	N

Update Surgery Details | Cancel and Return to Assessment List

Last edited by mgaston

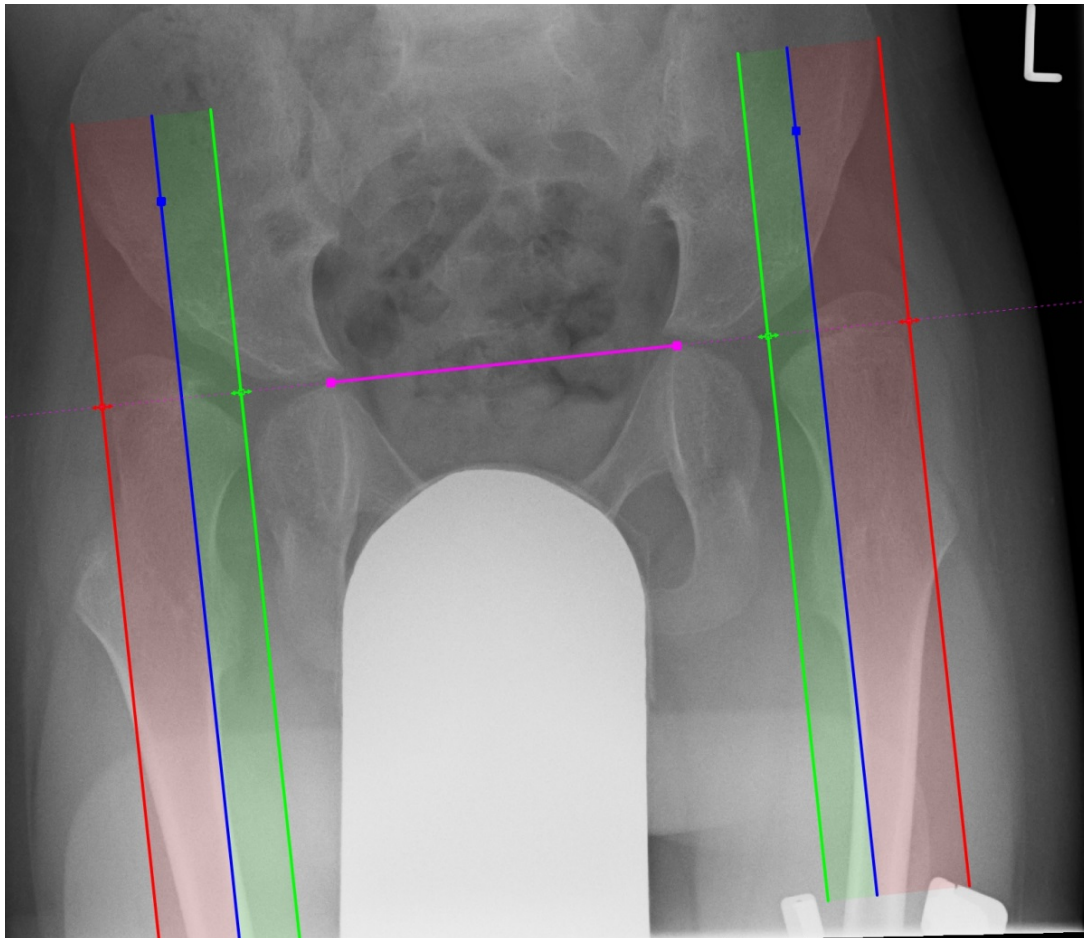
Edit Fracture Details for 25/02/2015 Assessment

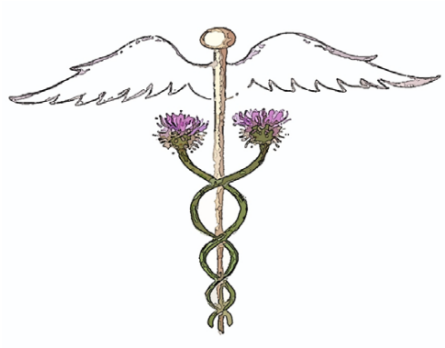
Assessor: Lesley Harper Patient: [redacted] - (0502070692)

Fracture Since Last Assessment (Y/N)	N
Tibia (Y/N)	N
Femur (Y/N)	N
Pelvis (Y/N)	N
Lumbar Spine (Y/N)	N
Thoracic Spine (Y/N)	N
Cervical Spine (Y/N)	N
Radius (Y/N)	N
Ulna (Y/N)	N
Humerus (Y/N)	N
Other (Y/N)	N
Fracture Description if answer above is Y	

Update Fracture Details | Cancel and Return to Assessment List

Cerebral Palsy Integrated Pathway Scotland (CPIPS)





