



National Steering Group for Specialist Children's Services

Paediatric Dermatology Report

Index

1. Executive Summary of Paediatric Dermatology in Scotland

2. Incidence and Scope of Dermatology

Incidence

Severity

Quality of Life

Clinical Practice

Changing Demographics

Paediatric Consultations

Adolescence & Transitional care

Delivery of Care

Training

2.9.1 Generic

2.9.2 Paediatric

3. Manpower

4. Descriptor of common conditions and current management

Introduction

Atopic Eczema

Food Allergy

Haemangiomas & other Complex Congenital Naevi

5. In-Patients

6. Specialist Services

6.1 Specialised Dermatology

6.2 Food Allergy

6.3 Vascular lesions

6.3.1 Haemangiomas

6.3.2 Malformations

6.4 Complex Pigmented & other naevi

6.5 Neonates

6.5.1 Epidermolysis Bullosa

6.5.2 Severe Ichthyoses: Collodion baby & Harlequin foetus

6.6 Genodermatoses: Congenital Inherited Neurocutaneous Disorders

6.7 Childhood Genital Diseases

6.8 Phototherapy

7. Interdependence on Other Specialities

7.1 Combined Atopic Eczema clinics

7.2 Multidisciplinary clinics

7.3 Multi-system disease

7.3.1 Connective tissue disease

7.3.2 Psoriasis

8. Delivery of care

General Practitioners

Paediatricians

Paediatric Surgeons

8.4.1 General Dermatologists

8.4.2 Dermatologists with a Special Interest in Paediatric Dermatology

8.5 Dermatology Nurses

9. Regional Services

Teaching Centres

Glasgow

Edinburgh

Dundee

Aberdeen

District General Hospitals

9.2.1. Argyll North

9.2.2 Ayrshire

9.2.3 Clyde

9.2.4 Dumfries & Galloway

9.2.5 Fife

9.2.6 Forth Valley

9.2.7 Inverness

9.2.8 Lanarkshire

10. Other health Professionals

10.1 Paediatric Dieticians

10.2 Clinical Psychology

11. Recommendations

12. Tables

13. References

14. Working Party Members & Acknowledgements

15. Appendices: Sample Questionnaire

Executive Summary

Introduction

This review of children's dermatology services in Scotland was commissioned by the National Steering Group for Specialist Services for Children with focus on the quality and sustainability of the existing service.

Background

While many common skin conditions such as atopic eczema can be adequately managed in primary care, children with severe or complicated presentations of common conditions and children with rare skin disease require access to specialised Paediatric Dermatology services and it is essential that all children in Scotland should have equitable access to these services. Regional tertiary referral centres are sited in Glasgow, Edinburgh, Aberdeen & Dundee. Glasgow and West of Scotland served by 2.2 (WTEs) consultants at Royal Hospital for Sick Children (RHSCG); Edinburgh and the Borders by 0.4 WTEs; Aberdeen by 0.4 WTE; and Dundee and North East Fife by 0.8 WTE consultant.

Children's dermatology services are not currently viewed as a key priority. Costs to the government of atopic eczema, the commonest condition seen are extremely low in comparison to other chronic diseases of childhood but costs to the children and their families both financially and in terms of quality of life impairment are significant.

Scope: A wide range of skin problems need specialised paediatric dermatology including: severe atopic eczema (AE) & other inflammatory skin conditions, complex vascular and other naevi, neonates (special care & ITU), genital disease, rare genetic disorders such as epidermolysis bullosa (EB - blistering disorders) and children with multisystem diseases such as the connective tissue diseases.

Changing incidence of atopy: There has been a striking increase in all atopic conditions since the late fifties. Atopic eczema (AE) now affects up to 20% of children in the UK. Food allergy (FA), which often co-exists and may trigger AE, is of national concern, as highlighted by the House of Lords report (2007) and now affects 5-7% of children in the UK.

Severe eczema seriously disrupts a child's life, impairs normal growth & development, significantly effects education and requires aggressive treatment. Young children with atopic eczema and food allergy require specialised investigation & management with access to paediatric dieticians & a diagnostic allergy service.

National / Regional / Local Planning

National Multidisciplinary clinics (MDC):

Complex vascular and large congenital pigmented naevi: These should be managed in a MDC, currently provided in Glasgow & Dundee. Interventional (available in Glasgow) and other specialised radiology services are also necessary. MDC for children with EB are run in Edinburgh, Glasgow, Dundee and Aberdeen.

Food allergy in the setting of atopic eczema: Establishment of a national food allergy service for the management of children with multiple food allergies who are often more difficult to manage. A comprehensive service could be delivered locally if linked to a centre such as RHSCG which has a long established service, integrated with paediatric dieticians and specialised nurses (Skin prick test & food challenges). This would offer training for staff in the investigation & management of food allergies in young children with atopic eczema and provide advice & support from staff. An overall increase in paediatric dieticians & allergy service will be needed in Scotland.

Integrated services: Some conditions need specialised care such as those infants with blistering diseases and severe ichthyoses (in neonatal intensive care units in Edinburgh and Glasgow). Paediatric Dermatology interacts with most other paediatric specialities and significant skin problems can be seen in children attending Haematology & Oncology, Rheumatology, Ophthalmology, Nephrology and Cardiology.

Quality of life can be severely impaired in children with skin problems who can have major psychological problems requiring input from clinical psychologists. There needs to be a significant increase in clinical psychologists with dedicated time to paediatric dermatology.

Regional and local Networked Services:

The current network of nurses for blistering conditions funded by DebRA is well established and provides a valuable service. The management of some other conditions could be significantly improved by networked services.

Atopic eczema:

The appointment of a network of specialist liaison nurses would allow for the provision of education and training to community nurses and the setting up of eczema clinics in primary care allowing delivery of a high class equitable service for all children with AE in the community by bridging primary & secondary care as piloted in Fife. Within this setting they could also identify those children with severe disease and young children with possible food allergy who should be referred to a Specialist Centre for further investigation & treatment avoiding inappropriate management.

Inclusion of skin disease within the GP contract would encourage this re-establishment of eczema clinics in primary care allowing delivery of care close to home whilst maintaining access to specialists.

Risks

Workload

In the past, the majority of atopic eczema has been managed in primary care and only 6% referred to secondary care. Many of these children were managed in eczema clinics by a practice nurse. With the introduction of the new GP contract and no financial incentive for managing skin disease many of these eczema clinics have been replaced with clinics to manage other chronic disease such as diabetes. This and the resulting loss of experience in the community may have contributed to the increasing number of referrals to secondary care and the service could potentially become overwhelmed by cases of eczema and other minor skin ailments such as viral warts.

The appointment of a network of specialist liaison nurses would alleviate this additional workload. Additional nurse funding would allow for the training required to

establish nurse-led minor surgery which would free consultant's time to reduce waiting times.

With the increase in the cut-off of referral age to 16 suggested by the National Framework (Kerr Report) Paediatric dermatology services in the Children's Hospitals are likely to be impacted significantly, particularly in relation to referrals for acne which affects 80% of 13-18 year olds. In addition severe acne may require treatment with isotretinoin which is an expensive drug much of it currently funded by the adult service.

This increase in workload will require additional manpower including medical, nursing, dietetic and psychology.

Specialist facilities

In Glasgow, Aberdeen and Dundee children are seen in a Children's Hospital / Department with all the additional facilities this provides (paediatrically trained staff, child friendly spaces, play leaders etc). In Edinburgh paediatric dermatology is predominantly sited within the adult department and an expansion of the service at the Children's Hospital would seem desirable. The British Society for Paediatric Dermatology and the British Association of Dermatologists, acknowledge the need for a small number of centres throughout the UK providing whole-time specialist Paediatric Dermatology services which would allow for the development of expertise and tertiary referral services.

Specialist training

Currently paediatric dermatology is a developing speciality. Increasingly children are seen in child friendly clinics in both Teaching and District General Hospitals. Paediatric dermatology services are currently delivered by adult dermatologists with a specialist interest. No formal training posts for sub-specialisation currently exist with the development of specialist experience dependant on individuals undertaking additional training as allowed by their deanery or taking honorary posts which are unfunded and as such prohibitive to many. With the shorter duration of training introduced by MMC sub-specialist training will be under further threat. This may in turn lead to difficulty in recruiting adequately trained dermatologists and delivering education and training in paediatric dermatology to dermatologists, general practitioners and paediatricians. Sub-specialist training should be encouraged by training flexibility and funded posts.

Specialist dermatology nurses are a valuable resource for children and their families. They should be encouraged to undertake courses in: child protection, nurse prescribing and nurse practitioner training as well as surgical training if possible. This would facilitate extension of the role of specialist nurses in care provision.

Key Recommendations	Timescale
<p>Services</p> <p><u>National</u></p> <ul style="list-style-type: none"> • A national food allergy service should be established for the management of children with multiple food allergies to facilitate training of staff and provide advice & support to regional dermatologists. • All children in Scotland with vascular anomalies should have access to a MDC if necessary. RHSC could provide a National Service for Scotland for Interventional Radiology for complex vascular lesions. <p><u>Regional/Local</u></p> <ul style="list-style-type: none"> • A national network of Liaison Nurses based in secondary care should be established to improve eczema management in primary care allowing delivery of a high class equitable service for all children with AE in the community. • Inclusion of skin disease within the GP contract would encourage the re-establishment of eczema clinics in primary care allowing delivery of care close to home. 	<p>2009</p> <p>2009</p> <p>2008/ 2009</p> <p>2008 / 2009</p>
<p>Staffing</p> <ul style="list-style-type: none"> • The appointment of specialist liaison nurses to provide a service to the community. Health Boards should review the Fife Nursing model for management of children with Atopic Eczema. • Regions to establish the shortfall of existing dietetic services for children with food allergies and address these • Regions to review access to Psychology for children with severe skin problems • Additional nurse funding would allow for specialist training to extend the role of nurses in care provision. • NHS GGC and Lothian to review Dermatology services locally to establish the effect of a raise in admission age to 16 years on referrals. 	<p>2008</p> <p>2008 /2009</p> <p>2008 / 2009</p> <p>2009</p> <p>2008</p>
<p>Facilities</p> <p>Health Boards to ensure that children are seen in a paediatric environment or that adult Dermatology and medical illustration departments within hospitals providing a paediatric service are child friendly.</p> <p>A move towards dedicated paediatric clinics should be actively encouraged and will require additional medical manpower.</p>	<p>Immediate</p> <p>2008/ 2009</p>
<p>Training</p> <p>Sub-specialist training should be encouraged by training flexibility and funded posts.</p> <p>Specialist Training in Paediatric Dermatology for Dermatologists, Paediatricians, GPs and nurses in dermatology, paediatrics and the community should be developed.</p>	<p>2009 / 2010</p> <p>2009 /2010</p>

2. Incidence and Scope of Paediatric Dermatology

2.1 Incidence

Skin disease is very common: Rook, the standard UK textbook runs to four volumes and suggests that there are over 2000 skin conditions (1) and over 3000 if rare complex genetic diseases with dermatological manifestations are included. (2)

Dermatology is an unusual speciality as it has both such a wide spectrum of diseases, and there is such a wide range of severity. 70- 80 % of consultations in adults are for skin cancer, acne, psoriasis, viral warts & other skin infections, benign tumours, leg ulcers & various forms of dermatitis. (3;4) Though the pattern in children has some similarities, there are also some distinct differences (table 1). In common with adults, viral warts are common but young children also commonly have molluscum, another viral infection, which is rare in adults unless immunocompromised. Bacterial infections such as impetigo are also commoner in children and may cause significant problems in nursery schools. Atopic eczema is common in both adults and children, though adults often have other forms of eczema such as contact dermatitis, seborrhoic dermatitis & stasis eczema, whereas the vast majority of children have atopic eczema. Other differences include psoriasis and acne, both of which are less common in the first decade of life. Acne tends to affect the older teenagers, though increasingly is affecting younger children now with the earlier onset of puberty. Some conditions of adults such as skin cancers and leg ulcers are rarely seen in children, whereas other conditions may present exclusively in children such as those affecting the neonate (Section: 6.5). Table 2 illustrates the range of skin conditions seen in children, although this list is not exhaustive.

2.2 Severity: There is also a huge range of severity. Some conditions in children are trivial such as benign pigmented naevi (moles) whereas others such as portwine stains may be a major cosmetic problem. Some cause considerable morbidity with chronic persistent itch (eczema) or pain (juvenile plantar dermatosis), but are rarely fatal. Others can be life-threatening if untreated, and may be fatal within days (toxic epidermal necrolysis), weeks (pustular psoriasis), months (sarcomas) to years (cutaneous T cell lymphoma). Even within a single condition the severity can vary significantly: atopic eczema can be very mild or can be very severe and though rarely fatal, can be life ruining. Other conditions such as infantile haemangiomas (strawberry marks) are common, affecting up to 10% of infants, and usually cause little morbidity, though a significant minority can cause serious complications and

rarely be life threatening. Even small haemangiomas may prove a major cosmetic problem in certain sites, such as the tip of the nose.

2.3 Quality of Life

Many skin diseases have a significant effect on the quality of life of the child & their family. Many vascular lesions such as capillary malformations (portwine stains) are a major cosmetic problem, a problem that is also shared with the large congenital melanocytic naevi. These can have a major effect on a child's self-esteem and can make them a target for cruel teasing at school.

Even moderately severe atopic eczema (AE) is distressing, because of the severe persistent itch, often worse at night. Itch seriously disrupts the child's sleep & also that of their parents, which is exhausting and can be destructive to family life. (5) Psoriasis can also cause significant problems, particularly if the face is involved and teenage acne can cause misery during adolescence. (6)

2.4 Clinical Practice

In practice, a comparatively small number of conditions are seen commonly, for example atopic eczema, skin infections (bacterial, viral, fungal, yeasts) & naevi (melanocytic, vascular), as illustrated in Table 1, which shows the diagnoses of children presenting to the Royal Hospital for Sick Children (RHSC) in 1997. Almost 70% of the children had one of 8 eight conditions: atopic eczema (32%), warts & molluscum (14.5%), various birthmarks (10.5%), psoriasis (3.5%), urticaria (3.0%), alopecia (2.2%) and acne (2.2%) A further 16 children (2.6%) presented with various benign 'lumps' and an additional 53 children had one of 22 less common conditions. 13 children (2.2%) presented one of the rarities, and in this group the rarities vary 10 from year to year. A similar pattern of referral was also seen in Wrexham. (7)

Although, the range & percentages will have changed somewhat over the last 10 years, with the earlier age of puberty & changing demographics (see below), the overall pattern remains very similar.

