The Scottish Parliament
Pàrlamaid na h-Alba

PUBLIC PETITIONS COMMITTEE

AGENDA

5th Meeting, 2021 (Session 5)

Wednesday 24 February 2021

The Committee will meet at 9.30 am in a virtual meeting and will be broadcast on www.scottishparliament.tv.

1. **Decision on taking business in private:** The Committee will decide whether to take items 3 and 4 in private.

2. **Consideration of continued petitions:** The Committee will consider the following continued petitions—

   PE1662: Improve Treatment for Patients with Lyme Disease and Associated Tick-borne Diseases and will take evidence from Mairi Gougeon, Minister for Public Health and Sport; Dr Gill Hawkins, Senior Medical Officer Health Protection and Public Health; and Professor Tom Evans, CMO Specialty Adviser in Infectious Diseases, Scottish Government.
   PE1804: Halt Highlands and Islands Airports Ltd's Air Traffic Management Strategy and will take evidence from Michael Matheson, Cabinet Secretary for Transport, Infrastructure and Connectivity; and Gary Cox, Head of Aviation, Transport Scotland.

3. **Review of the Public Petitions system:** The Committee will consider a paper on the Review of the Public Petitions system.

4. **Annual report:** The Committee will consider a draft annual report for the parliamentary year from 12 May 2020 to 24 March 2021.

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The papers for this meeting are as follows—

Agenda item 2

PRIVATE PAPER	PPC/S5/21/5/1 (P)
Note by the Clerk	PPC/S5/21/5/2
PRIVATE PAPER	PPC/S5/21/5/3 (P)
Note by the Clerk	PPC/S5/21/5/4

Agenda item 3

PRIVATE PAPER	PPC/S5/21/5/5 (P)

Agenda item 4

PRIVATE PAPER	PPC/S5/21/5/6 (P)

Public Petitions Committee

5th Meeting, 2021 (Session 5)

Wednesday 24 February 2021

PE1662: Improve Treatment for Patients with Lyme Disease and Associated Tick-borne Diseases

Note by the Clerk

Petitioner	Janey Cringean and Lorraine Murray on behalf of Tick-borne Illness Campaign Scotland
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to improve testing and treatment for Lyme Disease and associated tick-borne diseases by ensuring that medical professionals in Scotland are fully equipped to deal with the complexity of tick-borne infections, addressing the lack of reliability of tests, the full variety of species in Scotland, the presence of 'persister' bacteria which are difficult to eradicate, and the complexities caused by the presence of possibly multiple co-infections, and to complement this with a public awareness campaign.
Webpage	parliament.scot/GettingInvolved/Petitions/lymedisease

Introduction

1. This is a continued petition, last considered by the Committee on 16 December 2020. At that meeting, the Committee agreed to invite the Minister for Public Health and Sport and the Chief Medical Officer to give evidence at a future meeting.

2. At this meeting, the Committee will take evidence from Mairi Gougeon MSP, Minister for Public Health and Sport, and, in place of the Chief Medical Officer, Gill Hawkins, Senior Medical Officer in Health Protection and Professor Tom Evans, CMO Specialty Adviser in Infectious Diseases.

3. The Committee is invited to consider what action it wishes to take.

Committee consideration

4. During its last consideration of the petition, the Committee discussed several issues highlighted in the written submissions received from the then Minister for Public Health, Sport and Wellbeing, Professor Lambert, Dr Cruikshank and the petitioners. These issues included—

    - The need to raise awareness of, and improve training on Lyme disease, amongst primary and secondary care teams to combat a lack of

experience, understanding and confidence in the diagnosis and treatment of patients.

- A lack of understanding regarding tick-borne infections as well as a lack of understanding regarding appropriate tests, the sensitivity of those tests and the possibility of co-infections.

- The need to raise public awareness, which could lead to better tick avoidance behaviour, early correct tick removal and early presentation to a primary care clinician should symptoms of Lyme disease develop.

- 10-20% of Lyme disease infections result in persistent symptoms so there is a need to better understand and be able to treat and support patients with chronic and persistent symptoms of Lyme and other tick-borne infections.