Cerebral Palsy Integrated Pathway Scotland (CPIPS)

Create Hip X-ray Details for 29/05/2014 Assessment

Assessor: [redacted] **Patient:** [redacted]

X-Ray Not Applicable ☐

Date of Last X-Ray

Technical Quality Satisfactory (Y/N)

Migration % Right (degrees)

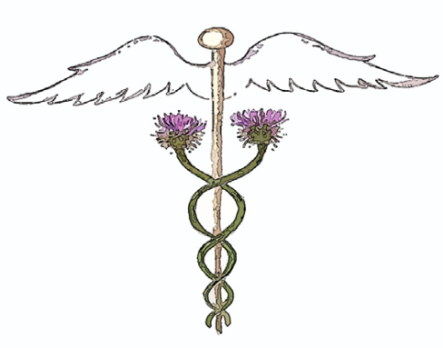
Migration % Left (degrees)

Assessor Detail

Onward Referral (Y/N)

Filename: Browse...

Create Hip X-Ray Details | Cancel and Return to Assessment List



Cerebral Palsy Integrated Pathway Scotland (CPIPS)

Edit Hip X-Ray Details for 26/11/2013 Assessment

Assessor: [redacted] **Patient:** [redacted]

X-Ray Not Applicable	☐
Date of Last X-Ray	20/03/2014
Technical Quality Satisfactory (Y/N)	Y
Migration % Right (degrees)	0
Migration % Left (degrees)	7
Assessor Detail	Mark Gaston
Onward Referral (Y/N)	N
Filename:	Browse...

Update Hip X-Ray Details | Cancel and Return to Assessment List

Select CPIPS Report from list below:

1. Patient Summary Report
2. Patient Summary Report (XRay Median Means)
3. Patient Report (Red Zone XRays)
4. Examination Schedule Report
5. X-Ray Schedule Report
6. X-Ray Missing
7. Patient XRays
8. User Rights

3. Current status

Launched September 2013

Status October 2015

- 1535 patients on system
- 2914 assessments completed
- 1638 x-rays taken and MP reported

Patient Summary Report - XRay Means

Show 25 entries

HealthBoard	Children	Assessments	XRays	MeanLeft	MeanRight	Left123	Right123	Left45	Right45
Total for Scotland	1535	2914	1638	17.86	18.47	12.65	12.97	22.85	23.68
Ayrshire and Arran	122	223	138	19.01	19.83	17.71	18.03	20.84	19.56
Borders	36	100	77	13.6	14.61	10.75	13.51	20.8	17.4
Dumfries and Galloway	36	72	48	16.75	17.28	10.9	10.4	22.6	24.15
Fife	100	147	120	23.24	23.93	16.18	18.81	30.78	29.41
ForthValley	107	196	106	17.87	17.33	14.32	16.85	22.53	17.96
Grampian	188	408	211	16.27	20.26	12.3	13.96	19.91	26.1
Greater Glasgow and Clyde	328	557	244	14.93	14.94	10.74	10.42	20.04	20.52
Highland	105	203	179	10.44	9.95	6.86	4.4	11.93	13.33
Lanarkshire	187	358	106	22.32	23.53	13.93	13.57	27.71	30.67
Lothian	212	446	300	22.32	21.16	13.23	11.35	27.81	27.07
Orkney	5	7	3	12.8	11.6	12.8	11.6		
Shetland	11	22	14	7.52	11.09	12.38	10.15	1.2	12.3
Tayside	93	166	90	18.64	18.12	13.72	14.15	26.41	24.41
Western Isles	5	9	2	21.25	21.0	40.0	39.0	15.0	15.0

Showing 1 to 15 of 15 entries First Previous 1 Next Last

Red zone x-rays

MP > 40% 7.5 % (115 out of 1535 pts)

MP > 100% 1.4 % (21 out of 1535 pts)

(Sweden started at 11%)