2.5 Change in demographics

In Glasgow, the increase in asylum seekers has impacted the Dermatology Service in Secondary care. Children may present with unusual fungal and viral infections. There is frequently a need for interpreters, and, on average most clinics would have at least one family where an interpreter is needed, this inevitably increases the length of the consultation. Interpreters are also needed for all the other health

professionals involved with the family such as: dermatology nurses, out-patient staff, paediatric dieticians, the allergy service and the ward staff, if the child needs admission.

2.6 Paediatric Consultations:

Dermatology consultations for children differ from those for adults. An adult patient usually comes alone, is the spokesperson, gives the history, can usually undress easily for examination and can give verbal consent to many simple procedures. So adults with many common skin conditions such as warts, acquired pigmented naevi, seborrhoeic warts and tumours such as basal cell carcinomas can be dealt with very rapidly.

In contrast, children require much longer as usually the parents are the main history givers and not the child. Examination takes longer as both undressing & dressing a child takes time, and both child and parents require explanations of procedures and treatment. In addition, procedures such as cryotherapy, which are painful may need time spent reassuring the child and multiple attempts at initiating what is a very quick procedure in adults. Others such as imaging for clinical photography may also need signed informed consent.

Even the 'mechanics' take longer as other family members (siblings & grandparents) or friends may also come and young children often come in push chairs.

There is also a great range in the types of consultation. Some conditions such as molluscum or acquired pigmented naevi need a single consultation, in contrast the chronic debilitating congenital diseases such as epidermolysis bullosa (EB), one of the severe blistering disorders need life time support. Children with mild to moderate atopic eczema may need only a single review appointment, while those children with severe eczema may need numerous appointments over many years. Some of these skin conditions are life ruining & children may become social outcasts without psychological help.

2.7 Adolescence & Transitional Care:

As children get older it is important that their views are heard and respected. Teenagers need to be given the chance of seeing the medical staff on their own, and should be encouraged to take over the responsibility of their skin condition and its care. Enabling this to happen involves sensitive consultation and education for the child, their parents or carers and for the adult Dermatologists who will be involved in

their ongoing care. This change-over should be done at a speed that is comfortable for the child and their family.

Timing and venue for Adolescent Clinics: The possibility of holding teenage clinics after-school hours should be considered to minimise the disruption to their education. Ideally these clinics would be situated in an environment tailored for teenagers and young adults and separate from main paediatric outpatients which cater for younger children.

Transfer of care: Children seen in paediatric hospitals will eventually have to transfer to the adult sector if they need continuing care. The development of appropriate transitional care, ideally with joint clinics involving both adult and paediatric dermatology staff is key to this. Transitional care is more than simply transfer of clinical responsibility and when done well should enable children with a long history of skin disease to pass into the adult service with ease. In practice this may be simpler in dermatology than in other chronic disease specialties as there are currently many Scottish Dermatologists practicing in both the paediatric and adult service.

2.8 Delivery of Care

Though many of the commoner conditions can be adequately handled in Primary Care, it is essential that more specialised conditions are referred to a Consultant Dermatologist, who will be aware of the full range of skin conditions so that less common, atypical or severe conditions can be appropriately investigated and managed.

2.9 Training in Dermatology

2.9.1 Generic As many skin diseases have systemic manifestations it is important for dermatologists to have a solid background in General Medicine. The foundations years have recently been modified with the new training programme: Modernising Medical Careers. Prior to this in the UK, the minimum entry requirements for Specialist Training in Dermatology were 2 years of General Professional Training and a postgraduate medical qualification of an MRCP (or MRPCH). Specialist training in dermatology requires 4 years in an approved post, with training in general dermatology & minor surgery in both teaching and district general hospitals. In addition, experience in all the sub-specialities is essential and these include contact dermatitis, photobiology, more complex surgery, sexually transmitted diseases, pathology and paediatric dermatology.

Trainees must also complete satisfactory annual reviews before he /she gains the Certificate of Completion of Training (CCT) and is accredited as a Dermatologist by the Postgraduate Medical Education & Training Board (PMETB).

Most consultant dermatologists practice as a General Dermatologist though increasingly, particularly in the teaching centres, they develop a special interest in one of the sub- specialities.

2.9.2 Training in Paediatric Dermatology

Experience in Paediatric Dermatology is an essential component of the specialist training dermatology programme. All general dermatologists are therefore equipped to treat most children presenting with skin problems. Additional training & /or experience in paediatric dermatology is needed for those consultants who want to develop a special interest in paediatric dermatology, particularly those working in a major teaching or tertiary referral centre.

Within the UK there are only five dermatologists who work exclusively with children: two at Great Ormond Street, one at Birmingham's Children's Hospital & two (1.4 WTEs) in Glasgow. As the British Society for Paediatric Dermatology and the British Association of Dermatologists, acknowledge the need for a small number of centres throughout the UK, which will provide whole-time specialist Paediatric Dermatology services, this number of 'supraspecialists' is likely to increase over the next decade. In addition, with the trend within dermatology to sub-specialise (eg contact allergy, surgery, photobiology) there will be an increasing number of General Dermatologists working with adults, who have paediatric dermatology as their Special Interest. All this has a direct bearing on the delivery of an effective safe service for Paediatric Dermatology.

It is essential that all children should have access to a specialised Paediatric Dermatology service as and when needed. However as the majority of skin disease is mild, it is appropriate that there are other pathways of care. Many skin conditions can be adequately managed in Primary Care. Of those referred to secondary care, children seen in a DGH may be seen by a dermatologist or a paediatrician, the pattern of referrals varies between centres. Like primary care, paediatricians tend to see children with infections, infestations and mild atopic eczema and only refer a proportion of these on to dermatology.

3. Manpower

There are currently 51 WTEs Dermatology Consultants serving Scotland (population 5,078,400) and the population is currently increasing. Overall this equates to 1 dermatologist per 100,000 population, but varies from 1:75,000 to 1:150,000. The target figure set in 1997 by the British Association of Dermatologists was one dermatologist for 85,000 population, though similar economies in Western Europe have 3-4 times as many dermatologists. Increased demand for skin cancer diagnosis and treatment has meant that the BAD target is an underestimate, but according National Workforce Planning Framework 2005, NHS Boards envisage consultant expansion in dermatology of ~0.5 per annum until 2015 to meet waiting times targets. Consultant expansion has certainly been directly or indirectly driven by the need to meet cancer or waiting times targets and an overall increase in consultant numbers will not of itself improve access to Paediatric Dermatology. Similarly, emphasis on increased consultant or other specialist services in the community may improve access to basic care but will not benefit dedicated children's dermatology services. (8)

About 90,000 new patients are seen in dermatology outpatients per annum in Scotland, or about 1,800 per consultant team. Paediatric referrals represent about 10% of these, and assuming twice the complexity (in clinic time and additional needs) implies that 0.2 WTE Consultant sessions are needed for 100,000 population, which equates to 10 WTEs Consultant sessions for Paediatric Dermatology in Scotland, with additional administrative time for co-ordination of a team bridging primary and secondary care. By May 2008 there will be 4 WTEs consultant sessions in teaching centres & only 0.6 WTE in district general hospitals, leaving a shortfall of 5.4 WTEs sessions in Paediatric Dermatology. At least part of this shortfall can be accounted for by those children who are currently seen in adult clinics. Nevertheless, children have different needs from adults. The move towards dedicated paediatric clinics should be actively encouraged and will require additional medical manpower.

Training for paediatric dermatology to be practiced as a subspecialty requires significant experience additional to the CCT in dermatology and expansion in

consultant services will need to be accompanied by measures to ensure adequate numbers of appropriately trained dermatologists.

Effect of raising cut-off age for paediatrics:

Greater Glasgow Health Board intends to raise the cut-off for referral to RHSC from 14 to 16 years. This will have a significant effect on the number of referrals to paediatric dermatology and will also increase the need for phototherapy for psoriasis and isotretinoin for acne. Isotretinoin is both a costly drug and needs more resources to monitor the side effects of the drug and implement the pregnancy prevention programme.

Consultant Sessions

As well as direct clinical care, medical time is needed for:

- Training: clinical & tutorials etc for
 - Dermatology trainees
 - Paediatricians
 - General practitioners
 - Nurses
 - Other health professionals: dieticians
 - Undergraduates
- Clinical Governance
- Medical Audit
- Appraisal
- Research

Research: To improve patient care & to increase our understanding of disease, it is important to promote research. Paediatric dermatology also lends itself to linking basic science with the patient such as the ground breaking research on the filaggrin gene in Dundee University, in which NHS Tayside, RHSC and other centres are continuing to collaborate.

4. Common conditions and current management

4.1 There are a number of common conditions. Many of these such as the infections and mild eczema can be adequately dealt with in primary care, some need referral to secondary care & a minority need referral for specialised care as discussed in Section 6.

Common conditions include:

- Atopic eczema
- Haemangiomas

- Transient neonatal disorders

4.2 Atopic Eczema (AE)

Atopic eczema is a common condition affecting up to 20% of children in the UK.(9) In common with other atopic diseases such as asthma the incidence has increased significantly over the last 30 years. QRESEARCH estimated that 5.8 million people in England are affected by eczema and 1 in every 74 people was newly diagnosed in 2005. (10) Six to seven year olds in the United Kingdom have the highest incidence of eczema amongst the Western European countries surveyed in the ISAAC study, with the prevalence increasing from 13% to 16% over a period of approximately five years. (9)

Though there are recognised diagnostic criteria for AE (11;11;12) the diagnosis is usually straightforward. In most patients the disease is mild and can be managed in the community (13;13); one study showed that only 6% of the children with AE were referred to secondary care. (14) Though secondary care sees only the tip of the iceberg, atopic eczema is the single commonest condition presenting to paediatric dermatology, accounting for about 25% of the referrals. Severe eczema is a distressing condition which seriously impairs quality of life for both the child and their family. (5).

Cost of Atopic Eczema

Atopic eczema affects 15- 20 % of children in the UK and has been increasing in prevalence over decades. (15) Any costs involved with its management therefore have a significant financial burden on parents of affected children and on the National Health Service (NHS). Although prescriptions are free to children, parents often pay for extra emollients, expensive washing powders, alternative therapies, special clothing and anti-house dust mite measures such as bedding and flooring. Emerson et al (16) estimated that the annual total cost in 1995 to UK families of treating children < 5 yrs with AE was £17 million and in Australia this was Aus\$480, \$1712 and \$2545 for children with mild, moderate & severe eczema respectively in the same year. (17) Costs are often hidden and include reduced capacity at work in exhausted parents and loss of earnings in parents who are unable to work as a result of their child's eczema (reported as 28% in an Australian study). (17) In addition there may be loss of potential in many children who miss school as a result of severe disease. In a study in Lothian, a mean of 17 school days were missed in

children with atopic eczema over a two month period. (13) Costs to the NHS are also considerable and include GP and health visitor consultations (often multiple), prescribing costs, hospital visits & admissions. For children < 5 yrs the annual cost to the NHS was £30 m in 1995 (16) and in Lothian the mean 2 month cost to the NHS was £18.72 per patient under 2 years and £10.86 per patient aged 2-15 years. As cost has been shown to correlate with severity, the small proportion of these children attending hospital will be the most 'costly'. Hospital costs include consultation with consultant and nurse specialists, investigations and in-patient treatment. In the US the cost of treating children annually was estimated as US\$364m in the early 1990s (18) and recently estimated to cost a total of Cdn\$1.4 billion in Canada (19). Annual treatment costs in Germany have been estimated at US\$911, US\$ 417 and US\$ 164 for children with mild, moderate and severe eczema respectively (20) and in Italy to be 1254 Euros (21). This disease therefore has a significant financial burden for both families and for the NHS. Education of carers and investigation within the hospital environment leads to better compliance and therefore less wastage of creams, better control of disease severity and, as a result, less need for more expensive therapies.

Because AE is so common, it also places a heavy load on resources in secondary care. Children with AE need a longer first consultation and require more review appointments than children presenting with other conditions such as alopecia, naevi etc. Some families also come with a number of concerns: these often centre round a fear of topical steroids and a desire to avoid these and to seek alternative methods of treatment such as homeopathy and / or herbal medicine. Their steroid phobia may have come from family, friends, health food shops and the popular press, though, more worryingly this sometimes comes may from other health professionals including General Practitioners and pharmacists. There is a real need for re-education to correct this 'misinformation'. Some parental concerns can be addressed during the initial consultation, and be reinforced again later by the Specialised Dermatology Nurses.

Nurses play a key role in the management of atopic eczema. They give general advice about the condition, the avoidance of triggers and the correct use of topical steroids. They also give practical demonstrations of how to apply the treatments, which is very necessary as families may be given 6-8 different topical preparations to use. Nurses also see families for review in independent nurse-led clinics, which would include review of new patients to make sure the child is improving and the

parents are coping and also children needing an urgent review. Nurses in some departments such as RHSC offer a hotline advice service to families for telephone advice or for urgent reviews.

In addition, some of the younger children with possible food allergy need appropriate investigations including blood tests and skin prick tests (SPT), which requires input from the out-patient Staff and the allergy team. If food allergy is a real possibility, children may need a trial of an appropriate elimination diet and require input from Paediatric Dieticians. (Section: 10.1).

If eczema deteriorates unexpectedly in the older groups, the possible development of allergic contact dermatitis should be considered and patch testing arranged if necessary.

Some of the teenagers and toddlers – the terrible twos' may have significant problems with compliance and families may be considerably helped from input from Clinical Psychology (Section 10.2). The older group may also have a miserable time at school which can lead to poor attendance & even school refusal. Help from Clinical Psychologists is needed to improve their self-esteem and give them coping strategies.