- Antibody testing is the routine diagnostic test methodology for Lyme disease world-wide and the antibody testing protocol used by Scottish Lyme Disease and Tick-Borne infections Reference Laboratory (SLDTRL) can detect all the main pathogenic genopecies of Borrelia burgdorferi sensu lato.

  Professor Lambert states in his 31 October 2020 submission, however, that the antibody test misses many cases of Lyme. He furthers states that there is a lack of understanding of appropriate tests, the sensitivity of these tests, and little availability of testing of other infections that ticks can carry, that can also infect humans. He has therefore called for a review of current testing strategies.

- The need for more research on Lyme disease. In their written evidence, Dr Cruikshank stated that the NICE Guideline is restrictive, and its recommendations based on poor-quality evidence. Professor Lambert has called for funding to be made available so that more research can be conducted on tick-borne infections, their impact on humans and animals and optimal treatments and interventions can be developed.

Action

The Committee is invited to consider what action it wishes to take. Options include—

- To continue this petition and include it in its legacy paper for its successor Committee, along with a suggestion to seek an update from the Scottish Government on any progress made to address the issues raised during the evidence session;

- To take any other action the Committee considers appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- PE1662/PP: Minister for Health, Sport and Wellbeing submission of 30 October 2020 (152KB pdf)
- PE1662/QQ: Professor John S Lambert submission of 31 October 2020 (91KB pdf)
- PE1662/RR: Dr Anne Cruikshank submission of 23 November 2020 (68KB pdf)
- PE1662/SS: Petitioner submission of 3 December 2020 (108KB pdf)

All written submissions received on the petition can be viewed on the petition webpage.

PE1662/PP
Minister for Health, Sport and Wellbeing submission of 30 October 2020

Thank you for your letter of 09 October 2020, to Cabinet Secretary for Health and Sport regarding the petition PE1662: **'Improve Treatment for Patients with Lyme Disease and Associated Tick-Borne Diseases'**. As the Minister with responsibility for Public Health I am responding.

You highlight the petitioners' most recent submission, PE1662/OO, and have asked for a response to the points raised in that submission. You indicated that the Committee is particularly concerned at the reports from the petitioner that:

- The RCGP Lyme Disease Spotlight Project has been "shelved", without any apparent education being delivered to Scotland as part of it;
- The patient representative on the Scottish Health Protection Network (SHPN) Tick Borne Diseases subgroup "is not resident in Scotland, is not a patient of NHS Scotland, does not have Lyme disease, and does not have regular contact with Scottish patients";
- The issues raised regarding antibody testing

The Scottish Government takes the issue of Lyme disease very seriously and, together with Health Protection Scotland, is committed to raising awareness and supporting those affected.

As officials have stated in our previous responses, the Scottish Government receives expert advice on Lyme disease and tick-borne infections from the multi-disciplinary, multi-agency Scottish Health Protection Network (SHPN) Tick Borne Diseases subgroup previously known as Lyme Borreliosis group. Membership of this group is drawn from a wide variety of expertise, and includes Infectious Disease Consultants, Pharmacists, Microbiologists, Veterinary Advisors, Primary Care Physicians, Health Protection Teams, Tick Ecologists, and representatives from Environmental Health, Health and Safety Executive, the Forestry Commission, NHS Education for Scotland, NHS24, Public Health England, Scottish Government and Health Protection Scotland.

So that answers can be provided as fully as possible, this response has again been developed with input from the SHPN Tick Borne Disease sub group and the Scottish Lyme Disease and Tick-Borne infections Reference Laboratory (SLDTRL).

Education and Training

While I cannot comment on the independent Royal College of General Practitioners (RGCP) submission or the Lyme Disease Spotlight project, education and training in Scotland has been and will continue to be developed. NHS Education for Scotland (NES) has hosted a 90-minute webinar entitled 'Lyme Disease in Scotland: Clinical Update' on 28th July 2020. Topics included: 'How do we learn to live with ticks?'; 'How do we diagnose and treat Lyme disease?' and 'What are the clinical dilemmas in management and future for testing?' Speakers included a GP, two infectious diseases consultants, a representative from Public Health Scotland and a Clinical Scientist from the Scottish Lyme Disease and Tick-borne infections Reference Laboratory (SLDTRL). The webinar was open to a wide range of healthcare practitioners, including clinicians, pharmacists, scientists, laboratory and primary care staff and was attended by approximately 300 individuals. I understand feedback has been very positive.

