



Scottish Paediatric Endocrine Group Managed Clinical Network Standards

Children and Young People Specialist Endocrine
Services

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Specialist Paediatric Endocrine Services for Children and Young People Living in Scotland

Introduction

Paediatric endocrinology is concerned with the diagnosis and management of children and young people with hormonal disorders (including growth problems).

Many specialist paediatricians in paediatric endocrinology also care for patients with diabetes mellitus; paediatric diabetes is never managed exclusively in primary care but is managed predominantly by children's diabetes teams based in secondary care.

This document is not intended to discuss Diabetes services, even though the majority of specialists providing paediatric endocrine care in Scotland also provide diabetes care for children and young people.

The Scottish paediatric endocrine group managed clinical network (SPEG MCN) was set up on the agreement that diabetes services would not be included in its remit, and should be managed separately.

It is vital that paediatric diabetes services in Scotland follow the same structure as paediatric endocrine services.

As treatment and follow-up are life-long, planned transition to adult services (via joint and/or hand-over clinics) is also an essential part of specialist endocrine services and transition services are an important part of specialist services.

Paediatric endocrine care is delivered by professionals working in many different areas of child health services. Most common endocrine conditions can be managed in a primary or secondary care setting. Some of the more complex and rare conditions need to be managed in conjunction with a specialised children's endocrine service.

It is important to note that a significant number of endocrine problems are variations of normal development and can and usually are managed locally. In some cases more complex conditions requiring referral or liaison with more specialist services.

The national delivery plan for specialist children's services in Scotland was set up in order to ensure that children with conditions requiring specialist services could be cared for locally without the need to travel to a regional centre for their care. In order to achieve this model, resources needed to be in place at both secondary and tertiary level for this to take place. Significant funding was provided to allow this model to deliver care locally.

Common Endocrine Disorders

Common endocrine disorders include the following, as defined by the Royal College of Paediatrics and Child Health:

- Short and tall stature
- Delayed puberty in boys
- Obesity
- Variations in pubertal development in girls
- Hypothyroidism
- Idiopathic isolated growth hormone deficiency.

A minority of these children may require further detailed investigation and the more complex or difficult cases will require the expertise of the specialised tertiary endocrine services.

Uncommon or Complex Endocrine Disorders

A number of rare or more complex conditions require specialised expertise and should be managed by, or in conjunction with a paediatric endocrinologist. Examples of these include:

Adrenal disorders (including Congenital Adrenal Hyperplasia)

Thyrotoxicosis

Turner Syndrome

Hypopituitarism

Precocious puberty in boys

Rare endocrine tumours

Disorders of calcium and bone metabolism

Hypoglycaemia (non-diabetes related)

Disorders of sexual development

Ambiguous genitalia

Endocrine disorders associated with chronic disease

- Growth and pubertal problems associated with chronic renal failure
- and inflammatory bowel disease
- Care of endocrine problems in cancer survivors

Endocrine Transition

It is vital that close relationships exist between paediatric and adult endocrinology services to ensure successful collaboration and transition planning.

Clinical Biochemistry

It is recognised that close liaison with specialist clinical biochemistry is integral to paediatric endocrinology.

The Current Service Model

Shared care and informal networks in endocrine services are well established across secondary and tertiary services for the children and young people in Scotland. The National Delivery Plan (NDP) for Specialist children's services was developed in order to ensure that these models were formalised. The NDP provided the opportunity for additional funding to resource the model of a national managed clinical network.

The SPEG MCN has allowed for the development of local joint specialist clinics where patients with uncommon or complex endocrine disorders are seen together with a paediatric endocrinologist. Formal links have also developed between secondary and tertiary care to enable ongoing support and advice to local teams delivering the care.

Common Endocrine Disorders

Children and young people are seen at their local district general hospital (DGH) by general paediatricians and are referred to or discussed with the local regional centre as appropriate.

Uncommon or Complex Endocrine Disorders

Children and young people requiring specialised care for complex endocrine disorders are seen at their local DGH and/or at the local regional centre. If seen locally, the regional centre clinicians support the local teams through outreach clinics and regular communication. Some children with rarer endocrine disorders are managed solely in regional centres.

Access to specialist nurse advice is currently available on an ad-hoc basis where needed.

Transition Clinics are run at both local and regional centres, often on an ad-hoc basis in local DGH's.