Management:

- **Guidelines** for the management of AE in children under 12 years have recently been developed by NICE (22). NICE have previously published guidelines on the frequency of topical steroid application (23) and the use of the immunomodulators in eczema (24).
- Simple emollients may be all that is required in the milder cases,
- The main stay of treatment in the moderate to severe cases is the sensible use of topical steroids of appropriate strength.
 - All families need a management plan for maintenance treatment
 - All families need a plan to cope with flares of the condition
 - All families need rapid access to medical / nursing staff if the coping strategy fails.
- The immunomodulators (topical tacrolimus and pimecrolimus) may offer an alternative for severe eczema that has failed to respond to topical steroids and may be useful in certain sites such as round the eyes where topical steroids are relatively contraindicated (24).
- The management of AE is intensive and is a major user of nursing time for:
 - Education about atopic eczema, its triggers & topical steroids

- Demonstration of application of treatments & bandaging techniques
- Avoidance of trigger factors e.g. irritants such as fragranced bath oils & washing powders & domestic pets

Referral of children with atopic eczema to secondary care is needed:

- If there is diagnostic doubt
- Severe atopic eczema
- Failure to respond to treatment with mild / moderate steroids as per NICE guidelines
- Complications: severe bacterial infection
 extensive Herpes Simplex virus infections

Improved care for Children with AE

- Management of AE in the community could be significantly improved by a network of Specialised Dermatology Liaison nurses bridging primary & secondary care

Recommendation of Working Group:

- Establishment of Specialised Dermatology Liaison Nursing Network (See 8.5)

4.3 Atopic Eczema & Food Allergy

- Young children (< 1-2 years) with AE may also have food allergies
- Food allergies which may be the 'driving force' behind the AE.
- These children need to be seen in a department that has the expertise to investigate & manage food allergy (Section: 6.2).

4.4 Haemangiomas & other Birthmarks (Congenital Pigmented Naevi & others)

Haemangiomas:

Most haemangiomas regress spontaneously over a period of years and run a benign course, leaving little in the way of a persistent cosmetic problem.

Management at Initial Visit:

- Assessment of any impairment of any vital function such as the airways or eyes (6.3)
- Explanation: Natural history & likely prognosis
- Clinical photography is essential to monitor progress

Follow-up:

- Clinical assessment v initial photographs

- Serial photography
- Reassess after spontaneous regression to ensure there is no significant persistent cosmetic problem

Requirements: A good Medical Illustration department on site is essential (table 5).

After the initial visit & first review, many children with haemangiomas can be monitored annually with clinical photographs.

A minority of haemangiomas can cause serious problems and these children need referral to a specialised unit (Section 6.3)

Recommendation: A child friendly Medical Illustration department should be on site.

Congenital & Acquired Pigmented Naevi

The management & initial follow up is very similar to the haemangiomas. However, as the risk of malignant change is small, many families can monitor the smaller naevi themselves. The family is given a photocopy of the naevus, told what changes to look for, asked to check it two or three times a year against the photograph and to have a low threshold for asking for review.

4.5 Skin problems in neonates:

These include common conditions such as:

- Transient dermatoses of neonate:
 - Erythema toxicum neonatorum
 - Milia / Miliaria
 - Sebaceous gland hyperplasia

Although these conditions are mild and transient, they can appear very worrying to the parents. It is important that these infants are seen so that new parents can be reassured about the benign nature of these conditions.

- Vascular: harlequin change

In this condition the infant develops a colour change over half the trunk with a sharp cut off at the mid-line. This is a harmless physiological vascular change, though for new parents, can give rise to extreme distress that the child has a serious underlying problem.

However, as much of neonatology is specialised and, because the conditions are rare, there is a need for dermatologists with a special interest in paediatric dermatology to have an expertise in this field. (Section 8.4)

4.6 Vulval disease:

Some children with simple vulvitis can be managed by the local team whereas some of the more complex conditions, particularly if sexual abuse is an issue need, to be referred to a specialised unit (6.7).

5. In-patient Treatment

Paediatric Dermatology is predominantly an out-patient speciality. However it is essential to have access to in-patients beds for children with:

1. Atopic eczema

AE is the commonest skin condition in children to require in-patient treatment & is needed for:

- Acute flare of eczema unresponsive to usual 'rescue' treatment
- Infected eczema requiring intravenous antibiotics
- Widespread herpes simplex
- Family exhaustion and inability to cope which can be compounded by the effects of poor social circumstances and social isolation.

2. Psoriasis: extensive guttate or plaque psoriasis unresponsive to outpatient treatment

3. Infections:

Bacterial:

- extensive impetigo - infectious and distressing for parents
- staphylococcal scalded skin syndrome - very worrying for parents as the skin shears off, leaving denuded areas. Rarely may be life threatening
- Viral: severe herpes simplex infection
- Fungal: Scalp: acute kerion – needs urgent dermatological assessment to avoid unnecessary surgery

4. Others

- scabies & head lice: unusually extensive or heavily secondarily infected
- epidermolysis bullosa – severer types often with 2° infection and complications such as oesophageal strictures.

Care of Inpatients

- Shared care with the paediatricians is the optimum approach
- General care by paediatric nurses with input from dermatology nurses
- Access to specialised services e.g. pain team , dietetics, imaging
- Support from play leaders
- Schooling

In-patients in other Specialities

- Some children have associated skin conditions e.g.
 - children with asthma may also have AE
- Children in all specialities may have or develop an acute skin problem e.g.
 - Adverse drug rash
 - Skin manifestations of medical diseases eg.rheumatology (section 7:3)
 - Graft versus Host Disease in Bone Marrow transplant patients

6 Specialised Services

6.1 Specialised Dermatology: (table 3)

Introduction: Because of the wide range of severity of even the common conditions, children who have severe or atypical skin problems need to be referred to a specialist unit. These include children where there has been problems with the diagnosis & / or management; those who need specialised investigations; children with multisystem disease & needing a multidisciplinary approach and children with rare problems such as cutaneous T cell lymphoma (2).

Atopic Eczema This would include young children with possible food allergies (see below), severe eczema that has not responded to conventional treatment and those in whom second-line treatment is being considered. Severe eczema may affect growth & development & assessment by a paediatric endocrinologist may be necessary. Severe eczema can also have profound psychological effects and may lead to a significant loss of schooling.

6.2 Food Allergy

The importance of food allergy has recently been highlighted by a Report from the House of Lords published in 2007 (25). Children with atopic eczema are at increased risk for developing Type 1 allergy such as peanut allergy with the potential risk of anaphylaxis. However food allergy in infants with AE may not be a simple type 1 reaction which would cause immediate urticaria & angioedema, but be a more complex late IgE reaction involving other cells such as T cells, Langerhans cells and cytokines (26). Food allergy may be the driving force behind atopic eczema in children (27;28). A randomized study in Glasgow found that egg exclusion in young children with atopic eczema and sensitivity to eggs significantly improved the eczema (29). Another study found 23 of 63 children with atopic eczema had clinical food hypersensitivity, a prevalence rate of 37% (30). At RHSC in 1998 70% (31/44) infants had a raised specific IgE to eggs, raising the possibility of egg allergy. If the allergen is correctly identified (commonly milk & eggs) and eliminated from the diet the eczema significantly improves and may clear completely. The gastro-intestinal tract may also be affected in some of these food allergic children leading to a 'leaky' gut, and a failure to thrive in the more severely affected children. Paradoxically a restricted diet in which the allergen has been eliminated, can lead to improvements in the height and weight, presumably because of improved absorption.

Reactions to food in atopic eczema can be immediate (within 2 hours), delayed (24-48 hours) or be biphasic (early & late). Though there is an increased risk of food allergy with increasing severity of eczema (31), severity is probably more related as to how much and how often the allergen is ingested. If little is eaten, the AE may be relatively mild. If food allergy is suspected, referral for specialist investigation & management is necessary with input from a paediatric dietician.

Food Allergy service at RHSC: established in 1992. It is now staffed by:

- Dermatologist with expertise in food allergy (0.4 WTE)
- Clinical Assistant: 1 session
- Paediatric Dietician: 0.4 WTE
- Food Allergy Sister: 2 Clinics (+ part of Allergy Team)

In addition to this specialised dedicated service, the other dermatology consultants also manage young children with AE and food allergy, who also require additional dietetic support.

Paediatric dietician (see 10.2) is essential to ensure:

- the allergen is completely excluded from the diet
- the diet is nutritionally adequate
- the diet is interesting & varied as far as the dietary restrictions will allow

Other Support Requirements:

- Diagnostic Service:
 - Blood tests: Full blood count including eosinophil count
Circulating total & specific IgE
 - Skin Prick Tests
 - Food challenges
- Clinic nurses for height & weight monitoring

Food Allergy in other centres: Different centres may have different patterns but will require similar staff & facilities.

Recommendation of Working Group:

- Establishment of a National Food Allergy Network for young children with atopic eczema

6.3 Complicated vascular lesions

- Haemangiomas
- Vascular malformations

6.3.1 Infantile Haemangiomas

- Most haemangiomas regress spontaneously over a period of years, run a benign course and leave little in the way of a persistent cosmetic problem. However a minority can cause serious problems such as:
 - rapid growth can compromise essential vital functions such as vision & respiration
 - ulceration causing considerable pain and morbidity
 - persistent cosmetic problems requiring plastic surgery and /or laser treatment.
- Many of the complex lesions require a multi-disciplinary approach with input from other specialists
 - ITU for intubation and / or tracheostomy if airway compromised
 - Ophthalmology if vision is threatened

- Radiology for imaging (Ultrasound & MRI scans)
- General Surgeons for some complicated haemangiomas
- Plastic surgeons for cosmetic surgery

Benign disseminated haemangiomatosis is a condition with numerous small cutaneous haemangiomas that may also involve other internal organs such as the liver and which can cause serious complications including high output cardiac failure

Management with high dose systemic steroids: may be required for children with complex vascular lesions if:

- the haemangioma is interfering with vital functions such as the airways or the eyes
- a coagulopathy has complicated some of the rarer vascular lesions e.g. tufted angioma & Kaposi's haemangioendothelioma

High dose systemic steroids are not without risk. These children require special monitoring until steroids are withdrawn and normal adrenal function is restored.

6.3.2 Vascular Malformations: these include:

- Capillary Malformations
 - Portwine stains
 - Sturge-Weber Syndrome (± Epilepsy, Developmental delay)
 - Klippel-Trenauny Syndrome (+ limb hypertrophy)
- Venous Malformations
- Arterio-venous Malformations (AVM)
- Lymphangiomas: ± internal involvement
- Mixed e.g. capillary & lymphatic malformations

Capillary malformations are relatively common and may be a major cosmetic problem. They may also be associated with other abnormalities including glaucoma, epilepsy & discrepancy in limb size.

Venous malformations can be both unsightly & can be painful.

Arterio-venous malformations can cause significant discrepancies in limb size and other abnormalities.

Investigations may need specialised imaging such as:

- Soft Tissue Ultrasound ± Doppler

- MRI
- Angiography

Management:

Some conditions may not be amenable to treatment; others may require a multi-disciplinary approach with input from other specialists for:

- Laser unit: Pulsed dye & resurfacing laser
- Surgery (± Sclerotherapy)
 - Sclerotherapy may reduce size of lesion and improve surgical outcome.
 - Surgery is potentially hazardous in AVMs unless completely excised, as there is a risk that recurrence will cause gross hypertrophy of the affected part.
- Orthopaedic surgeons when limb growth discrepancy occurs
- Orthotics / lymphoedema service for compression garments

Recommendations of working party:

- Children with complex vascular lesions should be seen in a multidisciplinary clinic (RHSC Glasgow & Dundee)
- Children requiring interventional radiology should be seen at RHSC
- A few children with very complex lesions (probably less than 1-2 /year) may need referral to Great Ormond Street, London

6.4 Extensive pigmented naevi & other congenital naevi.

There are three associated problems:

- Significant cosmetic effect needing plastic surgery or laser treatment, although lasers are less effective for the pigmented naevi
- Giant pigmented naevi may have an increased risk of malignant change
- Investigations: some may be associated with neurodevelopmental abnormalities which require input from paediatric neurologists & require specialised imaging

6.5 Neonates

Neonatology is a specialised field within paediatrics and similarly there is a need for paediatric dermatologists to have an expertise in this field. Many of the dermatological conditions of the neonate are rare & some need specialised nursing in a Special Baby Unit or in Paediatric Intensive care. These infants need close collaboration between the neonatologists (medical & nursing staff) and the

dermatologists (medical & nursing staff). The babies with the severer form of epidermolysis bullosa also need input from the DEBRA team (a supra-regional service).

The dermatological conditions of the neonate include:

- Epidermolysis bullosa (EB - the rare blistering disorders) :
 - Simplex including Dowling- Meara
 - Dystrophic: Recessive (severe) & Dominant
 - Junctional :
- Congenital Ichthyoses including the rare life threatening conditions such as:
 - Collodion baby
 - Harlequin foetus
- Genodermatoses e.g. incontinentia pigmenti, neurofibromatosis
- Congenital naevi
- Vascular anomalies

6.5.1 Severe form of Epidermolysis bullosa (EB)

Neonates with this condition have fragile skin and develop extensive blistering at sites of slight trauma which causes shearing of the skin. Normal activities such as lifting can cause extensive blistering and children need nursing on special padded mats. Parents need education on handling and skin care and be shown how to burst blisters and dress the denuded areas. Dressings are painful & children need adequate analgesia supervised by the pain team and opiates are often needed. Nutrition is often poor and many of these children need enteral feeding (Section 10.1).

Over 98% of children with Junctional EB die within 2 years, usually from septicaemia or asphyxiation as the blistering also affects the mucosal surfaces. Those with severe recessive dystrophic EB may live into the fourth or fifth decades of life, but are severely handicapped with loss of function of hands (& feet) because of fusion of the fingers (& toes) secondary to the chronic blistering. Squamous cell carcinomas may complicate the chronic scarring of the skin and can occur as early as the second decade of life and metastatic carcinoma may be the cause of death.

6.5.2 Severe Ichthyoses including

- Collodion baby
- Harlequin foetus

A collodion baby is encased in a thick tight membrane, which may affect the eyes & digits. These infants need to be nursed in a humidified incubator in a Special Care Baby unit and covered with a greasy moisturiser. Input from ophthalmologists is necessary to protect the eyes & surgical excision of the tight bands may be necessary. The harlequin foetus is a more severe grotesque form which is very distressing for the parents. This condition is often lethal though may respond to treatment with systemic retinoids and intensive nursing care & life support.

Ichthyosis is a lifelong problem, and the severe forms causing extreme dryness & heavy scaling of the skin, needing regular applications of moisturisers throughout the day. These patients may justify systemic treatment with oral retinoids. Even though this drug is teratogenic (which persists for 2 years after the drug is stopped), it still may be the preferred option for young women who may become very depressed by their appearance, especially in their teenage years.