As noted in the Scottish Government's previous response to the petition, the SLDTRL is involved in the multiyear European funded Northtick project. One of the local project objectives is to work with GP practices within NHS Highland to identify ways to improve managing patients with suspected Lyme disease and more accurately estimate the number of such patients within primary care. At the beginning of the year, all GPs in NHS Highland were contacted, and discussions were held with the NHS Highland GP subcommittee, and those in NES involved in GP training within NHS Highland, with the offer to facilitate educational sessions on Lyme disease in primary care. These sessions commenced at the beginning of March but had to be postponed due to the COVID-19 pandemic. I understand the intention is to recommence this work, possibly in a more 'virtual' format, but the ultimate aim is to roll out the work nationally, potentially in collaboration with NES/SHPN.

The Northtick project also aims to develop tools to meet the challenges of tick-borne diseases other than Lyme disease (i.e. Anaplasmosis, Babesiosis, Neoerlichiosis, Tick-borne encephalitis and *Borrelia miyamotoi*) and work is already underway to gather information on the epidemiology, diagnosis and management of these diseases within each of the 7 different partner countries. This knowledge sharing and gap analysis activity will allow a determination of the optimal diagnostic strategies and best patient management recommendations. At the end of the project, this information will be used to educate and inform health practitioners and stakeholders in each partner country and to form testing and management strategies.

Patient representation on the SHPN Tick Borne Diseases subgroup

Nicola Rowan (Manager of the Scottish Health Protection Network) and Dominic Mellor (co-chair of the SHPN Tick Borne Infections subgroup) met with representatives of the Lyme Resource Centre early in 2020. In that meeting, I understand it was made clear that the SHPN is a network for health professionals to support professional learning, education and collaboration concerned with health protection. Although clinicians are included in some of the SHPN groups, as clinical practice and health protection are closely linked, clinical management and diagnosis of individual patients is not within the scope of the network and therefore patients are not specifically represented. The network also engages with third sector and health care professionals pertinent to the health protection topic areas, many of whom are working directly with the public, but again, their role is not to represent individual patients.

Testing

The antibody testing protocol used by SLDTRL can detect all the main pathogenic genopecies of *Borrelia burgdorferi* sensu lato: *B. burgdorferi* sensu stricto *B. afzelii, B. garinii, B. spielmanii* and *B. bavariensis*. Antibody testing is still the routine diagnostic test methodology for Lyme disease world-wide. Indeed, antibody testing is the routine diagnostic test methodology for a wide variety of organisms, not least for HIV, Hepatitis B and C.

With regard to petitioners' reference to a recent meta-analysis of test kits which found that *'The mean sensitivity of all test kits with all samples was 59.5%, and ranged from 30.6% to 86.2%.'* I have been informed that this statement does not take into account the stage of disease. Whilst it is widely acknowledged that the sensitivity of antibody tests can be reduced in the early stages of disease (which is why a second follow-up sample is always requested in these patients, and why patients presenting with the characteristic erythema migrans rash should be treated without testing), sensitivity is extremely high within 8-10 weeks. Indeed, the aforementioned review found sensitivity in patients with early disease to be 35.4-46.5% but rose to 87.3-95.8% for patients with disseminated symptoms. Similarly, in-house verification of the screening tests currently in use at SLDTRL found that sensitivity was 61.3%

when tested on patients with early disease but rose to 100% for those with clinically confirmed late disease. In addition to antibody testing, SLDTRL, also offers a molecular test that can detect the DNA of all Borrelia genospecies (both the Lyme disease and the relapsing fever forms).

SLDTRL is committed to investigating new testing methods and technologies and is constantly aiming to adapt and improve the service provided. However, as the NICE guidelines state, tests should only be used if they have been sufficiently validated, and this validation should include peer-reviewed published evidence on the test methodology, its relation to Lyme disease and independent reports of performance. To their knowledge, there are no other tests available that fulfil these criteria.