Proposed Service Model

The following proposed model takes into account what is already being delivered in most areas.

Local paediatric endocrine services

Each Health Board should have a local team who can deliver the care that most children with endocrine disorders need. This may be with support from the designated regional centre to a greater or lesser extent.

The local team should consist of:

- A link paediatrician with an interest in paediatric endocrinology and diabetes
- A paediatric nurse with an interest in paediatric endocrinology
- A dietitian with knowledge of endocrine disorders and childhood obesity
- A pharmacist with good links to the local team with experience in paediatrics
- Access to clinical psychology services
- Access to occupational therapy services
- Administrative support
- Good local links with clinical biochemistry
- An adult endocrinologist with good links to the paediatric endocrine team
- Access to an adult gynaecologist with an interest in adolescent gynaecology.

The local service should have the following in place:

- Designated local paediatric endocrine clinics run by the local link paediatrician and nurse
- Regular transitions clinics run together with the local named adult endocrinologist
- Regular joint outreach paediatric endocrine clinics held jointly with the named regional paediatric endocrinologist and regional endocrine nurse.

- A formal referral mechanism for ensuring efficient arrangements for complex investigations (e.g. pituitary function tests, thyroid imaging).
- A formal link between local and regional endocrinology for second opinions of imaging performed locally.
- A local shared care package for prescribing of growth hormone therapy.
- Easy access to agreed guidelines, referral pathways, and information leaflets.
- Each local centre should be active members of the SPEG MCN.
- Regular monitoring and review of the local service to ensure they are adhering to nationally agreed standards.

Regional paediatric endocrine services

Each region should have a full paediatric endocrine facility as defined by the BSPED standards.

For paediatric endocrinology, there are three regions in Scotland with facilities to provide tertiary paediatric endocrine services:

- West of Scotland – based in RHSC, Glasgow
- East of Scotland – based in RHSC Edinburgh
- North of Scotland – based in Aberdeen Children's hospital

Each regional centre should have the following:

- Paediatric endocrinologists who work predominantly in paediatric endocrinology and diabetes (One whole time equivalent per 500,000 total population).
- Specialty Trainee in paediatric endocrinology and be a recognised training centre for paediatric endocrinology.
- Paediatric endocrine nurse specialists who only have a paediatric endocrinology caseload.
- Readily available access to regional biochemistry laboratories.
- Clinical psychology with time designated to children with paediatric endocrine disorders
- Dietitians with expertise in paediatric endocrinology and obesity.
- Occupational therapists with expertise in bone disorders.
- Readily available access to radiology services with expertise in imaging of the endocrine system, including isotope imaging, ultrasound imaging and MRI.
- Access to full tertiary services, particularly paediatric surgical services.
- Clinical geneticist
- Data manager
- Administrative support

Standard 1: Access to Endocrine Services

Statement: All children identified with an endocrine health need have access to high quality, evidence based care provided by appropriately trained multi-disciplinary teams.

Key Action	Outcome Measure	Responsible Organisation	Target
1.1 All children and young people with endocrine disorders have access to the DGH endocrine team	A local endocrine team is available in each health board area	Health Boards	100%
1.2 Children with uncommon or complex endocrine disorders are managed in conjunction with a specialist paediatric endocrine team	A regional paediatric endocrine team is available in each area and readily accessible to every DGH in Scotland	Regional Centres	100%
1.3 Children, young people and their families referred to the endocrine service are made aware of the services available to them within the MCN	An information leaflet about the SPEG network and local endocrine services is available in each Health Board area	SPEG MCN	100%
1.4 Nationally agreed guidelines are in place for children and young people in Scotland requiring investigations, diagnosis and management of endocrine disorders	Up to date guidelines and pathways are available on the SPEG MCN web site. These guidelines are reviewed regularly.	SPEG MCN	100%
1.5 There are national guidelines, care pathways and hazard alerts in place to support all children and young people who may require immediate treatment in an emergency situation	A management plan is available for all children with adrenal insufficiency. Management plan is available to patients, local ED and SAS. All children have a hazard alert on the SAS.	All centres	95%
1.6 Tertiary paediatric endocrine teams should be available in each area and readily accessible in every DGH in Scotland	WTE paediatric endocrinologists at tertiary level per 500,000 total population. WTE paediatric endocrine nurses at tertiary level per population	Regional Centres	100%