6.6 Genodermatoses are inherited conditions & includes:

Incontinentia Pigmenti is characterised by blistering in the neonate, followed by scaling & in later life by pigmentary change. There are associated abnormalities in the eyes, the teeth, nervous system & other organs.

Neurofibromatosis (NF) is a condition in which the cutaneous signs (café au lait spots) are one of the earliest clinical features. Later signs include axillary freckling, soft tissue tumours (fibromas) & Leisch nodules in the eye. NF patients can also develop hypertension and other complication includes a risk of malignant change in the fibromas.

Tuberose sclerosis: again the cutaneous signs may be the first clue to the diagnosis. But these children may also have developmental delay & other systemic signs.

6.7 Childhood Genital disease:

Genital problems can cause both physical & emotional problem for the child and the parents. Genital warts can raise complex child protection issues as in adults, genital warts are sexually transmitted. Though this is much less common in children, the possibility should always be considered.

Simple vulvitis in young girls can cause similar anxieties for the parents, though this condition is usually relatively benign & clears within a few years. A rarer condition, lichen sclerosis, is associated in adults with an increased risk of malignant change if the condition proves a persistent problem. Though in young girls the condition can go into remission, they need to stay on long term follow-up over a period of years.

6.8 Specialised Treatment: Phototherapy

Some children with psoriasis and atopic eczema may need second line treatment with UVB phototherapy. The number of children treated in Scotland courses between 2006/ 2007 is shown in table 4. Because of the long term risk of increased skin cancer, there is a greater reluctance to use UVB in children. UVB treatment therefore is usually reserved for children with severe eczema or psoriasis that has failed to respond to intensive topical treatment as an outpatient or as an inpatient.

UVB phototherapy is not without hazard, unless properly supervised there is a real risk of burning. Treatments should be carried out in departments where phototherapy is used on a regular daily basis as in the adult units. This practice should be continued for the foreseeable future unless, raising the referral age to 16 significantly increases the number of teenagers needing UVB phototherapy.

7. Interdependence with other Specialities (table 5)

For effective management many conditions need liaison with other specialities for their investigation & / or treatment. This can range from paediatric input into the overall care of dermatology in-patients, to the pain team (ulcerated haemangiomas and the severe blistering disorders) to multidisciplinary clinics.

7.1 Combined atopic eczema clinics: A significant number of hospitals (Teaching & DGHs) in secondary care run these. Many will also have concurrent nurse-led clinics running in parallel, for teaching new eczema patients (from the dermatology clinics) and also to see their own review patients.

Others health professionals at topic eczema clinics may include

- Dermatologists
- Dermatology & Allergy Nurses
- Paediatric Dieticians
- Paediatricians / Allergists
- Allergy service: SPT
- Care Assistants: height & weight

7.2 Multidisciplinary clinics (MDC): held in some of the Teaching Hospitals (table 7)

Severe Blistering Diseases including children with epidermolysis bullosa (EB) and bullous ichthyosiform erythroderm (BIE) who may require input from:

- Dermatologists
- Specialised dermatology nurses
- Specialised DEBRA nurses (supraregional EB nurses)
- Pain team

- Paediatric endocrinologist & bone metabolism specialist
- Orthopaedic surgeons
- Dental surgeons
- Dieticians
- Occupational therapy (bathing aids, splints, wheel chairs)
- Psychology
- Vascular & Complex Naevi Clinic:
 - Dermatologists
 - Plastic & Laser Surgeon
 - Radiologist: Imaging
 - Interventional Treatment – sclerotherapy
 - Pain team
 - Orthotics
- Genetics:
 - Dermatologists
 - Geneticists
- Connective Tissue Disease Clinic
 - Rheumatologist
 - Dermatologist
 - Nephrologist
 - Immunologist

7.3 Multi-system diseases:

7.3.1 Connective Tissue Diseases

- Systemic Lupus Erythematosis (SLE) ,
- Mixed Connective Disease
- Dermatomyositis.

These diseases can present with predominantly cutaneous features to dermatology or with muscle or joint symptoms to rheumatology, and more rarely to other specialities such as nephrology or neurology. Photosensitivity & cutaneous signs may be helpful diagnostically & the skin is an accessible site to biopsy for histology. Topical steroid treatment may also be a useful either alone or as an adjunct to systemic treatment. Most of these patients also need adequate photoprotection with high factor sunblocks and sensible sun advice.

7.3.2. Psoriatic arthropathy can affect both the skin & joints and is best managed jointly by the rheumatology and dermatology.

7.3.3 Neurocutaneous conditions such as:

- Incontinentia Pigmenti
- Tuberose sclerosis
- Neurofibromatosis

- Oculocutaneous albinism
- Rarities such as Goltz syndrome

This group may need input from dermatologists, paediatricians, neurologists & ophthalmologists and may need specialised imaging.

8. Current services: Who sees the patients?

Children with skin disease may be seen by:

- General Practitioners (GPs):
 - some with a Special Interest in Dermatology (GPWSIs)
- Paediatricians
- Paediatric Surgeons
- Dermatologists
- Dermatologically trained Nurses

8.1 General Practitioners Many skin problems can adequately be diagnosed & treated in general practice such as skin infections, mild to moderate eczema, benign acquired pigmented naevi and small haemangiomas. It has been estimated that up to 10-15% of consultations in General Practice relate to a dermatological problem (32) Though the majority of GPs have little or no training in dermatology, despite this being a high part of their workload.

Topical preparations: Many GPs commonly prescribe topical steroid / antibiotic preparations such as hydrocortisone / fusidic acid. Topical antibiotics used in this way leads to a significant increase in resistant strains of staphylococcus aureus which is highly undesirable and education is needed to change this practice.

Primary care eczema clinics: Previously some GPs and/ or nurses ran eczema clinics in the community. With the new contract, eczema clinics are no longer remunerated, and have been largely been discontinued to be replaced with clinics that attract funding such as those for asthma & diabetes.

Referrals: Some general practitioners are also reluctant to refer children with eczema, even those with relatively severe disease. This issue must be addressed so that the overall care of all children with eczema is improved. This could be facilitated with a Network of Specialised Dermatology Nurses (8.5).

Recommendations:

- Improve training of GPs
- Reinstate funding for eczema clinics in primary care

- Provision of a Nursing Network

8.2 Paediatricians

In the larger centres, such as the Royal Hospital for Sick Children (RHSC) Glasgow, the majority of children with skin problems are seen by dermatologists. Paediatricians see some children with skin problems where the skin problem is an 'incidental' finding such as eczema in an atopic child with asthma. Paediatricians also see and treat children who present acutely to secondary care with skin problems, again usually infections (impetigo, HSV), infestations (scabies or head lice with 2° infection) or atopic eczema. They would refer those children where the diagnosis was uncertain, those who needed continuing dermatological review and those needing input from dermatology nurses.

In contrast, as the questionnaires revealed, in many other hospitals, particularly the District General Hospitals, paediatricians see significant numbers of children with skin problems (some >100 annually), though the figures may not be representative as relatively few Paediatricians returned the questionnaires. Paediatricians see a similar range of conditions as primary care, predominantly infections and mild to moderate eczema. Most would treat these children themselves & would only refer some of them on to Dermatology.

Few paediatricians in either Scotland or England receive training in dermatology and this issue should perhaps be addressed. There is only one course in the UK run in Birmingham, which aims to equip Paediatricians to treat common skin disorders, to recognize rarer ones and when to refer to Dermatology (table 9).

Recommendations of working party:

- To improve dermatological training of paediatricians

8.3 Paediatric Surgeons

Children with 'lumps & bumps' may be referred to the paediatric surgeons with conditions such as haemangiomas, acquired and congenital naevi, sebaceous cysts, dermoid cysts, pyogenic granulomas. Most will simply excise the lesion if appropriate but will refer those that need monitoring, such as pigmented naevi to dermatology.

8.4.1 Dermatologists

In *District General Hospitals* children with skin problems are seen by general dermatologists. As training in paediatric dermatology is an essential part of the training of all dermatologists, they are equipped to diagnose & treat most children they see, though will refer on those whose diagnosis is unclear, those with severe disease and those who require one of the specialised services.

8.4.2 Dermatologists with a Special Interest in Paediatric Dermatology

Increasingly, both in DGHs & in Teaching Centres, one or more of the consultant dermatologists within the department develops a special interest in paediatric dermatology and sees the majority of the children. This trend is seen in the DGHs as in Clyde for example. The trend is more marked in teaching hospitals as in Aberdeen, Dundee & Edinburgh where there is one Consultant Dermatologist (Aberdeen & Dundee) or two (Edinburgh) who have a special interest in Paediatric Dermatology and see most of the children. In Glasgow, there is a department of Paediatric Dermatology at the Royal Hospital for Sick Children, which sees most of the children with skin disease seen in Glasgow & some from the surrounding area.

8.5 Nurses

Dermatology Nurses

Specialised dermatology nurses are key figures in paediatric dermatology, particularly in the management of atopic eczema. All dermatology departments have specialised dermatology nurses, though not all have paediatric training. In most departments, with the exception of RHSC, dermatology nurses see both adults and children. The ideal would be for all nurses treating children to have experience and / or training in paediatrics. However all specialist dermatology nurses have expertise in applying treatment and in the care of atopic eczema and, most are more than capable of treating children.

Nurse- led clinics: Nurses run nurse-led clinics in a number of centres including: Glasgow, Dundee, Edinburgh, Fife, Forth Valley & Lanarkshire. In most centres nurses see only review patients, though some see new patients with consultant cover such as paediatric clinic in at RAI and the food allergy clinic at RHSC. In both Edinburgh & Fife, nurses see new patients independently and receive direct referrals from primary care.

Nurse prescribing: Nurses in some centres (Glasgow, Dundee & Fife) have done the nurse prescribing course which is a valuable asset, as it enables nurses to prescribe

antibiotics for infected eczema and modify topical treatments for eczema and psoriasis without medical input.

Scope:

Although atopic eczema is the commonest condition seen and treated by the paediatric dermatology nurses, they also see and treat children referred by the dermatology medical staff with:

- Psoriasis (with nurse prescribing dithranol strength can be modified))
- Ulcerated haemangiomas for dressings
- Leg ulcers for dressings
- EB children: dressings & review

Other activities:

- Hot-line for telephone advice &/or early review (RHSC)
- Cryotherapy clinic:

At RHSC the nurses run a cryotherapy clinic for the treatment of warts. A wart clinic is run 2 or 3 times a year by the medical staff to confirm the diagnosis, as some referrals are incorrectly referred as warts such as Spitz naevi. Subsequently the nurses see the children every three weeks for repeat liquid nitrogen as needed (up to a maximum of 10 treatments).

- Minor surgery: assist dermatologists (RHSC) *.
- Patch testing with consultant cover *
- Phototherapy (within adult units)

** In the adult sector some nurses do minor surgery (punch biopsies & curettes) & patch testing independently on adult patients.*

As an illustration, the activity of the dermatology nurses at RHSC is shown in table 6. These figures do not include the hot-line telephone advice calls. Of note is the relatively high default (DNA rate), but these include the cryotherapy patients who do tend to have a high default rate.

Community Dermatology Liaison Nurse Service

The service was introduced in Fife in 1998. Based in secondary care, liaison nurses (2 WTEs) are accountable for delivery of dermatology services at the interface of

primary and secondary care. Each does one paediatric dermatology clinic with consultant cover and also a review /drop in session. Both adults and children are seen, with an approximate 30/70 split between adults & children, and most children have atopic eczema. The nurses work closely with GPs and Health visitors (HVs).

A dermatology record sheet has been developed to go into the child's Personal Child Health Record, which is presented by the parent at any dermatology consult, to aid communication between professionals and to provide an accurate and up to date record of treatments prescribed and used.

This is a useful model and could form a prototype for the development of a national network of specialised dermatology nurses for the treatment of atopic eczema in children, linking community and secondary care. Initially the service could be piloted in two of the main centres in Glasgow and Dundee &, if successful extended to Edinburgh and Aberdeen and other interested centres. The liaison nurses should be based in secondary care with strong links to consultant dermatologists, though most of their work will be in the community. In addition, they could also train nurses, health visitors etc in Primary Care so the expertise can be cascaded out.

The majority of children with atopic eczema could be managed in the community. However not all GPs refer appropriately, and some do not refer even quite severely affected children with AE. Within the network it should be possible to identify children with more severe eczema &/or food allergy who should be referred to secondary care.

A nursing network closely linked to the dermatologists would ensure that all children with atopic eczema:

- received a high calibre diagnostic & management service
- all children had equity of care

Manpower: A network of nurses would require an increase in manpower. Fife has 1.4 WTEs nurses providing a service for children. Extrapolating from these figures, Glasgow would need an additional 2.5 WTEs nurses, and to provide a networked service nationwide for Scotland a total of 12WTEs nurses would be required.

Recommendations of working party:

- The establishment of a National Network of Specialised Dermatology Nurses

- An increase in the number of dermatology liaison nurses would be needed

9 Regional Services for Paediatric Dermatology

9.1 Teaching Centres: (table 7)

9.1.1 Glasgow & Greater Glasgow Health Board (GGHB):

Staffing: The Royal Hospital for Sick Children (RHSC) is staffed by five Consultants (2.2 WTEs), an Associate Specialist (0.6 WTE). Of the five Consultants, two work exclusively at RHSC (1.4 WTEs) and three Consultants (0.8 WTE) have split posts with the adult sector: two with GGHB and one with Ayrshire. At RHSC support medical staff include a Staff Grade (0.6 WTE) & a Clinical Assistant (1 session). Specialist Registrars (SpRs) rotate through RHSC as part of their training programme.

Other Health care Professionals: include three Specialised dermatology Nurses (2 WTEs), a Food Allergy Sister (2 dermatology clinics & Allergy service), Paediatric Dieticians (see below) & a Clinical Psychologist (2 sessions).

Royal Hospital for Sick Children (RHSC) is both a secondary & tertiary referral centre for children with skin problems for GGHB & its surrounds. RHSC is also the Scottish Centre for Haematology & Oncology, Renal transplantation, Rheumatology, Cardiac Surgery & Paediatric Intensive Care and these complex patients may develop skin problems such as Graft versus Host Disease, adverse drug reactions, or the cutaneous signs may be a diagnostic feature of the disease as in the connective tissue diseases (rheumatology).