The petitioners state that *'many patients are being diagnosed in private testing for Babesia, Bartonella, Anaplasma, and Rickettsiae species but tests for many of these infections are impossible to get via NHS Scotland. Many GPs have never heard of these infections, and yet they have been found in abundance in animals.'* My understanding is that the petitioners are correct that SLDTRL offers molecular testing for Anaplasmosis. However, due to the low incidence of this disease in Scotland (and thus lack of positive samples) the test has not yet been included in scope for UKAS accreditation. There is the facility to send samples to Public Health England for antibody testing. The same service is provided for suspected Rickettsial infections. Whilst Babesia can be diagnosed by any hospital blood sciences laboratory via examination of blood smears, SLDTRL has recently formed a collaboration with the Moredun Research Institute, University of Glasgow, Public Health Scotland and the Scottish Parasite Diagnostic Reference Laboratory to look at developing other testing methodologies. Although Bartonella is a recognised disease in the UK, it has not been established as a tick-transmitted infection. Whilst ticks may take blood meals from animals infected with Bartonella species, transmission to humans has not been confirmed.

The Scottish Government remains committed to understanding more about Lyme disease and related conditions, and recognises the severe challenges faced by those who suffer from them. We appreciate that there remains much to do to improve understanding of these conditions, and are committed to working with partners to reduce their impact on the lives of people in Scotland.

PE1662/QQ
Professor John S Lambert submission of 31 October 2020

Further to my submission of 15 February 2020, PE1662/DD, I would like to reiterate that I strongly agree with this petition.

As a clinician in the area of tick-borne infections, I have treated many Scottish patients who have requested consultations by me. These consultations have identified to me that:

- Tick-borne infections are not well understood by many Scottish doctors, GPs and consultants alike, and there is little training for health care providers covering the condition commonly called 'Lyme disease'.
- There are many 'missed diagnoses' of Lyme disease that could have been avoided through appropriate education of the doctors involved.
- Many Scottish doctors depend on the Lyme antibody test, which misses many cases of Lyme, and that there is a lack of understanding of appropriate tests, the sensitivity of these tests, and also that there are other infections that ticks can carry, that can also infected humans. Currently there is little availability of testing for these 'co-infections' (for example Rickettsiae, Anaplasma, Babesia) and thus patients are not appropriately diagnosed and treated. Many patients go to foreign private laboratories to get testing; and are then told by the Scottish doctors that the tests are not licensed and not accredited, when indeed they are licensed and accredited.
- There is only a limited understanding of the acute phase of Lyme, early Lyme infection, and treatment guidelines only exist to diagnose and treat those with early infection. If you have longer term infection (commonly called 'chronic Lyme disease', and have longer term symptoms beyond the acute infection stage, there is no Scottish plan to evaluate, diagnose, treat and support these patients.
- Scotland has one of the higher seroprevalence of tick-borne infections in the UK, and yet there is a lack of critical preventive messages to inform the public of 'tick awareness' and virtually no campaigns to educate the public to enhance their awareness of tickborne infections. There is an absence of signage in outdoor and recreational areas where ticks are prevalent and Scots and tourists are visiting. USA has tick warning sites in most recreational sites, Scotland has almost none. The incidence of tick-borne infections are very similar in these two countries. Why is there such a difference in the approaches used between these countries in providing prevention messages; an ounce of prevention is worth a pound of cure.

I have established a Lyme Resource Centre in Scotland to form a platform to better understand of the impact that tick-borne infections are having in Scotland. On our website are a number of scientifically reviewed and approved publications in the medical literature. Many of these publications have not been included in either Scottish or UK governmental documents regarding Lyme disease. I feel the most up to date information should be made available to the Committee and the Scottish Government.

- Epidemiology studies show increasing incidence of multiple tick-borne diseases in Scotland [i] [ii] [iii] [iv].
- Testing has been shown by numerous studies to be insensitive, and misses many cases of clinical infection with Borrelia, the Lyme bacteria, as well as there are no tests available for the co-infections. Ticks spread other infections besides Borrelia. [v] [vi] [vii].
- Studies and clinical experience show that patients get better with long-term antibiotic treatment, as they do not always respond to the standard 'shorter course guidelines.