1.7 A transition pathway is in place for all young people with endocrine disorders to transfer to adult services where necessary	An information leaflet about transition of care is available in each health board area. The leaflet is given to each patient and family at the start of the transition process.	Health Boards	100%
1.8 Young people with an endocrine disorder have the opportunity to be seen by a local gynaecologist with an interest in adolescent endocrine problems	Each area should have access to a gynaecologist with an interest in adolescent gynaecological disorders.	Health Boards	100%
1.9 Local and specialised endocrine teams have access to biochemistry services	All centres have easy access to routine and specialist biochemical investigations	Health Boards	100%
1.10 Children and young people with endocrine disorders have access to specialised multi-disciplinary outreach services and clinics	All Local centres have a regular outreach paediatric endocrine clinic with visiting paediatric endocrinologist and paediatric endocrine nurse.	Regional centres Health Boards	100%
1.11 Access to radiology services: <ul style="list-style-type: none"> urgent MRI at regional centres (for non-neurosurgical emergencies) is available and reported on within 24 hours non urgent MRI scans (including those under general anaesthetic) are available and reported on within 4 weeks at all regional centres pelvic ultra-sound scanning is available and reported on within 12 weeks at all DGHs bone age is available at each local and regional centre dual energy x-ray absorptiometry (DEXA) is available and reported on within 12 weeks at all regional centres 	Each area should have a named radiologist with an interest in paediatrics. The named radiologist should have a formal link to their regional radiology centre for advice and second opinion.	Regional centres Health Boards	100%

Standard 2: Resourcing and Facilities for Endocrine Services

Statement: Endocrine services are staffed with appropriately trained, multi-disciplinary professionals. Services are fully equipped to deliver appropriate and equitable care across the network in a child friendly environment with suitable faculties and equipment for their age and developmental needs.

Key Action	Outcome Measure	Responsible organisation	Target
2.1 A fully resourced multi-disciplinary team exists in the regional centre with the capacity to outreach.	Regional centres have appropriate staff levels in order to provide a specialised paediatric endocrine service. There is capacity in each regional centre to provide outreach to the neighbouring DGH's.	Regional centres	100%
2.2 A DGH local multi-disciplinary team is resourced to provide the local element of specialised endocrine care.	Each Health board area has the appropriate medical and nursing resource to provide a local endocrine service.	Health Boards	100%
2.3 Paediatricians with an interest in endocrinology/diabetes have a minimum of 2 sessions per week committed to the SPEG MCN.	Each Health board area has a designated link clinician in paediatric endocrinology, and a designated nurse with proportionate time allocated based on the local paediatric population	Health Boards	100%
2.4 Facilities are available in the regional centre and local DGH to provide biochemical investigations.	All centres have easy access to routine and specialist biochemical investigations	Regional centres Health Boards	100%
2.5 Facilities are available in regional centres/DGH to provide radiological investigations and expert interpretation.	All centres have access to appropriate radiological investigations and access to expert interpretation	Regional centres Health Boards	100%
2.6 Facilities for day case investigations for children with endocrine disorders are available in each centre (local and regional).	Each local centre has the ability to perform routine investigations. Each centre has access to more complex	Regional centres Health Boards	100%

	investigations at the tertiary centre.		
2.7 Standardised Shared care packages are in place for growth hormone Prescribing in each centre	A standard GH shared care package is available in each area, agreed by the local prescribing committee	Health Boards	100%
2.8 There are allocated IT and administrative services to enable rapid transmission of clinical information across the network	All correspondence from regional to local centres is received in a timely manner. There is appropriate administrative support in each centre to allow for effective communication	Regional centres Health Boards	100%
2.9 Workforce planning mechanisms are in place to allow for year on year growth and service development dependent on a local needs assessment	All general managers have a documented workforce plan for paediatric endocrine services	Regional centres Health Boards	100%

Standard 3: Care of the Child and Family

Statement: The child and family receive child and family centred care appropriate to their needs.