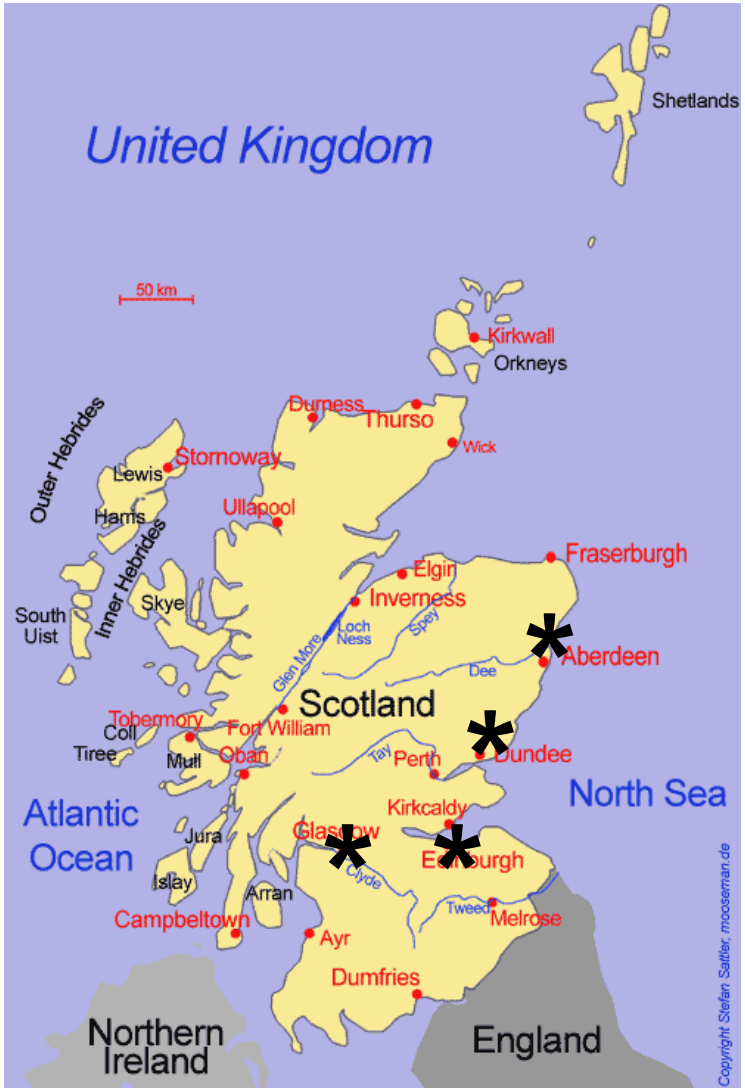
Patient Summary Report - RedZone XRays

Show 25 entries Search:

HealthBoard	PatientName	MigrationLeft	MigrationRight
Lothian	[redacted]	100	0
Lothian		100	23
Lothian		100	100
Lothian		100	100
Lothian		57	65
Lothian		11	62
Lothian		92	100
Lothian		85	53
Lothian		43	20
Lothian		17	46
Lothian		53	65
Tayside		75	63
Tayside		41	29

Showing 51 to 63 of 63 entries First Previous 1 2 3 Next Last

Orthopaedic access for patients



PICUs in Glasgow, Edinburgh, Aberdeen and Dundee

Hub and spoke system for orthopaedic surgeons and patients

Surgical management of the hip in CPIPS

Surgeons report the MP and follow their own clinical philosophy

Two strategies:

- reactive ("wait-and-see")
- preventive ("early intervention")