No other infection besides Borrelia has strict limits on treatment, as no 'one size fits all' for infectious diseases. (Currently Scottish patients are denied longer course treatments, based on English NICE guidelines, when it is deemed clinically necessary) [viii] [ix].

- Persistent infection has been demonstrated by multiple researchers [x] [xi] [xii] [xiii] [xiv] [xv] [xvi] [xvii].
- Co-infections have been found to be the rule and not the exception and yet are virtually ignored in Scottish patients [xviii] [xix] [xx] [xxi]

I suggest the following actions be initiated and followed through to completion.

1. Include tick-borne diseases as a major remit in the health protection efforts of Public Health Scotland [1] including coordination of a strategic national plan to deal with all aspects of tick-borne diseases.
2. Testing:
    a. Review current testing strategies for tickborne infections performed within Scotland and the UK, and in parallel assess the 'private' tests that Scottish people are obtaining as a result of their perceived limitations of current testing.
    b. Establish testing for all co-infections and improved testing for Lyme disease which does not rely on antibody response alone (ie PCR).
3. Fund research to
    a. Identify all tick-borne infections in Scotland
    b. Identify the true burden of infection and illness from tick-borne infections in humans and animals in Scotland
    c. Understand the impact of polymicrobial co-infections on human health
    d. Research optimal treatment for persistent infections and interventions to support recovery
4. Education:
    a. Educate the community, including outdoor signage
    b. Train GPs and specialists in diagnosing and treating all tick-borne diseases
5. Allow appropriate representation on the Scottish Health Protection Network (SHPN) Tick-borne Diseases subgroup of qualified Lyme experienced clinicians and patients who have been affected by Lyme. Currently the Scottish patient group representative is an English doctor who neither has Lyme infection nor has any communication or understanding on the patients in Scotland who are experiencing problems with accessing care and support for their conditions. This lack of true Scottish patient group representation is unacceptable and needs remediation.
6. Establish a multidisciplinary treatment service for the evaluation, support and management of patients with chronic and persistent symptoms of tick-borne infections.

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[i] Millens C et al., Emergence of Lyme disease on treeless islands in Scotland, UK. bioRxiv 2020.08.31.263319; doi: https://doi.org/10.1101/2020.08.31.263319

[ii] Gray A et al., Sheep as Host Species for Zoonotic Babesia venatorum, United Kingdom. Emerg Infect Dis. 2019 Dec;25(12):2257-2260. doi: https://doi.org/10.3201/eid2512.190459

[iii] Bartley PB et al., Detection of Babesia DNA in blood and spleen samples from Eurasian badgers (Meles meles) in Scotland. Parasitology. 2017 Aug;144(9):1203-1210. doi: https://doi.org/10.1017/S0031182017000476

[iv] Hagedorn P et al., Human Granulocytic Anaplasmosis Acquired in Scotland. Emerg Infect Dis. 2014 Jun; 20(6): 1079–1081. doi: https://doi.org/10.3201/eid2006.131849

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[1] https://www.publichealthscotland.scot/our-areas-of-work/protecting-our-health/overview-of-how-we-work-to-protect-health/

[v] Ang CW, et al., Large differences between test strategies for the detection of anti-Borrelia antibodies are revealed by comparing eight ELISAs and five immunoblots. Eur J Clin Microbiol Infect Dis. 2011 Aug;30(8):1027-32. doi: https://doi.org/10.1007/s10096-011-1157-6
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PE1662/RR
Dr Anne Cruikshank submission of 23 November 2020

As a General Practitioner based in Oxfordshire, I have a long-standing interest in Lyme disease, ever since a close family member contracted the infection in 2007. I fully support this petition and am grateful for the opportunity to submit comments from a primary care perspective. I note the submissions from Professor John Lambert, with which I fully concur.

I have managed several hundred Lyme disease patients within NHS and military primary care settings, as well as within a specialist Lyme disease clinic led by Dr Matthew Dryden (lead microbiologist at the PHE Lyme Research Laboratory.)