Key Action	Outcome Measure	Responsible organisation	Target
3.1 Children, young people and their families are aware of the SPEG MCN and have a choice in where their care is based	Information leaflets are available in all centres describing the MCN. Patients are aware of links between tertiary and DGH centres	SPEG MCN	100%
3.2 Children, young people and their families are aware of the options available to them in their care management in order to make an informed choice	Patients commencing GH are given a choice of device to use.	Regional centres Health Boards	90%
3.3 Parent/carers are actively encouraged to participate in care	Information leaflets are available for specific conditions and should be provided to patients and families	SPEG MCN	100%
3.4 Transition pathways are in place to allow for seamless transition to adult services	A transition statement is in place, and each health board has a clear pathway to transition in place	Regional centres Health Boards	100%

Standard 4: Communication

Statement: There is good two-way communication between the local and regional centre between professionals and children, young people and their families.

Key Action	Outcome Measure	Responsible organisation	Target
4.1 Local and regional centres maintain, with administrative staff, a database of patients	CAS is the database that SPEG MCN will use to record all patients seen in an endocrine clinic	Regional centres Health Boards	90%

Standard 5: Clinical Governance, Education and Training

Statement: Endocrine services are staffed with appropriate multi-disciplinary professionals who are fully trained and supported to maintain their continuing professional development.

Key Action	Outcome Measure	Responsible organisation	Target
5.1 All paediatricians responsible for endocrine service delivery have undertaken specialist endocrine training to an appropriate level. They will continue to maintain their knowledge through CPD and have protected time	Local teams attend training events at least 3 times per year. Clinicians should attend a national meeting at least every 3 years	Regional centres Health Boards SPEG MCN	90%
5.2 Regional centres are accredited training centres.	Each regional centre should fulfil the criteria set by the BSPED for Accreditation	Regional centres	100%

Standard 6: Patient experience

Statement: Patients and their carers/families are actively involved in decisions relating to their care.

Key Action	Outcome Measure	Responsible organisation	Target
6.1 Patients and carers are given the opportunity to be actively involved in their care	Regular patient experience questionnaires should be performed in each health board area	Regional centres Health Boards SPEG MCN	90%

6.2 Patients and carers have an opportunity to have a say in how their care should be delivered	Regular patient experience questionnaires performed in each health board area	Regional centres Health Boards SPEG MCN	100%
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Definition of a Training Centre

A training centre can be a single institution or a group of related establishments accredited for training purposes by the British Society for Paediatric Endocrinology and Diabetes (BSPED).

Full Training Centre

The centre must provide adequate experience in all fields of endocrinology including emergency care. A full component of the secondary and tertiary courses must be provided. The number of activities must be sufficient to provide at least a minimum experience for a trainee. A group of related establishments can be considered a centre and each component considered as a unit contributing one or more modules to either the secondary or tertiary course.

The centre must have easy access and close relationships with other relevant specialties such as nuclear medicine, imaging facilities, surgery and laboratory facilities. The centre must provide evidence of ongoing clinical research and access to basic research.

The centre will be responsible for weekly clinical staff/seminar teaching and participation in regional/national meetings. Basic textbooks in endocrinology/diabetes should be immediately available and there should be access to a comprehensive reference library either in paper or electronic format.

Training Unit

Training units are institutions that provide training in one or more aspects of the secondary and/or tertiary courses. They must provide adequate exposure in the defined area and a teacher who is deemed competent in these areas.

Standards relating to clinical biochemistry

All centres where children are admitted should have access to 24 hour, 7 days a week standard 'routine' biochemistry services. Routine endocrine biochemistry services should be available Mon-Fri 9am - 5pm. (Define what is routine)

These services should also be available by arrangement outside normal working hours when urgently required. There should be access to hour, 7 days a week advice from clinical biochemists or chemical pathologists.

Laboratories should be accredited by an appropriate body e.g. Clinical Pathology Accreditation (UK) Ltd (CPA). Laboratories should participate in appropriate external quality assurance (EQA) schemes for each analyte offered.

It may not be possible to offer specialist peptide hormone and steroid hormone services in DGHs. There should be access to comprehensive high quality specialist peptide and steroid hormone assays and expert advice Mon-Fri 9am - 5pm at a specialist centre.

Specialist services should also be available by arrangement outside these hours when urgently required.

Resources should be available for referral of samples for specialist peptide and steroid hormone services as required.

Provision of specialist laboratory services requires:

- Experienced personnel trained to MRCPATH standard to provide specialist interpretative advice.