As a Children's Hospital, the hospital is child friendly with child friendly waiting areas & consulting rooms and with paediatrically trained staff: nurses, imaging (X-ray, U/S, MRI) play leaders, school teachers and so on). Specialist services are also readily available, for example from paediatricians, pain team, dental surgeons.

RHSC Referrals: In the year 2006/2007, 1757 new referrals were seen at RHSC. Most of the referrals come from within Greater Glasgow (1493) and 264 came from other Health Boards mainly Lanarkshire (144) and Argyll & Clyde (79).

In the adult sector, the North Glasgow Trust, (Western Infirmary [WIG], Glasgow Royal Infirmary [GRI] and Stobhill Hospital) automatically re-route all referrals of children aged < 12 years to RHSC. In contrast, some children are seen in the South Glasgow Trust (Victoria Infirmary & the Southern General Hospital [SGH]).

RHSC	Referrals	2006/07
	New	Returns
< 2 years	355	845
2 - < 5 yrs	373	872
5-10 yrs	543	1491
5 – 12 yrs	744	2021
> 12yrs	147	897
Totals	1732	4835

Dermatology South Glasgow
April 06 - March 07
Paediatric patients seen

Age	New	Return
0-5	10 (0.1%)	12 (0.1%)
5-10	38 (0.4%)	38 (0.3%)
10-12	35 (0.4%)	83 (0.5%)
12-16	234 (2.6%)	351 (2.3%)
All 0-16	317 (3.5%)	484 (3.2%)

These tables show paediatric referrals to RHSC & South Glasgow, children aged < 16years accounts for <5% of the workload, at the SGH for both new & review patients.

Several important points come out of this data:

- South Glasgow sees few children aged < 5 years (total 22: 10 New;12 Reviews)
- The number of children seen increases with increasing age:
 - 76 children aged 5 -10 years (38N, 38 R)
 - 118 children aged 10-12 years ((35N, 83 R)
 - 585 children aged 12-16 years (234 N, 351 R)

In the > 12 age group South Glasgow sees more new referrals than RHSC and this would impact on RHSC if the cut-of age for referrals was raised to16 as planned by GGHB.

Summary

- RHSC sees the vast majority of children aged <5 years referred to Secondary Care in GGHB
- Changing the cut-off age to 16 would significantly increase referrals to RHSC and would raise manpower issues.

On Call: There is a Consultant Dermatologist on call at RHSC daily from 9am – 5pm for urgent referrals from within RHSC and from primary care... The out-of-hours cover is provided by the adult service (of which the 2 RHSC dermatologists with sessions in the adult section participate).

Services on RHSC Site

- 12 out-patient clinics are run weekly
- Minor surgery: 3 lists per month (Ω 15 slots)
- Speciality Paediatric Dermatology nurse-led clinics with nurse prescribing including rapid access for patients
- Allergy testing:
 - Skin Prick Tests (SPT)
 - Patch testing for Contact Allergy Ω 6 patients slots/month
- Food challenges
- Paediatric Dietician (0.5 Dedicated) (+ Ω 0.4 Not dedicated)
- Clinical Psychologist (2 sessions)
- Medical Illustration
- Imaging / Radiology
- In-patient beds
- Laser Treatment (Under GA by plastic surgeons)
- Physiotherapy
- Occupational Therapy
- Orthotics

Services available off site:

- Phototherapy at the site closest to the family.

Combined Clinics: as shown in table 6 are run for

- *Vascular & complex naevi* clinic is run 3-4 monthly with the dermatologists, a plastic surgeon, interventional radiologist and general surgeon. Other specialised services ophthalmology, orthopaedics and pain team are available if necessary
- *Epidermolysis Bullosa* (EB) clinic is run four monthly with the Specialised Dermatology Nurses & the Specialist EB nurses from DEBRA (Scottish & GOS), a paediatric dietician, dental surgeon, with input from paediatric endocrinology, pain team, orthopaedic surgery, physiotherapy, occupational therapy and orthotics as needed.
- *Joint Connective Tissue Disease* clinic three monthly with rheumatologist & immunologist

Combined clinics:

- *Genetic Diseases* (virtual clinic with photographs) six monthly with the clinical geneticists

9.1.2 Edinburgh, Lothian & the Borders:

Two consultant dermatologists working in Edinburgh have a special interest in Paediatric Dermatology and see the majority of the children <12 years. Each consultant does one paediatric dermatology clinic per week. Children may be seen by other Consultants at out-reach clinics which are run in West Lothian at St John's Hospital, Roodlands Hospital, Haddington in East Lothian and the Borders General Hospital. In addition, children may also be seen in specialist or general adult clinics such as the pigmented lesion clinic or, if the child presents acutely, to the on call dermatologist.

Children are seen within the Dermatology department at Edinburgh Royal Infirmary, Lauriston site which does not have a child friendly space. The waiting room is shared with concurrent adult phototherapy and plastic surgery clinics. The clinics are staffed by adult dermatology nurses. Once a month the paediatric dermatology clinic takes place in the out patients of the Royal Hospital for Sick Children (RHSC). Two senior dermatology nurses also see children with atopic eczema and take direct referrals from Primary Care.

Services on Site within Dermatology Dept (Children), Lauriston site:

- 3 doctor led paediatric dermatology clinics/ week staffed by 2 consultants (0.6 WTE) and one registrar)
- 3 nurse led paediatric eczema clinics
- Dressings clinics (with adults)
- Minor surgery (Ω 4/month)
- Patch test (with adults)
- Phototherapy (with adults)
- Photography

Off Site Services available at the Royal Hospital for Sick Children Edinburgh

The following services are only available at the children's hospital Consequently many children who attend the paediatric dermatology clinics at RIE, Lauriston site have to attend both sites if they need:.

Off Site Services available at Children's Hospital

- Phlebotomy
- Dietetics
- Allergy clinic
- Psychologist
- Plastic Surgery
- Radiology
- In-patient beds

Combined Clinics

- *Combined Paediatrician/ Dermatologist*: Once a month a combined paediatric clinic is performed at the Children's Hospital in place of the usual weekly paediatric dermatology clinic done in Lauriston Place.
- *Epidermolysis bullosa* clinic: this was the first Scottish clinic dedicated to EB. It serves both adults and children and occurs four monthly at Lauriston Place. It is staffed by three doctors, specialised EB nurses from DEBRA, a paediatric dentist and a social worker from DEBRA.
- *Connective Tissue Disease* clinic: This started in 2007 and will run 6 monthly. 4 patients will be seen in a combined setting with a paediatric rheumatologist and a dermatologist. This clinic is done in addition to the normal general clinic.

9.1.3 Dundee: Ninewells Hospital

The Dermatology Department also houses the Scottish Centre for Photobiology in Ninewells Hospital. One of the Consultants at Dundee has a special interest in Paediatric Dermatology and 80% of their work load (0.8 WTE) is Paediatric Dermatology), and will become 100% (1.0WTE) from April 2008. She sees the majority of the children with skin disease in secondary care in Tayside. All paediatric referrals (< 16 years) are directed to her and she provides a day-time on call service through the Specialist Registrar (SpR) on call.

Clinics: She is supported by a 3rd year SpR in training (12 months attachment for 2 clinics per week, 1 each at Ninewells and Perth Royal Infirmary) and runs paediatric out-reach clinics at St Andrews (with paediatrically trained dermatology liaison sister) 2 per month and Stracathro 2 per month (1 SpR and 1 clinical assistant). Adults are also seen in the Stracathro clinic.

The other consultants in Dundee may see a few children within their Specialised clinics such as Photobiology and may also see occasional children when they are on-call.

Services on Ninewells site:

- 1 Weekly out patient clinic
(other departmental clinics running in parallel: asthma, food allergy, ENT)

Services on Ninewells site continued:

- Minor surgery : <1 /month in adult list (by SpR in training for paed)s
- Patch testing: 4 /month within adult service
- Phototherapy (and photo investigative service): 4/month
- Paediatric Dietician (not dedicated)
- Paediatric Psychologist (not dedicated)
- Laser treatment
- Prick testing for latex and some food allergy (rarely)-Consultant Immunologist

2 Off-site:

- Out reach paediatric clinics:
 - 1 per week Perth Royal Infirmary (Consultant +SpR)
 - 4 per month: St Andrews or Stracathro hospitals (alternate weeks)

Dermatology Treatment Centres: Ninewells & Off-site

These are established in Ninewells, Stracathro and Perth (soon to be established in St Andrews) for both adults and children. Children are seen for phototherapy, bandaging techniques, cryotherapy, intralesional steroids, roaccutane 'pregnancy prevention programme' for female teenagers.

Combined Clinics:

- Vascular anomalies clinic with Plastic surgeon, general paediatric surgeon and clinical geneticist plus input from ophthalmology, radiology and orthopaedics as necessary. (Ω x 3 /year). They also have an informal fast track 'on call' for vascular lesions agreed with the neonatal unit.
- Epidermolysis bullosa clinic: 1-2 annually (to be increased to 3 in 2008)
- Genetics: 4 (or more if necessary)/ year

Nurses

- Parallel Nurse-led eczema clinic weekly in Ninewells (paediatrically trained dermatology liaison sister with nurse prescribing skills).

She also runs:

- adult clinics for dermojet and cryotherapy and minor surgery clinics & children may be referred to these.
- Telephone help-line and home visits when necessary

9.1.4 Aberdeen

One of the 4.5 consultant dermatologists in Aberdeen has a special interest in paediatric dermatology (0.5WTE) and does a clinic in the Children's Hospital.

General Dermatology outreach clinics are held in Orkney, Shetland, Elgin, Huntly, Banff, Peterhead & Fraserburgh where some children are seen admixed with adult patients.

Aberdeen: Services on site:

- 2 out patient clinics
- Minor surgery 3-5 /month (booked onto a mixed adult/paediatric biopsy list which is carried out in the adult out-patient dept. in Aberdeen)
- Patch testing: 4 /month in adult list)
- Paediatric Dietician not dedicated
- Psychologist not dedicated

9.2 Paediatric Dermatology in District General Hospitals (Table 8)

9.2.1 Argyll (North)

A Consultant Dermatologist (1 WTE) provides a Dermatology Service to the Lomond area (Dumbarton, Vale of Leven) and Argyll. The main base hospital is the Vale of Leven Hospital Alexandria though clinics are also held in Campbeltown, Oban and Lochgilphead.

Staffing: The clinics are supported by 1 Associate Specialist (0.3 WTE)) and 3 Hospital Practitioners (0.2 WTE). There are 2 specialist dermatology nurses at Vale of Leven.

Both children and adults are seen at all dermatology clinics. Children requiring phototherapy are treated in the local dermatology unit. The clinic waiting areas have

been adapted to allow space for children to play. Any children requiring in-patient treatment or tertiary care are referred to RHSC (Yorkhill).

Paediatrics: There is an out-patient and community paediatric service at Vale of Leven hospital based in the Acorn Centre. This is led by Consultant Paediatricians and specialist children's nurses. There is a close liaison with the dermatology department and children with skin problems can have procedures such as skin biopsy, dressings, or venesection performed in the Acorn Centre with assistance from paediatric staff.

Oban:

There is a Consultant Paediatrician and Specialist Children's nurse providing out-patient and community paediatric services at Oban. They provide advice and assistance in dermatology clinics when required.

9.2.2 Ayrshire

Crosshouse Hospital is the main base hospital for Dermatology in Ayrshire and also has dermatology beds for in-patients. Clinics are also held in Ayr (6 clinics), Irvine (2 clinics) & Cumnock (1 clinic). Ayr also has a Day treatment Unit & UVB phototherapy.

Staffing: There are 5 Consultant Dermatologists (4.2 WTEs), all of whom may see children. Children are seen within the adult clinics though some play materials are available.

Services on site:

- Minor surgery: <1 / month for those aged < 14 years
Some younger children also referred to General surgeons or Plastic surgeons
- Patch testing: 0.5 /month within adult service
- Phototherapy: rarely
- Paediatric Dietician (not dedicated)
- Laser treatment: Plastic Surgeons

9. 2.3 Clyde Division: GGHB (Previously South Argyll & Clyde)

The main base hospital is the Royal Alexandra Paisley (RAI), though there is also a large hospital at Inverclyde (Inverclyde Royal Hospital- IRH). There are three Consultant Dermatologists (2.6 WTE) of which one has a special interest in Paediatric Dermatology and runs a fortnightly paediatric clinic at the RAI (0.1 WTE),

which sees about 50% of the children seen in the RAI dermatology clinics. Children at IRH are seen in the general adult clinics.

Staffing: The paediatric clinic is supported by 1 Dermatology Specialist Registrar, 1 Staff Grade Dermatologist & 1 nurse specialist. There is also a parallel paediatric clinic run by an Associate Specialist. Children are seen within the adult hospital, though in a dedicated child friendly space.

Services on site:

- Dedicated weekly Paediatric Dermatology
- Minor surgery: rarely
- Patch testing: rarely
- Phototherapy: approx 4/month in adult dept
- Dietician (not dedicated)

9.2.4 Dumfries

A population of approximately 147,000 is served by a single handed Consultant Dermatologist; a general practitioner with special interest (three sessions) and two specialist nurses. Clinics take place in Dumfries, Stranraer, and Newton Stewart.

Dumfries: 3.5 clinics each week; the outpatient department is child friendly with a dedicated area for paediatric patients. Paediatric patients are seen in the general clinics. Paediatric admissions are to the paediatric ward and there is close cooperation between dermatologists, paediatricians and paediatric trained nurses. Phototherapy for children is administered in the hospital.

Stranraer: one clinic every two weeks; child friendly outpatient department; no other dedicated paediatric facilities.

Newton Stewart: one clinic monthly; child friendly outpatient department; no other dedicated paediatric facilities.

9.2.5 Fife:

There are three Consultant Dermatologists (2.7 WTEs) in Fife all of whom have a special interest in Paediatric Dermatology. General Dermatology clinics are held at both Queen Margaret and Kirkcaldy Hospitals. Children are seen within General Dermatology adult clinics although in a child friendly space.

Fife Paediatric Clinic: There is a weekly Consultant specialist clinic for children with atopic eczema and psoriasis supported by Dermatology Community Liaison Nurses (2 WTE).