In 2018 I was appointed as RCGP Clinical Champion for Lyme disease and led the RCGP Lyme disease Spotlight Project. The focus of this was to address the NICE Lyme disease Guideline (NG95) recommendation to 'raise awareness of the disease amongst both the medical profession and the general population'. The project was funded by charitable donations and ended in December 2019, following reorganisation within the RCGP.

The Spotlight team included GPs and Infectious diseases consultants with personal and professional experience of the disease. The key project outputs included the RCGP Lyme disease Toolkit, GP workshops, and promotion of the RCGP/LDA Lyme disease e-learning module. (Two Scottish workshops had been envisaged for 2020.)

The toolkit provides a single point of access to relevant and accredited information, including multiple links to Health Protection Scotland. Both the toolkit and the e-learning module are endorsed by the NICE Quality Standard on Lyme disease. Unfortunately, neither were mentioned in the Chief Medical Officer's letter of June 2019.

UK-wide surveys revealed that the majority of GPs reported limited experience or confidence in providing advice on tick avoidance, managing tick bites or diagnosing and treating Lyme disease.

Improving patient outcomes

Prevention

Since 10-20% of Lyme disease infections result in persistent symptoms the health and financial implications for individuals and society as a whole are significant.

With concerted effort, a public health campaign could effectively raise the profile of Lyme disease. A significant amount of educational material is already available, via a range of government, NHS, local and patient-led organisations.

Heightened public awareness would result in better tick avoidance behaviour, early correct tick removal and early presentation to a primary care clinician should symptoms of Lyme disease develop. An asymptomatic skin rash or 'summer flu' will hold more significance for individuals who are 'lyme aware'.

Primary Care

Early Lyme disease must be considered to be a ‘primary care illness’, with patients likely to present to GPs, practice nurses and community pharmacists. Uncertainty regarding the features of an erythema migrans (EM) rash or the relevance of a test result regularly results in missed or mis-diagnoses. This despite clear NICE guidance that

a) tick bites may go unnoticed,
b) an EM rash, if present, is diagnostic,
c) a negative test result does not exclude the diagnosis and
d) antibiotic treatment may be instigated based on clinical suspicion.

Most GPs are unaware of the genuine scientific uncertainties and ongoing research in relation to both diagnosis and treatment of this disease. They struggle to know how best to support patients with persistent symptoms. Meanwhile their patients often access more detailed information from accredited sites such as the Lyme Resource Centre, Lyme disease Action and Lyme disease UK, leading to a discrepancy in understanding which then serves to undermine the doctor-patient relationship.

Since early diagnosis and treatment provide the best chance of cure, an educational programme aimed at developing ‘Lyme Aware’ primary care teams could reduce the incidence of late or missed diagnoses, thereby reducing the risk of chronic debilitating illness and potential medical litigation.

Secondary Care

The inexplicable climate of controversy and litigation that surrounds Lyme disease has resulted in a reluctance to develop expertise within secondary care. Clinicians frequently report a limited understanding of the disease whilst still insisting that “Chronic Lyme disease does not exist”. Very few seem prepared to step outside of the restrictive NICE Guideline - despite the acknowledged poor-quality evidence upon which its recommendations are based. Those consultants who do attempt to follow non-UK guidelines are frequently disparaged by colleagues.

Significant progress could be achieved by the establishment of a Scottish multidisciplinary treatment service for the evaluation, support and management of patients with chronic and persistent symptoms of tick-borne infections

Meeting the challenge

Improving patient outcomes in relation to tick-borne diseases will require considerable commitment. Some aspects of the process could be initiated with relative ease, whilst others will take longer.

However, consideration of all that has been learnt and achieved during the present pandemic, highlights the certainty that, with team work, education, scientific curiosity and empathy, this challenge is not insurmountable.

PE1662/SS
Petitioner submission of 6 December 2020

Contrary to the Minister for Public Health's statement, we do not believe that Lyme disease is taken seriously. Government awareness since 2018 has consisted of one YouTube video and three tweets, reaching only a few thousand people. There are no clinical specialists in tick-borne diseases in Scotland, GPs have virtually no training, and patients have no forum. Scottish Health Protection Network (SHPN) developed leaflets haven't even been printed.