Don't know at the moment if one strategy produces better results than the other

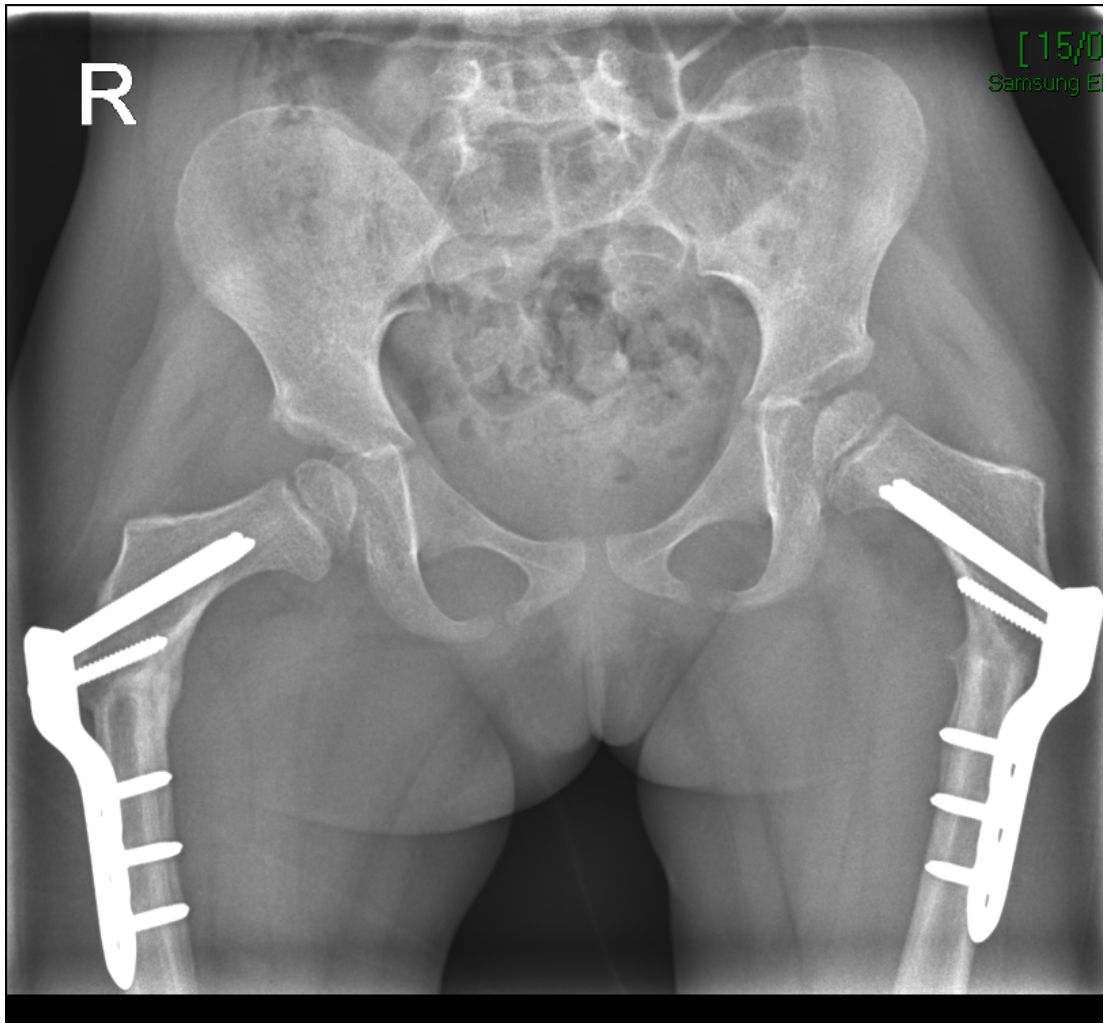
Adductor/psoas myotenotomy	Femoral osteotomy	Pelvic osteotomy
When?	When?	When?
What muscles?	What degree?	How?
Tenotomy or lengthening?	Shortening?	
Uni- or bilateral?	Derotation?	
	Uni- or bilateral?	

The ‘CPIPS Hip’

- 3 y.o.
- GMFCS 5
- Pain free.
- Wide range of abduction

- <u>Clinically ‘silent’</u>

The ‘CPIPS Hip’



CPIPS is changing practice

Right Hip External Rotation (degrees)	67	Left Hip External Rotation (degrees)	57
Right Hip Internal Rotation (degrees)	40	Left Hip Internal Rotation (degrees)	44
Right Hip Flexion Deformity	N	Left Hip Flexion Deformity	8
Right Hip Extension (degrees)	0	Left Hip Extension (degrees)	8FFD
Right Hip Abduction Bilateral (degrees)		Left Hip Abduction Bilateral (degrees)	
Right Hip Abduction Unilateral (degrees)	12	Left Hip Abduction Unilateral (degrees)	5
Right Hip Adduction Contracture (degrees)		Left Hip Adduction Contracture (degrees)	
Right Duncan Ely Test (degrees)	132	Left Duncan Ely Test (degrees)	122
Right Hip RoM Pain (Y/N)	N	Left Hip RoM Pain (Y/N)	N
Right Abduction in hip and knee extension R1 (optional) (degrees)		Left Abduction in hip and knee extension R1 (optional) (degrees)	
Right Knee Popliteal Angle (degrees)	46	Left Knee Popliteal Angle (degrees)	48
Right Knee Fixed Flexion (degrees)	18	Left Knee Fixed Flexion (degrees)	17
Right Knee Popliteal Angle R1 (optional) (degrees)		Left Knee Popliteal Angle R1 (optional) (degrees)	64
Right Ankle Dorsiflexion knee flexed (degrees)	18df	Left Ankle Dorsiflexion knee flexed (degrees)	10df
Right Ankle Dorsiflexion knee extended (degrees)	4pf	Left Ankle Dorsiflexion knee extended (degrees)	4pf
Right Ankle Dorsiflexion knee extended R1 (optional) (degrees)	6pf	Left Ankle Dorsiflexion knee extended R1 (optional) (degrees)	10pf
SPINE Lumbar lordosis excessive (Y/N)	N	SPINE Scoliosis sitting (Y/N)	N
SCOLIOSIS MANAGEMENT X-ray since last assessment (Y/N)	N	SPINE Thoracic kyphosis excessive (Y/N)	N

Generated on: 04/06/2015 09:33:19 (c) 2013 - University of Dundee

hic health informatics centre

CPIPS Assessment

- Efficient use of clinic
- Fewer random X-rays
- ‘Discharge to CPIPS’
- Security for patients / carers / surgeons
- Optimal / equality of service delivery
- Life without CPIPS?