- Qualified biomedical scientists registered with health professions council who are experienced in the techniques employed with appropriate scientific supervision to perform specialist assays.
- A programme of training in specialist services for biomedical scientists, clinical biochemists and chemical pathologists.
- Specialist centres should be equipped with the required technology to provide a quality analytical service.
- Development of services as appropriate to clinical requirements.
- A programme of multidisciplinary clinical audit to maintain the quality of services.
- A programme of sample exchange with other laboratories offering specialist services if EQAs are not available.

Appendix

SPEG MCN Quality Standards						
Areas		Service Standards	Outcome Measure	How to measure	What to Measure	Target
Access to specialist services	SS1	All children and young people with endocrine disorders have access to the local DGH endocrine team.	A local endocrine team is available in each health board area	Annual service directory enquiry to all health board areas with information about medical and nursing time available for paediatric endocrine service	Time available to local endocrine team to provide service	100%
	SS2	All patients with *complex endocrine conditions should have ready access to paediatric endocrinology medical expertise when necessary *Def of complex based on BSPED criteria	Tertiary paediatric endocrine teams should be available in each area and readily accessible in every DGH in Scotland. At least 1WTE paediatric endocrinologist per 100,000 childhood population based in a regional centre.	Number of paediatric endocrinologists at tertiary level per 100,000 childhood population.	WTE regional paediatric endocrinology time per 100,000 childhood population	100%
	SS3	All patients with *complex endocrine conditions should have ready access to paediatric endocrinology nursing expertise when necessary *Def of complex based on BSPED criteria.	Tertiary paediatric endocrine teams should be available in each area and readily accessible in every DGH in Scotland	Number of paediatric endocrine specialist nurses at tertiary level per 1000 childhood population	WTE regional paediatric endocrinology nurse time per childhood population	100%

	SS4	Children with uncommon or complex endocrine disorders are managed in conjunction with a specialist paediatric endocrine team in a local joint outreach clinic with the regional tertiary centre. *Def of complex based on BSPED criteria.	All local areas have a tertiary joint outreach endocrine clinic	Number of *level 2 hospitals who have a tertiary joint clinic. *levels 1, 2 and 3 based on BSPED classifications	Number of clinics held/Number of level 2 paediatric hospitals.	Minimum 2 clinics per year
	SS5	Children, young people and their families with an endocrine condition, referred to the endocrine service are made aware of the services available to them within the MCN	An ** information leaflet about the SPEG network and local endocrine services is available in each Health Board area. **information leaflet will provide details of SPEG MCN including service map.	Leaflets available in each health board area	Number of areas who have a leaflet available to their patients about the SPEG MCN	100%
	SS6	There are shared care protocols and care pathways in place to support all children and young people who may require immediate treatment in an emergency situation	A management plan is available for all children with adrenal insufficiency. Management plan is available to patients, local ED and SAS. All children have a hazard alert on the SAS.	An up to date Emergency management plan is in the patient's case notes. An Emergency Plan is available in ED, and SAS. A hazard alert is in place in SAS database.	Number of patient with adrenal insufficiency with an emergency management plan and a hazard alert in place per local population	100%

	SS7	A transition pathway is in place for all young people with endocrine disorders to transfer to adult services	An information leaflet about transition of care is available. The leaflet is given to each patient and family at the start of the transition process.	A process for endocrine transition is in place in each health board area, or an endocrine transition clinic is in place in each area.	Number of transition clinics in place in each health board area. Number of transition plans in place in each area.	100%
Resources	R1	A fully resourced multi-disciplinary team exists in the lead centre with a capacity to outreach	Regional centres have appropriate staff levels in order to provide a specialised paediatric endocrine service. There is capacity in each regional centre to provide outreach to the neighbouring DGH's.	All staff have dedicated time allocated to paediatric endocrine service. Appropriate time is allocated to the MCN team in order to deliver paediatric endocrine services in a tertiary centre. Time is allocated to each centre in order to deliver an outreach service. Time allocated as per NDP requirements	Medical and nursing manpower is available to deliver a paediatric endocrine service	100%
	R2	A DGH local multi-disciplinary team is resourced to provide the local element of specialised endocrine care in partnership with the lead centre	Each Health board area has the appropriate medical and nursing resource to provide a local endocrine service.	Appropriate time for medical and nursing time to deliver a local service. Time allocated in job plans and KSF. Time allocated as per NDP agreements	Allocated time in job plans for all team members in order to deliver a local service	100%