Staffing: The Consultant clinics are supported by 0.4 WTE Associate Specialist and 0.6 WTE Clinical Assistants/ Hospital Practitioners.

Services on site: out patient clinics

- Weekly Paediatric Eczema clinic at each hospital
- 10 General Dermatology Clinics (Adults and Children)

Other Services on site

- Minor surgery (approximately 4 children \leq 16 years per month on adult list)
- Patch testing: <1 /month within adult service
- Phototherapy: <1 /month
- Paediatric Dietician (not dedicated)
- Availability Paediatric Psychologist (not dedicated)
- Laser service via Plastic Surgery referral at St. Johns Hospital, Livingston

9.2.6 Forth Valley:

There are two Consultant Dermatologists (2WTEs) serving Forth Valley (popn. 285000) though currently one is a locum pending the appointment of the substantive post. Stirling Royal Infirmary is the base Hospital though out reach clinics are also held at Falkirk Royal Infirmary, Alloa, Stenhousemuir, and Callander Health Centres.

Staffing: The clinics are supported by 3 GPwSIs (6 sessions).

Services on site:

- Weekly dedicated paediatric clinic alternating weekly between Stirling and Falkirk Royal Infirmarys (0.2 WTE) but children are also seen in all the general clinics (approx 50/50 split).
- Base: 3 Consultant out patient clinics, 3 GPwSI clinics and 5 nurse-specialist clinics
- Outreach clinics: 5 consultant and 5 nurse-led clinics at Falkirk Royal Infirmary,
3 GPwSI clinics at each of the above health centres weekly.

- All clinics see children, although all children are offered attendance at the weekly dedicated paediatric clinic
- Minor surgery (approx 1 /month within adult list)
- Patch testing: (approx 1 /month within adult service)
- Phototherapy: 2 /month
- Dietician (not dedicated) paediatric Dietician available on request
- Psychologist (not dedicated) - paediatric psychologist available on request.

9.2.7 Inverness

There are two consultants in Inverness, though the service was run single handed for a period. Inverness covers a large area of the Highlands and 14 general dermatology clinics are run weekly. There is no special provision for children who are seen within the adult clinics. The service is supported by dermatology community nurses who see both adults & children.

9.2.8 Lanarkshire:

There are 5 Consultant Dermatologists (5 WTEs) in Lanarkshire, though none have a special interest in children. Monklands General Hospital in Airdrie is the base Hospital though outpatient clinics are also held at Hairmyres Hospital, Wishaw General Hospital and Stonehouse Hospital.

Staffing: The clinics are supported by 3 Associate Specialists, 3 Hospital practitioners and 3 nurse practitioners. Children are seen within the adult clinics in a not particularly child friendly space, though there is a nurse led eczema clinic.

Services on site:

- Phototherapy:
- Laser service

10 Other Health Professionals:

- Paediatric Dietetics
- Clinical Psychologist

10.1 Dietetic Service to Paediatric Dermatology

Background

There are two main areas in paediatric dermatology which require dietetic input:

- Atopic eczema with associated food allergy
- Severe blistering disorders

Atopic Eczema

Food Allergy is an area of concern at national and international level as it appears to be increasing faster than other allergies and Type 1 allergy can have fatal consequences. A significant proportion of young children presenting with atopic eczema under the age of 2 years will have food allergy. Although most of them will have one or two allergies (usually milk & egg), some have complex, multiple allergies which may be associated with a failure to thrive. Most children with milk & /or egg allergy develop tolerance, though a small number have a persistent problem. In contrast to milk & eggs, nut & fish allergy tend to be life long. In addition, as children grow older, some may develop new allergies and some existing allergies may become more severe.

Blistering Diseases:

- Epidermolysis Bullosa (EB)
- Bullous Ichthyosiform Erythroderma (BIE)

Severe cases require intensive nutrition support. Children are seen at specialist centres: such as Edinburgh Royal Infirmary, Glasgow and Aberdeen Children's Hospitals and Ninewells Hospital, Dundee. As the children may come from a wide area, their care may be shared with centres local to where the family lives, such as Forth Valley and Orkney.

Role of the Dietician in treatment of atopic dermatitis/eczema

- To provide up to date, accurate advice regarding careful food avoidance, including interpretation of food labels.
- To provide appropriate meal suggestions, especially during weaning, for toddlers and those with complex, multiple allergies

- To ensure good nutrition is maintained for normal growth and development and avoidance of nutrient deficiencies. This is especially important where there are multiple allergies.
- To provide additional support by phone and/or at dedicated dietetic clinic.
- To liaise with local services: GP, health visitor, nursery, school and school meals.
- To provide patients with ongoing advice about suitable new products
- To advise prescribers on appropriate products
- To develop and update patient information sheets
- Advise and train other health professionals on dietary management of food allergy
- Develop guidelines and protocols and participate in audit and research, to improve clinical effectiveness
- If part of the dieticians' remit: to organise, prepare and/or administer food challenges

Comment: If parents are not properly supported, compliance may be poor, so that any benefit of the restricted diet may be missed. In addition the diet may either be stopped too soon or conversely extended longer than necessary. Children with multiple allergies are at risk of developing nutritional deficiencies and feeding problems and weight gain and growth may be compromised. A dietician with training in paediatrics and food allergy in relation to dermatology is essential to monitor these children.

Children with multiple allergies need regular review from weekly to monthly at first, decreasing to every 3 monthly, 6 monthly or annually, depending on the age of the child, the number of food allergies (e.g. egg alone, egg and milk or multiple), and ability of parents to cope. All children with atopic eczema and food allergy should be offered at least one review with the dietician to answer any queries and to reinforce the advice already given to ensure that the elimination diet is being followed correctly. Only then will the clinician be able to assess if the diet has had any value in treating the eczema.

Role of the Dietician in treatment of Epidermolysis Bullosa

Children with severe forms of EB have blistering of the mucosal surfaces such as the mouth, making it painful and difficult to eat. These children have complex nutritional needs and require regular, intensive nutrition support. This will include food supplementation and enteral feeding.

The aims of nutrition support in children with severe EB are:

- to promote optimal quality of life.
- to alleviate stress associated with feeding difficulties.
- to address nutrient deficiencies.
- to promote normal bowel function.
- to promote optimal growth rates and catch up growth where required.
- to promote optimal immune status and wound healing.

A specialist dietician with training in paediatric nutrition support is a vital member of the team. EB children have shared care with Great Ormond Street Hospital & their dietician offers support, advice and periodic study days for dieticians looking after these children.

What Dietetic Service is Currently Available?

Questionnaires were sent out to Dietetic Managers across Scotland to scope the current service provision and model of care to children with skin conditions. From the initial questionnaire 6 responses were received and a further 4 from follow up emails.

From the responses and from personal knowledge of services, there are currently only 2 centres in Scotland with dedicated dieticians for children with food related eczema. The service at Yorkhill Hospital in Glasgow is provided by a dietician funded for dermatology, the service in Edinburgh Royal Hospital for Sick Children is provided as part of the Allergy Service. Other areas provide a food allergy service as part of the core Dietetic Service and have no specific funding or dedicated dietetic service to children with food allergy. There is no dedicated funding in any centre in Scotland for EB.

Dietetic time required

Glasgow, Royal Hospital for Sick Children has a dedicated paediatric dermatology dietician (0.4WTE – includes 2 clinic sessions/week), but this is inadequate to provide a full service for all the dermatology consultant at RHSC. Personal experience shows that, if a clinician is interested in the role of food allergy in the treatment of eczema, then required dietetic time increases with the rise in referrals. During 12 months July 2006 – July 2007 600 patients (120 new; 480 review) patients were seen at outpatient clinics.

Support Sessions: When calculating time needed for a dietetic service, it is **essential** that for each clinic session, a second support session is allocated to allow adequate time to complete all activities listed above. At least 0.6WTE dietician would be required for a paediatric dermatology clinic with similar numbers to the dedicated clinic at RHSC, and to provide a similar service for all the dermatology clinics at RHSC would require an additional 0.8WTEs: in total RHSC would require 1.4 WTEs paediatric dieticians to provide a full dietetic service for all the dermatology consultants. For other centres the exact amount of dietetic time needed, would depend on the number of clinics and patients seen per week.

An additional session is needed if the dietician is responsible for preparing the food for the food challenges, and a further increase if the dietician is required to 'feed' the food during the challenge.

Community When children with eczema are seen in the community, they also need access to a trained paediatric dietician. Again the hours required would depend on the numbers involved.

Epidermolysis bullosa: Time required for children with EB will vary according to the number of children and severity of the disease. In Glasgow, where there are 5 children with severe EB, approximately half a session a week is needed.

Fife:

The Fife paediatric team has a team of 3.5 WTE dieticians. The team provide an integrated (primary and secondary) allergy service, which now accounts for 21% of their total work load (approximately 0.8 WTE). A range of services is provided: including dietetic led assessment and advice in the form of urgent (within 48 hours, or within 5 working days) and routine (within 4 weeks in hospital or 6 weeks in the community clinics) clinics.

From January to September 2007, 285 patient (86 New and 199 Reviews) contacts were seen with food allergy, representing 24% of total patient activity. The figures of 285 include both dermatology and GI referrals, and it is estimated that 30-40% of these are children with eczema. These figures are in sharp contrast to previous years activity (2006), where food allergy contributed less than 5% of the total patient activity.

Numbers requiring dietetic advice

Between 30-50% of the young children with atopic eczema (aged < 2years) have food allergies and will require dietetic support (30). In the hospital setting, having a specialist paediatric dermatology dietician as part of the dermatology clinic team

ensures improved quality of care and patient experience. Children seen in the primary care setting also need access to dietitians with expertise in this area. Not all children with eczema are routinely tested for food allergy. In areas where there is a clinician interested in the role of food allergy in the treatment of eczema, then the proportion of children referred to Dietetic Services substantially increases.

Model of care

Dietetic referrals of children with atopic eczema can come from Consultant Dermatologists, Consultant Paediatricians or GPs. The model of care provided will vary across each Health Board. In some Health Boards all referrals (GP and Consultant) go to Specialist Paediatric Dietitians; in other Health Boards GPs may be able to refer directly to the community dietitians, with more complex referrals being seen by the specialist paediatric dietitian. This will depend on the expertise available locally.

There are only a small number of children with EB but they require intensive and specialist dietetic support and ideally should be managed in a specialist centre with shared care with local paediatric dietetic service if available.

Work force Issues

While there is clearly a role for specialist paediatric dietitians to manage complex cases in the hospital setting, some children could be managed within the primary care setting by community dietitians. In the community, food allergy can be a major reason for referral to dietitians. Training and education in paediatric food allergy, and working towards the development of managed clinical networks, would enable community dietitians to develop their role, alongside and supported by specialist paediatric dietitians.

In Fife currently about 0.4WTE dietitians are needed for the food allergic children. On these population figures RHSC would need at least 1 WTE paediatric dietitian to cover the food allergic children and additional sessions for the EB children. With a Scottish population of 5 million there is a need, as a conservative estimate for a minimum of 6 paediatric dietitians to cover the food allergic children in Scotland. It is likely that at least part of this is being delivered through the existing framework, but it is also likely with the recent government reports on the food allergy services that the demand for dietetic services will increase, mirroring the experience in Fife.

Education & Training

As part of their training, dietitians need information on the dietary and non-dietary treatment of atopic eczema, clarification of the role of skin prick testing and IgE (RAST/CAP) testing in diagnosis, and understanding of the role of exclusion diets and food challenges in treatment, including their limitations. Appropriate competencies for the management of children should also be developed. The post-graduate courses are listed in table 9.

Recommendations from working party:

- To establish the short fall of existing dietetic services for children with food allergy in Scotland
- It is likely that overall an increase in the number of paediatric dietitians will be necessary

10. 2 Clinical Psychology

Effects of childhood skin disease on psychological functioning and quality of life in children and their parents

Skin disease can have a marked effect on many aspects of life and general functioning. Atopic Eczema is a common childhood disorder with 5-20% of eleven year olds suffering from it (33) and general prevalence rates of 10-16% in westernised countries. (9) Eczema can be itchy and painful, requiring regular treatments which may smell, cause discomfort and impact on day-to-day life as a result of time required to apply creams and bandages. Other conditions including psoriasis and epidermolysis bullosa can equally cause pain and discomfort at the very least, with difficulties in eating, toileting and shortened life expectancy in the worst cases of EB. Alopecia is another dermatological disorder which can have negative psychological consequences as it is appearance altering which can impact self-esteem, social relationships and mood.

In general, children with a chronic illness, and particularly one that impacts on physical appearance, must go through a period of adjustment. There is a wide variation in how children and families cope that involves an interaction of factors including social support, social skills, optimism, perceptions of self-efficacy and coping styles. (34) Children with chronic medical problems are up to three times

more likely to experience increased psychological and/or behavioural difficulties. (35) Often conditions such as Atopic Eczema are seen as relatively minor, but they can, in fact, cause substantial disruption to the lives of children and their families. (36) Daud et al (37) found 23% of pre-school children with severe atopic dermatitis had behavioural problems compared with 5% of matched controls. Another study found children with moderate to severe atopic dermatitis had twice the rate of psychological problems than a control group without eczema. (38) Chronic eczema can negatively impact parent-child relationships emotionally and in terms of practical care. (5)

One issue around skin conditions is that physical appearance may be affected and children with eczema may have to contend with comments which may be well-meaning but cause embarrassment, or worse, involve bullying, teasing and peer rejection. (39) Adaptation can be complicated by the fluctuating nature of many skin diseases.

