

PE1682/C

Scottish Government submission of 17 June 2019

Thank you for seeking the Scottish Government's views on the two questions set out below in connection to the above petition.

The Scottish Government is committed to ensuring everyone living in Scotland is able to access the best possible care and support, and benefit from healthcare services that are safe, effective and put people at the centre of their care.

It may therefore be helpful to first set out the context of policy developments underway to improve the way services are delivered for people living with dermatology conditions, such as hidradenitis suppurativa.

Dermatology is one of the specialties involved in the Scottish Government's Modern Outpatient Programme. A series of design workshops have recently been conducted with representatives from healthcare professionals, third sector organisations and people with lived experience from across Scotland to consider ways to sustainably improve dermatology patient pathways, waiting times and outcomes. A report will be published in coming weeks that includes recommendations in four areas including inflammatory skin diseases. The recommendations will be taken forward with national support by dermatology services.

The Modern Outpatient Programme is also supporting work in relation to the dermatology nursing workforce within NHS Scotland. National Dermatology Improvement Nurses are currently working to standardise training provision, to develop new training materials (including both practical training courses and desk-based learning resources) and to develop cascade trainers to ensure training is rolled out consistently at a local level. Current education resources, future service developments, gaps in current training provision, future training need and barriers and facilitators to education have been identified and training materials are being developed.

Another development supported by the Modern Outpatient Programme is the creation and launch of a Dermatology Patient Management Pathways Website and Mobile App. This provides an accessible resource, which is intended to support Primary Care practitioners in Scotland in the diagnosis and management of patients presenting with common skin conditions. The pathways are designed to be a helpful, easily-accessible resource that reflects expert opinion and good practice recommendations. They are not intended to be a comprehensive overview and have deliberate focus on treatments available to prescribe in Primary Care. The website and App can be accessed via this link:

<http://www.dermatology.nhs.scot/dermatology-pathways/pathways/>.

In relation to the questions posed:

1) Whether the Scottish Government considers there to be enough people in Scotland with hidradenitis suppurativa to run a highly specialised clinic?

NHS National Services Scotland guidance states that specialist services are established for conditions requiring diagnosis and/or treatment that are rare and/or unpredictable and have low incidence. (Usually no more than 500 patients in a one year period). The prevalence of hidradenitis suppurativa is estimated at 1% of the UK population therefore it may be more than specialist services are designed for. NHS Information Services Division (ISD) may be able to provide an indication of prevalence for Scotland through the new data system in development for primary care (SPIRE). The functionality to extract data will be available later this year. ISD is accepting extract requests currently, however, which can be completed online at <https://spire.scot/professional/data-request/>.

All territorial boards in Scotland currently provide services to treat this condition delivered by dermatologists with input from regional plastic surgery services (as people can require surgical excision of the apocrine sweat glands that are chronically inflamed and infected).

Anyone can propose a national/specialist service. For example, proposals may be submitted by clinicians, supported by their NHS Board; by NHS Boards, Regional Planning Groups, or other national groups, and could concern, for example:

- existing services provided for only part of Scotland, which proposers wish to extend to provide treatment for all residents of Scotland with similar needs; or
- new developments involving recently proven techniques; or
- services not currently provided in Scotland for which patients have to travel to England or abroad; or
- gaps in current provision for which there is an established patient need.

Full details and outline submission templates are available at <https://www.nsd.scot.nhs.uk/about/nssc.html>.

NHS National Services Scotland has advised it has not been contacted by any clinicians seeking national designation of a service for this condition.

2) In recognising there is currently no SIGN guidance for hidradenitis suppurativa, who would be responsible for prompting the development of this guidance?

Any group or individual can propose a guideline topic by completing a proposal form - <https://www.sign.ac.uk/propose-a-topic.html>. Proposals are initially considered by the SIGN Executive senior management team. SIGN will work with the proposer to further develop the proposal by carrying out scoping searches to gauge the quantity of supporting evidence. This includes seeking additional relevant public health and epidemiological information and input from patient representatives.

Completed proposal forms are considered by the Guideline Programme Advisory Group (GPAG), a subgroup of SIGN Council. GPAG selects which proposals should be accepted for guideline development using the following criteria:

- Areas of medical uncertainty as evidenced by wide variation in practice or outcome;

- Conditions where effective treatment is proven and where mortality or morbidity can be reduced;
- Iatrogenic diseases or interventions carrying significant risks or cost;
- Clinical priority areas for NHS Scotland; and
- the perceived need for a guideline, as indicated by a network of relevant stakeholders.

The prioritisation and selection undertaken by GPAG is discussed and ratified by the SIGN Council.

I hope the Public Petitions Committee will find this information helpful.