	R3	Paediatricians with an interest in endocrinology have defined sessions built in to their job plan committed to the endocrine regional network	Each Health board area has a designated link clinician in paediatric endocrinology, and a designated nurse with proportionate time allocated based on the local paediatric population	Named link clinician with committed sessions to paediatric endocrinology	Time clearly identified in job plans for local paediatricians to deliver a paediatric endocrine service.	100%
	R4	Facilities are available in the lead centre and DGH to provide biochemical investigations	All centres have easy access to routine and specialist biochemical investigations	Turnaround time for common samples - TFT, 17-OHP. Turnaround time for samples sent to central labs.	Urgent 17-OHP result available within 1 week. TFT results available within 48 hours.	95%
	R5	There are allocated IT and administrative services to enable rapid transmission of clinical information across the network	All correspondence from regional to local centres is received in a timely manner	Correspondence is available within 14 days if patients have been seen in a regional centre	Randomly sample 10 case notes every 3 months	80%
	R6	Workforce planning mechanisms are in place to allow for year on year growth and service development dependent on a local needs assessment	All general managers have a documented workforce plan for paediatric endocrine services	Write to each manager and request a workforce plan	A written workforce plan is in place in each health board area for local endocrine services	100%
Patient experience	PE1	Children, young people and their families are aware of the SPEG MCN and have a choice in where their care is based	<p>**Information leaflets available about the MCN. Patients aware of links between tertiary and DGH centres</p> <p>**information leaflet will provide details of SPEG MCN including service map.</p>	Check if each area has information about the SPEG mcn available in clinics	Information leaflets available in each area	100%

	PE2	Children, young people and their families are aware of the options available to them in their care management in order to make an informed choice	Patients commencing GH are given a choice of device to use.	Examples are :-a)GH Audit- Results of GH testing available to referring paediatrician within 2 weeks of test being done. GH therapy initiated within 3 months of initial decision to treat, as defined by date GP shared care letter sent. b)Patient satisfaction questionnaire.c) Infants diagnosed with CH are managed as per CH guidelines.	Audit GH patient journey, Audit CH follow up.	100%
	PE3	Parent/carers are actively encouraged to participate in care	Information leaflets available for specific conditions	Patient satisfaction questionnaire	Perform patient experience questionnaires in all health board areas at local endocrine clinics and joint endocrine clinics	100%
	PE4	Information and training is available for children, young people and their families about services, their condition and care	Information specific to children's condition is available and given to each family.	All SPEG condition specific patient information leaflets available in each centre.	SPEG information leaflets for all conditions available in each health board area.	100%
	PE5	Transition pathways are in place to allow for seamless transition to adult services	A transition statement is in place, and each health board has a clear pathway to transition in place	Formal transition plans in place for patients moving to adult services	Number of transition plans in place in each area. Number of transition clinics.	Minimum 2 clinics per year

Communication	C1	Lead and specialist centres maintain, with administrative staff, a database of patients	CAS is the database that SPEG MCN will use to record all patients seen in an endocrine clinic	Randomly sample endocrine clinic lists to see how many are registered with CAS	Number of teams using CAS or who use a database of patients	90%
Clinical Governance	CG 1	All paediatricians and specialist nurses responsible for endocrine service delivery have undertaken specialist endocrine training to an appropriate level. They will continue to maintain their knowledge and skills through continuous professional development (CPD) and have protected time and funding	Paediatricians and nurses with an interest in endocrinology should attend endocrine specific training at least 3 times per year. Each clinician with an interest in paediatric endocrinology should attend a ***national meeting at least every 3 years. ***national meeting e.g. BSPED; ESPE; Annual Scientific Meeting; National Endocrine Study Day		Attendance at educational events	100%
	CG 2	Each year a clinical governance report will be produced	Review of GH patient journey in all health board areas. Review of CH management. Review of patients on CAS with endocrine conditions. Review complaints made to endocrine services. Review emergency admissions in children with endocrine conditions.	Review GH patients to determine whether investigations and commencement of therapy was timely. Regular review of use of CAS and number of patients on CAS. Review emergency admissions	Audit GH patient journey, Audit CH follow up. Number of patients on CAS for each area.	90%