Quality of Life (QoL) can be broadly measured as the discrepancy between how a child views his or her life and how they might want or expect it to be (40) and is an important health outcome measure in individuals with chronic conditions for which there is no expected cure. There are a large number of variables to consider when measuring QoL including gender, age, ethnicity, education, life experience, disease severity, social class and family functioning. (41) Several measures are suitable for using with children and young people with skin diseases, including the Children's Dermatology QoL Index which has demonstrated that, of all children with common skin diseases, those with eczema, psoriasis and scabies have the greatest mean impairment of health related QoL with high scores relating to itchiness, pain, sleep disturbance and school difficulties (6;39). Other findings suggest atopic dermatitis has an equal or greater impact on a child's health-related QoL than asthma, diabetes, enuresis and cystic fibrosis. (6)

This may be related to parental stress and a recent study found mothers of children with eczema reported higher levels of stress than mothers of children with insulin-dependent diabetes and profound deafness. (42) Indeed, 46% of mothers in that study scored in the 'clinical range' for stress which would indicate professional consultation is advised. Overall, there was a significant positive correlation between eczema severity and level of parental stress. (42) Furthermore, there is some evidence to suggest that improving parent-child dysfunctionality may improve skin condition overall. (43)

One of the key symptoms of eczema is itching, which can lead to sleeplessness for both child and parents. Moore et al. (44) analysed the psychological impact of caring for children with eczema and asthma and found rates of depression to be twice as high in mothers of the former group, with this related to disrupted night-time sleep rather than condition or severity per se. Sleep disturbance was also associated with increases in maternal and paternal anxiety. (44) Children themselves rate the itching and associated sleeplessness as the most important factors of their disease. (39)

Given the level of practical and emotional difficulty associated with chronic skin conditions there is a clear justification for integrating medical and psychosocial care. Integrated health care has been described as “a continuum of the extent to which mental health services are interwoven in the medical management of a child’s illness”, thus being delivered to children and their families as one. (45) Embedding mental health professionals within medical teams allows early identification of problems and thus early, preventative work with brief interventions. It also optimises communication between all professionals involved in the child or young person’s care. (46)

Since October 2006, dermatology services at the Royal Hospital for Sick Children, Yorkhill, Glasgow have had two dedicated clinical psychology sessions per week. As this still represents a general scarcity in comparison to the overall population attending RHSC, service has been limited to those most needy families. From October 2006 – September 2007 33 families have been referred to psychology. The range of problems has included treatment related problems, primarily non-adherence; parental stress and coping; mood difficulties including depression, anger and anxiety; and difficulties with peer and other social relationships. Often presenting problems are quite entrenched and long-standing; hence the referral to clinical psychology. Unfortunately this model does not allow for early intervention and preventative work.

As current services stand, there are no other psychologists working with dedicated time to dermatology in Scotland. Indeed there are very few dedicated paediatric clinical psychologists; that is, psychologists who work exclusively with children and young people with chronic and life-threatening illnesses. All clinical psychologists complete the same doctorate training but paediatric psychologists have particular expertise in the area of chronic health, focusing on promoting active coping and

facilitating normal adjustment and development despite occurrence of chronic health problems. The majority of clinical child and adolescent clinical psychologists in Scotland work in community mental health or child development teams. This often means limited or even no access to clinical psychology for children and young people who do not have an identifiable mental illness but who are struggling to cope with their skin disease, depending on local referral criteria.

Dedicated and protected clinical psychology time for children and young people with skin disease and their families would allow fully integrated working, with the corollary that services can focus on health promotion, patient empowerment and early intervention. In the longer term this would ensure optimal long-term development, enhanced coping and adherence with medical regimes, and reduced serious mental health problems.

Clearly this is a patient group faced with a wide range of adversities and difficulties. The high rates of psychological problems noted in the literature for children with skin conditions and their parents highlights the role psychological services could contribute to dermatological illness.

There is no single recommendation regarding psychology staffing levels for children and young people with chronic illness generally or specifically in relation to skin disease. Those guidelines which are available vary widely but all highlight the importance of clinical psychology services and suggest a much higher level than 0.2WTE is required.

- The National Renal Workforce Planning Group (2002) suggest a minimum requirement of 0.3WTE clinical psychologists per million population (pmp), divided as minimum 0.2WTE pmp for direct clinical work and a minimum 0.1WTE for consultation, training, giving and receiving supervision, CPD, audit and service evaluation.
- The Cystic Fibrosis Trust recommends 0.4WTE clinical psychologists per 50 patients receiving full care and 0.2WTE per 50 patients receiving shared care.
- The Dutch Society of Paediatricians recently recommended 0.3WTE paediatric psychologist for every 1.0WTE paediatrician.

Children with skin disease can have severe psychological problems and as such need support from a clinical psychologist. An estimate for paediatric dermatology would be 0.5 WTE paediatric clinical psychologist for each WTE dermatologist working with children. RHSC would therefore need at least 1 WTE and this is likely to be a considerable underestimate. A conservative estimate therefore for Scotland would be six WTE dedicated clinical psychologists are needed for paediatric dermatology.

Recommendations:

1. Delivery of care

1.1 Overall the current framework of delivery of paediatric dermatology is sensible & workable. Nevertheless there are regional differences in manpower provision and facilities for managing children with skin disease and quality of care for children with skin problems could be considerably improved if the following recommendations were adopted

1.2 Primary care:

- Most children with mild eczema could be well & appropriately managed in primary care if:
 - Funding for eczema clinics in primary care was re-instated
 - A Nursing Network was provided (as below)
 - GP education was improved
- Children with skin problems need referral for:
 - Diagnostic uncertainty
 - Severity
 - Failure to respond to treatment
- Skin infections and infestations are usually appropriately treated in primary care but the management of other common skin conditions in children could be improved with better education of GPs

1.3 Secondary Care.

- Children should continue to be seen in dermatology departments in both DGHs and Teaching Centres. But it is essential that all children should have access to Specialised Centres if needed.
- Regional differences in the provision of services for children with skin disease should be addressed according to population and local need.
- The move towards dedicated paediatric clinics should be actively encouraged and will require additional medical manpower.
- Specialist Training in Paediatric Dermatology: it is essential that this is available as the need for this sub-speciality is likely to expand.
- Currently no funded Paediatric Dermatology Fellowship available in UK for sub-speciality training. (In contrast to 3 Dermatology Surgical fellowships)

2. Dermatology Specialist Nurses

2.1 Paediatric Training All Departments of Dermatology have Specialist Dermatology Nurses, though not all are paediatrically trained.

- Nurses should be encouraged to take additional training in paediatric dermatology wherever possible:
 - Nursing prescribing
 - Nurse practitioners course

3. Network of Specialised Liaison Nurses for Children with Atopic Eczema

It is recommended that:

- A Network of Liaison Nurses should be set up, based in secondary care within a Department of Dermatology but whose primary aim would be to provide a service for the community bridging primary & secondary care.

Network of Specialised Liaison Nurses (contd)

- The liaison nurses would:
 - run eczema clinics within both primary & secondary care
 - educate & train District Nurses & Health visitors so that information is cascaded out to primary care & the Health Centres
 - identify children with severe eczema in the community who need referral to a Dermatologist in secondary care
 - identify young children with possible food allergy who should be referred to a Specialist Centre for further investigation & treatment. No child should be started on a restricted diet without input from a Paediatric Dietician

4. Food Allergy Network for Children with Atopic Eczema

Young children with atopic eczema may have associated food allergies and not all centres are set up to manage these children. These children would benefit from a co-ordinated food allergy service. The Dermatology Department at RHSC has been running a food allergy service for children with atopic eczema since 1992.

A National Network could:

- Facilitate the initial setting up of a food allergy service
- Offer training for staff in the investigation & management of food allergies in young children with atopic eczema
- Provide advice & support for the management of children with multiple food allergies who are often more difficult to manage

Requirements:

- Appropriate training for dermatologists, nurses, dieticians
- Facilities for allergy testing: Skin prick & Blood tests:
- Food Challenges
- Increased number of Paediatric Dieticians

5. Specialised Services for vascular anomalies:

- All children in Scotland should have access to a Specialist Vascular anomalies clinics if necessary
- Combined vascular clinics are held at RHSC & Dundee
- RHSC could provide a National Service for Scotland for Interventional Radiology for the complex vascular lesions.
- Referral to Great Ormond Street & Birmingham Children's Hospitals should be possible if needed.

4. Psychology:

- Children with skin problems may have a major problems & access to clinical psychology is difficult.

- An increase in manpower is needed

Conclusion:

Children with skin problems have a lot to contend with and deserve a high quality comprehensive that is delivered by appropriately trained staff in a child friendly environment

Table 1: Dermatology New Consultations

	1997 Glasgow (0.6 WTE Consultant)	Wrexham 1997
Total patients seen:	600	
<u>Total Dermatitis</u>	200 (33%)	15-20%
(Atopic Eczema	192 (32%)	
<u>Viral</u>		
Warts & molluscum)	78 (13%)	15%
Infestations:	9 (1.5%)	
<u>Birthmarks</u>	63 (10.5%)	
Haemangiomas	22 (4%)	
Pigmented Naevi	33 (5.5%)	
<u>Other Common Conditions</u>		
Psoriasis	21 (3.5%)	4%
Urticaria	18 (3.0%)	
'Lumps'	16 (2.6%)	Ω 5- 10% *
Alopecia	13 (2.2%)	
Acne	12 (2.0%)	10%
Acquired haemangiomas	12 (2.0%)	
Others*	67 (11.2%)	
Food Allergy (type1)	66 (11.0%)	
Rarities	13 (2.2%)	

Footnote: In the absence of accurate up-to date data , data from 1997 has been included to illustrate the spectrum of new consultations in Paediatric Dermatology. With the exception of Type 1 food allergy, which is now seen by the Allergists, the relative frequency of the common conditions has remained essentially unchanged.

Table 2: Dermatology Conditions

Infections:

Bacterial:	Staphylococcal:	Impetigo (Staphylococcal Scalded Skin Syndrome)
	Streptococcal:	Erysipelas Cellulitis
Viral:	Herpes Simplex:	Type 1 Type 2 (genital)
	Papilloma virus:	Warts
	Pox:	Molluscum
	HIV	
Yeasts:	Candida:	Thrush
	Fungal:	Kerion, Tinea capitis, Tinea corporis, Tinea
unguium Mycobacterium	Tuberculosis Leprosy	
Inflammatory dermatoses:	Dermatitis –	Atopic Seborrhoeic Contact: Irritant / Allergic Napkin dermatitis
	Pompholyx	
	Juvenile Plantar Dermatitis	
	Psoriasis	
	Phytophoto dermatoses	
Neonatal Disorders:	Transient dermatoses of neonate:	
Genodermatoses:	Neurofibromatosis	
	Tuberose sclerosis	
	Keratoderma	
	Incontinentia pigmenti	
	Darier's disease	
Blistering Disorders	Epidermolysis Bullosa Simplex	
	Dystrophic EB (Dominant: Recessive (severe))	
	Junctional EB	
Birthmarks:	Vascular:	Infantile haemangiomas Capillary Malformation (port wine stain) Venous Malformation A-V Malformations Lymphangiomas
	Melanocytic Naevi:	Congenital including giant pigmented naevi Acquired melanocytic naevi
	Others:	Mast cell naevi, Connective tissue naevi Smooth muscle hamartomas & others
Tumours:	Benign	Sebaceous & other cysts
	Malignant:	Melanocytic (melanomas) / sarcomas Xeroderma pigmentosa
Hair	Loss	Alopecia areata, totalis, universalis
	Excess:	Hirsutism
	Hair shaft / cycle abnormalities	
Nail	Congenital nail dystrophies	
	Others –	Infections, Psoriasis, Lichen planus
Connective Tissue Diseases:		SLE. Discoid LE, Scleroderma
Vulval Disease:	Lichen sclerosis Vulvitis	
Miscellaneous:	Urticaria Erythema multiforme Lichen planus Adverse drug reactions: Toxic Epidermal necrolysis	

Table 3: Specialised Services (Teaching / Tertiary Referral Centre)

1. Any skin condition in which a general dermatologist has been unable diagnose or manage, because it is atypical, severe or complicated by other paediatric medical or social factors. Such factors include:
 - Possible effects on growth & development
 - Psychological effects
 - Need for systemic immunosuppression or cytotoxics
 - Interference with education (due to medical, social or psychological factors) e.g. children with severe atopic eczema
2. Life threatening skin diseases such as TEN, SSS & severe drug reactions
3. Young children with atopic eczema and food allergy requiring specialist investigation & management & input from paediatric dieticians.
4. Complicated haemangiomas and vascular ± lymphatic malformations.
5. Extensive pigmented naevi & other congenital naevi e.g. epidermal & sebaceous
6. Vulval diseases & links with child protection
7. Need for diagnosis or therapeutic procedures (± general anaesthetic)
8. Children requiring in-patient treatment
9. Need for phototherapy, systemic immunosuppression or cytotoxics
10. Need for liaison with other paediatric generalists and specialists - e.g. plastic surgeons, immunologists, rheumatologists, neurologists, geneticists, radiologists, haematologists, ophthalmologists, child protection team.
11. Multisystem skin disorder – e.g. neurocutaneous disease, vasculitis, psoriatic arthritis, connective tissue disease, renal disease, immunosuppression
12. Rare disorders – e.g. immunobullous, lymphoma, hereditary angioedema, photodermatoses.
13. Skin problems in neonates
14. Rare genetic disorders – e.g. ichthyosis, xeroderma pigmentosum, ectodermal dysplasias
15. Epidermolysis bullosa (commissioned by National Specialist Commissioning Advisory Group from 2002/03)
16. Transplant Children may have complex dermatological problems e.g. Graft versus Host Disease, adverse drug reactions.