CPIPS organisational structure

Executive – two PT and two orthopaedic members

Steering group – PT representative from each health region and Executive meets six monthly

Annual meeting – audit and academic content

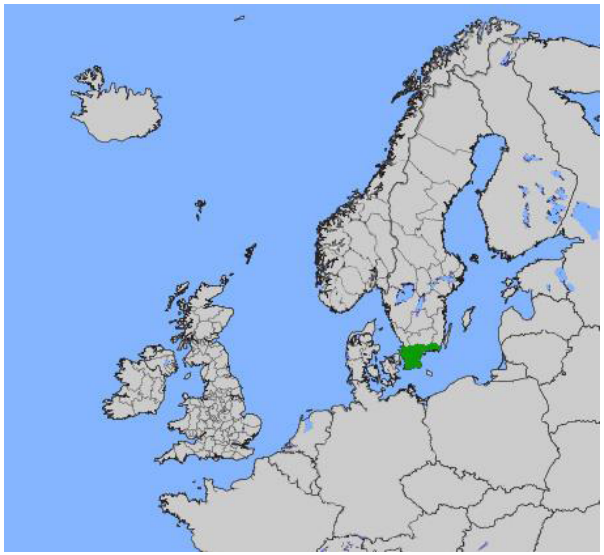
Named contact in the Health Informatics Centre

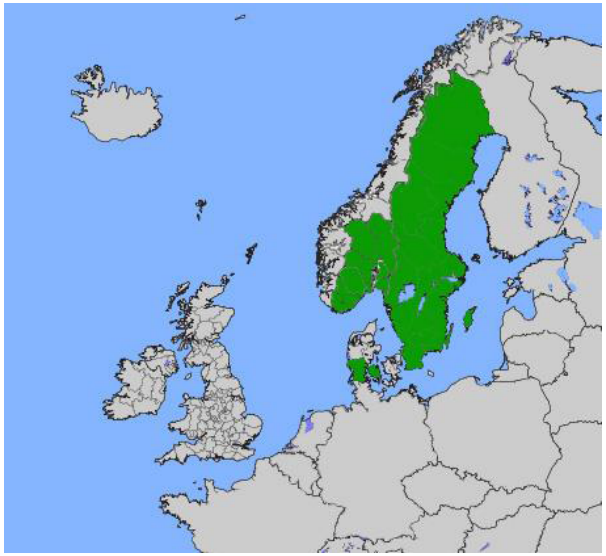
4. Future

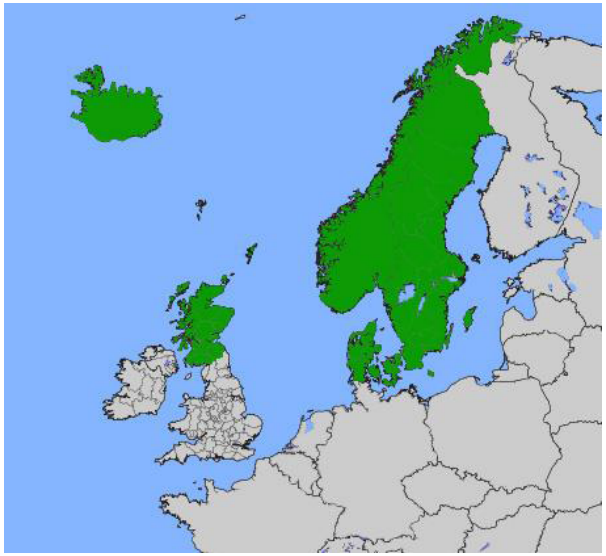
Funding:	Scottish Government
Development:	SDR and upper limb
Communication:	Other databases (CHI no.)
Research:	CP-E(urope)

CPUK!

CP-E consortium







1994

2002

2014

CPIPS is web based and allows

‘Working together to advance practice’

Core physiotherapy and orthopaedic practice

Evidence based approach based on CPUP

Shared professional aims

Clarity of purpose

Excellent inter-professional working relationships

Cerebral Palsy Integrated Pathway Scotland

Acknowledgements

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Keith Milburn / Kenny Morrison at HIC

Cerebral Palsy Integrated Pathway Scotland
CPIPS

Aim is to provide a high quality, standardised follow-up programme for children with CP that will identify musculoskeletal problems by regular physical and radiological examinations to enable effective management of these problems during childhood