NHS Education for Scotland did not invite any specialists in tick-borne disease from outside Scotland to present at their webinar on Lyme Disease, perpetuating limited viewpoints within Scotland.

Patients have issues surrounding testing and public awareness which are not being addressed by SHPN.

SHPN has no remit to address clinical diagnosis and management. Patients want the role of Patient Commissioner to include issues of non-treatment. Lyme disease patients are given no support and no treatment, and yet private treatment for tick-borne infections allows many patients to recover fully.

Treatment guidelines in the USA which have sharply limited treatment have been proven to be compromised by corruption[1].

As many of the restrictive recommendations in the NICE guidelines are based on these guidelines, UK patients have been harmed by similarly limited treatment. Patients want the Government to write to all consultants/GPs to inform them that the IDSA guidelines are flawed and that they will be supported to treat beyond the NICE guidelines.

With regard to the Minister's submission, the meta-analysis of test kits does take account the stage of disease, in Table 4[2].

The Minister acknowledges it is difficult to detect early-stage disease, with sensitivity 35.4%-46.5%, rising to 87.3%-95.8% with disseminated symptoms. As approximately 60% of all true early-stage positive cases will be found negative, we would like to know how many 'follow-up' tests are requested and fulfilled and the 'follow-up' detection rate.

Despite the Minister's assertation, 'follow-up' tests are not always requested. In such cases, patients are left untreated and may development chronic systems. We conducted a survey of 57 patients tested by NHS Scotland when ill after a known tick-bite. More than 50% of patients with a negative early test were not tested again,

[1] https://www.lymeresourcecentre.com/news/979
[2] Cook MJ, Puri BK. Commercial test kits for detection of Lyme borreliosis: a meta-analysis of test accuracy. Int J Gen Med. 2016 Nov 18;9:427-440. doi: http://doi.org/10.2147/IJGM.S122313

and 68% were not tested until more than 10 weeks after the bite, inexplicable for a condition in which early treatment is key.

The Minister said "*in-house verification of the screening test … used at SLDTRL [Scottish Lyme Disease and Tick-borne Infections Reference Laboratory] found that sensitivity was 61.3% … for early disease but rose to 100% for those with clinically confirmed late disease*". We understand the laboratory use two-tier tests by Mikrogen and Trinity Biotech. We are alarmed that the Minister claims 100% sensitivity when the manufacturers do not[3][4]. All Mikrogen sensitivity data was based on including borderline results along with the positive tests[4]. Does this mean SLDTRL also include borderline results in their sensitivity studies, and report these to the clinician/patient?

Both companies also state that a negative test result should not be used to exclude Lyme disease. However, we do not believe that SLDTRL inform clinicians of this.

There is significant scientific evidence that, as with COVID-19, antibody response can be weak and that some patients with chronic Lyme disease do not develop antibodies. There are now over 50 medical journal articles documenting Lyme disease despite negative antibody tests. This research spans all stages of illness, including late stage disease.

We want to know which tests used by SLDTRL are excluded from ISO 15189 accreditation, and when will the laboratory be fully compliant with ISO 15189?

As stated in previous submissions, only 5 of the 300 known species of Borrelia are currently tested for in Scotland. Borrelia miyamotoi is known to exist in Scotland and scientists believe it is responsible for a significant proportion of illness[5]. SLDTRL's test for Borrelia miyamotoi is not ISO accredited or routinely used, leaving many patients undiagnosed. This may also be the case for other recently discovered species. There is also strong evidence that many Lyme disease patients are also infected with tick-borne co-infections, but SLDTRL has no ISO accredited tests any co-infections.

The Minister states "*there is the facility to send samples to Public Health England for antibody testing*". However, such tests are often refused, sometimes because GPs do not know how instigate this and often on the grounds of cost.