Table 4: Phototherapy Treatment

Location	Patients	Courses	<5 yrs	<10	5-15	16-20	Range
Argyll & Clyde	30	32	0	5	24	6	5- 16
Ayrshire	11	11	0	0	6	5	12- 16
Borders	2	2	0	0	2	0	14 -15
Dumfries	5	6	0	1	2	3	7 – 16
Fife	10	10	0	1	7	3	7 - 16
Grampian	13	13	0	1	13	0	8 – 15
GGHB	26	29	0	2	20	6	8 – 16
Highlands	4	4	0	1	2	2	6-16
Lanarkshire	27	30	1	6	21	5	0- 16
Lothian	16	16	1	3	10	5	0 - 16
Tayside *	45	48	0	6	32	13	8 -16

Table 5 Interdependence with Other Specialities

	Condition		Team	Others
Atopic Eczema	+ Food Allergy	SPT Dietary advice Food Challenges	Allergy Service Paediatric Dieticians Allergy Service	Respiratory and ENT
Atopic Eczema	Compliance Lack of self esteem		Dermatology Nurses Clinical Psychology	
'Sick Children'			Paediatric Nurses General Paediatricians	
Failure to Thrive	Food Allergy Coeliac disease	Investigations	Speech & Language General Paediatricians Feeding Team	
Chronic Pain	Epidermolysis bullosa (EB) Glomangiomas		Pain team	
Blistering Disorders	EB BIE	FTT Chronic pain Bone pain Teeth Mobility	Dietetics Pain team Endocrinology Dentists Appliances O/T Genetic counselling Psychology	
Complex Vascular lesions	Haemangiomas Periocular Laryngeal	Imaging US MRI Clinical Photography Rx	Radiologists Ophthalmology Interventional Radiology Surgery: General / Plastics	
Complex Vascular lesions	Capillary Malformations Venous Malformations	MRI	Neurology (fits) Laser unit Interventional radiology	
Pigmented & other Naevi		MRI	Surgery: General / Plastics	
Lumps Bumps	Dermoid cysts	MRI	General / Plastic / ENT Surgeons	
Difficult dermatoses & skin tumours			General Surgeons Dermatopathologists	
Birthmarks	Lack of self esteem Bullying at school	Clinical Photography	Cosmetic camouflage Clinical psychology	Red Cross
Connective Tissue Diseases	SLE CDLE Dermatomyositis	MRI	Rheumatologists Immunologists	
Genodermatoses	Neurofibromatosis Incontinentia pigmenti		Genetic counselling	

Table 6: RHSC Dermatology Nurse Services

	01/01/06/ - 31/12/06
Referrals	
Review	522
Bloods	130
Cryotherapy	90
Biopsy	80
Patch Test	30
Total Referrals	852
Clinic Attendance	
Total appointments booked for nurse run clinic	1786 *
DNA	297
UTA/ cancelled	343
Total Attended *	1146
Patients from clinic for demo/education	370
Patch Test	38pts = 114 appointments
Biopsy	70

Table 7 Teaching Centres in Scotland: Paediatric Dermatology

	Aberdeen	Dundee	Edinburgh & Lothian	Glasgow 2006/07
WTE	0.4	0.8 (1.0: 1/4/08)	0.4 WTE	2.2 WTE
Cut-off age	14-16	16	12	14
Clinics	2	3 + OR		12
New	488	Ω 1000	1352 (263)	1732
Reviews	206	Ω 1000	2458 (413)	4835
Child friendly OPD	Yes	Yes	No	Yes
Specialist				
Minor Surgery/ Month	3 -5	< 1	4	8 -10
Patch test / month	3	4 (adults)	Yes (adults)	4-6
Paediatric Dietician	Yes ND	Yes ND *	Yes (adults)	Yes 0.5D +
Psychologist /week	Yes ND	Yes ND *	Yes (ND)	2 sessions: D
Phototherapy /month	1	4	< 1	< 1
Laser	No	Yes	Plastics	Plastics
Vascular / year	No	Ω 4 yr	No	Ω 4 yr
EB	No	1	Yes	3
Genetics	No	4	No	2
Connective Tissue	No	No	2	4
In-patients				
In- patients	Paed beds	Paed beds		Paed Beds
Care	Shared	Shared		Shared
Nurse led clinics	No	Yes	Yes (A & C)	Yes
Reviews		Yes	Yes	Yes
News (Consultant)		Yes		Yes (FA)
Direct referrals		No	Yes	No
Community			Yes (A & C)	No
Specialist clinics				Cryotherapy

Key: D = Dedicated

ND Not dedicated

Table 8: District General Hospitals

	N Argyll	Clyde /GGHB (S Argyll)	Ayrshire	Dumfries	Fife	Forth Valley	Lanarks
WTE	Single	2.6	4.2	Single	2.7	2	5
Dedicated Paed		0.1				0.2	
Cut-off age	NA	16	< 14	N/A	16	<12	14-16
Clinics	(5)	1		4/5		1	
News	Ωm100	248	500	N/A	544	320	200
Reviews	Ωm100	491	1000	N/A	499	Ωm624	400
Child friendly OPD	Yes	Yes	Play materials	Yes	Yes	Yes	No
Specialist							
Minor Surgery/ mth	No	Rarely	< 1	No	4	1 (adults)	1-2
Patch test /month		Rarely (A)	1	No	< 1	1 (adults)	< 1
Paed Dietician		Yes ND	Yes	Yes	Yes D	Yes ND	N/A
Psychologist /week		No	Yes	Yes	Yes	Yes ND	No
Phototherapy /mth		4	Rarely	Yes	1	2	1
Laser		No	Plastics	No	Yes	No	Yes
Vascular / year	No	No	No		No	No	No
EB	No	No	No		No	No	No
Genetics	No	No	No	Yes	No	No	No
Connective Tissue	No	No	No		No	No	No
In- patients	No	Paed beds	Paed beds	Paed Beds	Paed Beds	Paed Beds	Paed beds
Care			Shared	Shared	Shared	Shared	Shared
Nurse led clinics	No	Yes	Yes (A & C)	Yes (A only)	Yes	Yes	Yes
Reviews		Yes	Yes	No	Yes	Yes	Yes
News (Consultant)		Yes	Yes	No	Some	Yes	Yes
Direct referrals		No	No	No	No	No	Yes
Community	Yes (Vof L)	Adults only		No			
Specialist clinics				No			

Key: D = Dedicated

A= Adults

ND Not dedicated C= Children

Table 9 Training Courses:

Paediatric Dermatology for Dermatologists:

- Annual Scottish Advanced Paediatric Dermatology Course in Dundee
5 day course in Dundee aimed at Consultants & Special Registrars towards end of training with a good basic knowledge of paediatric dermatology provides an update of paediatric dermatology. The lecturers who are specialists in the field from all over the UK and Ireland will be available to discuss short topics in depth
- Birmingham Paediatric Dermatology Course
5-day classroom-based course is aimed at Specialist Registrars and Consultants. Run conjointly with a paediatrician. Course covers general aspects of Child Health, including Child Protection, paediatric prescribing and paediatric life support. Teaching methods include lectures, videos, practical demonstrations and self-assessment quizzes. Numbers are limited to 40
- Liverpool: Alder hay Children's Hospital
This clinical course is held annually in Liverpool in September and is aimed at Specialist Registrars and recently appointed Consultant Dermatologists and Paediatricians. An important component of the course is small group clinical teaching. Numbers are limited to 12. 3 day course

Further details of the courses can be found on the British Association of Dermatologists website www.bad.org.uk

Paediatric Dermatology for Paediatricians:

3 day course in Paediatric Dermatology for Paediatricians at Birmingham Heartlands Hospital, aimed to equip Paediatricians to treat common skin disorders, to recognize rarer ones and when to refer to Dermatology colleagues. Granted in association status with the RCPCH.

Paediatric Dietetics:

The following post-graduate courses are currently available to dieticians:

Food Allergy

- British Dietetic Association- Post Graduate Paediatric Dietetics Course, accredited to Masters level. Module 2 of this course includes food allergy, nutrition support and enteral feeding.
- British Dietetic Association - Introduction to Food allergy.
- Southampton University -MSc Allergy. The module, "Dietetic management of Allergic Disease", is a 2 day course, with additional assignments and clinic visits. This is the most advanced allergy course available to dieticians at present.

Epidermolysis Bullosa

- EB periodic study days at held at Great Ormond Street Hospital, London. Information on nutrition support and enteral feeding is also provided as part of the Paediatric Dietetics course, above.

Table 10 Voluntary Organisations: Support Groups

Skin Care Campaign Scotland 0131 539 5123 www.skincarecampaign.org

Acne Support Group 0870 870 2263 www.stopspots.org
Allergy UK 01322 619 898 www.allergyuk.org
Alopecia Awareness 01726 814 371 www alopecia-awareness.org.uk
Alopecia UK 0208 333 1661 www alopeciaonline.org.uk
British Association of Skin Camouflage 01625 871 129 www.skin-camouflage.net
British Red Cross (Camouflage Service) 020 7877 7284
www.redcross.org.uk/skincamouflage
Caring Matters Now 07970 498 787
Changing Faces 0845 4500 275 www.changingfaces.org.uk
Contact a Family 0207 608 8700 www.cafamily.org.uk
DeBRA (Epidermolysis Bullosa) 01344 771 961 www.debra.org.uk
Ectodermal Dysplasia Society 01242 261 332 www.ectodermaldysplasia.org
Hyperhidrosis Support Group www.hyperhidrosisuk.org
Ichthyosis Support Group 0845 602 9202 www.ichthyosis.org.uk
Latex Allergy Support Group 07071 225838 www.lasg.co.uk
Let's Face It 01843 833 724 www.lets-face-it.org.uk
Lupus UK 01708 731251 www.lupusuk.org.uk
Lymphoedema Support Network 0207 351 4480 www.lymphoedema.org/lsn
National Eczema Society 0870 241 3604 www.eczema.org
National Lichen Sclerosus Group 07765 947 599 www.lichensclerosus.org
Neurofibromatosis Association 020 8439 1234 www.nfauk.org
Primary Immunodeficiency 020 7976 7640 www.pia.org.uk
Pseudoxanthoma Elasticum (PXE) 01628 476 687 www.pxe.org.uk
Psoriasis Association 0845 6760 076 www.psoriasis-association.org.uk
Psoriatic Arthropathy Alliance 0870 770 3212 www.thepaa.org
Raynaud's & Scleroderma Association 01270 872 776 www.raynauds.org.uk
Scleroderma Society 020 8961 4912 www.sclerodermasociety.co.uk
Skin Camouflage Network 0161 485 1196 www.skincamouflagenetwork.co.uk
Tuberous Sclerosis Association 0121 445 6970 www.tuberous-sclerosis.org
Vitiligo Society 0800 018 2631 www.vitigosociety.org.uk
Xeroderma Pigmentosum (XP) 01494 890 981 www.xpsupportgroup.org.uk

January 2007, British Association of Dermatologists: www.bad.org.uk

Useful web sites for patient information sheets

British Association of Dermatologists: www.bad.org.uk
New Zealand Dermatological Society: www.dermnetnz.org
American Academy of Dermatology www.aad.org/public

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Consultant Dermatologist RHSC Glasgow

Dermatologists: Dr Clare Fitzsimmons Consultant Dermatologist
Royal Alexandra Infirmary Paisley

Dr Sheena Russell Consultant Dermatologist
Queen Margaret Hospital Dunfermline

Nurse: Barbara Page
Clinical Nurse Practitioner NHS Fife

Dietician Pauline Waugh RHSC

Clinical Psychologist Kathleen McHugh
Royal Hospital for Sick Children, Glasgow

Advisors:

Dr Sue Lewis- Jones Consultant Dermatologist Ninewells Dundee

Prof Colin Munro Consultant Dermatologist South Glasgow GGHB

Dr Paula Beattie Consultant Dermatologist RHSC

Dr Nigel Burrows Consultant Dermatologist (Chairperson of the BSPD)
Addenbrooke's Hospital, Cambridge

Dr Claire Benton Consultant Dermatologist Royal Infirmary Edinburgh

Appendix 1: Questionnaire
Specialist Review of Paediatric Dermatology

Background: (see attached file)

In brief: the Scottish Office is reviewing Specialist Services for Children in Scotland and is currently looking at Dermatology.

This aims to cover:

- definition and scope
- incidence and prevalence
- mapping of current provision
- current practice
- workforce planning and training
- quality standards and outcome indicators
- involvement of stakeholders
- options for service delivery

We therefore need to know:

- What is happening currently
- Future Plans
- What we need to make this happen

Stage 1: mapping of current practice:

- Who is providing the service?
- What services are we providing for children with skin problems?
- Where is the service delivered

So please complete the following questionnaire. If you think there are any glaring omissions or you provide services not covered please feel free to add these.

Staffing

1. Do you work in a DGH Yes No
2. Do you work in a Teaching Hospital Yes No
3. Do you work Single handed Yes No
4. Age: What is your cut off age for children < }

Other: please give details

5. If you work in a department how many of the team see children:

No of Consultants seeing children	
No NCGS seeing children	
Others eg Trainees, Clinical Assistants	

6. Does any doctor(s) have a special interest in Paed Derm Yes No
 Comments:

7. **Numbers: Clinics / week** **No Staff / clinic**

8. **Children seen per clinic** New Reviews

9. **Children seen per year** New Reviews

10. **Total children seen in Dept**

If your Records department can give you figures please include as much information as possible. Otherwise give as an accurate estimate as you can.

11. **Breakdown by age : if available**
eg under < 2 years 2-5 years 5-12 years
12-16 years

If your Records department can give you figures please include as much information as possible. If they use different bandings please specify

12. **Change of age** If the cut off age was risen to 16 what impact would that have on your clinics

13. Location: Where are the children seen?

- General Out Patient Department (adult hospital) Yes No
- Dermatology out-patients (adults & kids) Yes No
- **If yes:** is there a dedicated child friendly area Yes No
- Children's Hospital / Clinic Yes No
- Other

Comments:

14. Other health Professionals: Do other health professionals see children

Yes No

eg Paediatricians Yes No Nurses Yes No

Others Yes No

If yes: please forward this questionnaire to them or let me know & e-mail address & I will forward a questionnaire to them

15. Specialist Services: for children:

- Biopsy Yes No Nos/ month..... Where done
- Patch Test Yes No Nos/ month..... Where done
- Paediatric Dietician Yes No Dedicated Yes No
- Psychologist Yes No Dedicated Yes No
- Phototherapy Yes No Nos /month..... Where done.....
- Laser Yes No Within dermatology Yes No
 By others eg plastic surgeons Yes No

Any comments

16. Combined Clinics: Do you run any combined clinics eg

- vascular Yes No
- genetics Yes No
- EB Yes No
- Connective tissue Yes No
- Other please specify

If yes Please give further details eg

- Members of team;

- Frequency of clinic

- No of children seen New Revi

Any comments:

17. Nurses

- Are there dedicated dermatology nurses Yes No
- Do the nurses see:
 - Only adults Yes Adults & Children Yes Only children
- Are there dedicated community liaison nurses Yes No
- Do the community nurses see:
 - Only adults Yes Adults & Children Yes Only children

18. Nurse led clinics:

- Do nurses do nurse- led clinics: Yes No
- Are these independent nurse-led clinics Yes No
- Do they see Reviews only Yes No
- Do they see new referrals Yes No (with consultant cover)
- Do nurses receive direct referrals with no medical input
Yes No
- Do nurses do any specialist clinics eg cryotherapy Yes No
 - laser Yes No
 - biopsy Yes No
 - patch test Yes No

Others; please give details

Any Comments:

Please feel free to expand any section & give more details & to pass form on to others