The Minister states: "*Although Bartonella is a recognised disease in the UK, it has not been established as a tick-transmitted infection*". Bartonella has now been

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[3] TrinityBiotech. Trinity Biotech Captia TM Borrelia burgdorferi IgG / IgM. Available from: http://documents.trinitybiotech.com/product documents/2346580-29 EN.pdf

[4] Microgen Diagnostics. recomLine Borrelia IgG/IgM Instructions for Use. 2019. Available from: https://www.mikrogen.de/english/downloads.html

[5] 2nd European Crypto-Infections Conference, Dublin, Ireland, 26th-27th Sept 2020.

accepted as a tick-transmitted infection by the US HHS Tick-borne Disease Working Group[6] and specialist testing has been developed[7].

Although diagnosis of tick-borne infections should be a clinical diagnosis supported by testing, many patients find that testing is used as the only deciding factor. When such limited testing is available, many patients are told it is all in their head and denied treatment which could allow them to recover.

There is now more evidence that this topic needs much higher profile discussion and action by the Government and NHS. We call on the Government and Petitions Committee to hold a round table involving both Prof. Lambert and Dr. Cruikshank, whose submissions we agree with, to hear in detail from them the issues of diagnosis and management of tick-borne diseases.

[6] US HHS Tick-Borne Disease Working Group, 2018 Report to Congress https://www.hhs.gov/sites/default/files/tbdwg-report-to-congress-2018.pdf
[7] https://www.galaxydx.com/

Public Petitions Committee

5th Meeting, 2021 (Session 5)

Wednesday 24 February 2021

PE1804: Halt Highlands & Islands Airports Ltd's Air Traffic Management Strategy

Note by the Clerk

Petitioner	Alasdair MacEachen, John Doig and Peter Henderson on behalf of Benbecula Community Council
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to halt Highlands & Islands Airports Ltd's Air Traffic Management Strategy Project to conduct an independent assessment of the decisions and decision-making process of the ATMS project.
Webpage	parliament.scot/GettingInvolved/Petitions/airservices

Introduction

1. This is a continued petition, last considered on 17 February 2021.

2. At that meeting, the Committee took oral evidence from representatives of Highlands and Islands Limited (HIAL), via video conference.

3. At the meeting today, the Committee will be taking oral evidence, via video conference, from Michael Matheson MSP, Cabinet Secretary for Transport, Infrastructure and Connectivity and Gary Cox, Head of Aviation at Transport Scotland.

4. The Committee is invited to consider what action it wishes to take.

Committee consideration

5. During the evidence session on 17 February, HIAL reiterated that its Air Traffic Management Strategy (ATMS) project was the only option that delivers all the requirements to secure the future of lifeline services, which are—

    - the opportunity to enhance safety,
    - to improve resilience,
    - a changing legislative framework,
    - ageing operating models, and
    - staff recruitment and retention issues.

6. On the question of costs, HIAL stated that the budget is £29.2m, with a contingency of £5.5m, making a total budget of £34.7m, and sought to assure the Committee that the project was on budget.

7. Various written submissions have suggested that Primary Surveillance Radar, which was not included in the original ATMS proposal, had subsequently been added to the project, adding significant costs.

8. In its evidence, HIAL rejected this suggestion, stating that Automatic Dependant Surveillance Broadcast (ADS-B) was, and continues to be, the technology preferred in the proposal.

9. HIAL acknowledged that there would be additional costs, should an alternative to ADS-B be required. It stated, however, that it anticipates that the Civil Aviation Authority will adopt ADS-B as the method of surveillance going forward.

10. HIAL confirmed that before the Covid-19 pandemic, its turnover of Air Traffic Control Officers was 5.9%, which is approximately twice the industry average. Although the organisation was unable to provide a breakdown of the turnover, by airport, it committed to provide that to the Committee.

11. On the issue of whether Air Traffic Control Officers (ATCOs) are willing to relocate to Inverness, HIAL explained that this is an extremely complex change management project. To be successful, there will need to be—

    - more staff recruited.
    - some staff who relocate, and
    - some staff who commute.

12. HIAL stated that it had revised its policies and commuting, and that both of these policies are currently being considered by the ATCOs' union, Prospect.

13. The organisation recognises that there will be staff who wish to remain on the Islands. It has committed to do all that is practicable to help all members of staff to find the right solution for them.

14. The organisation was unable to respond to questions concerning the independent Islands Impact Assessment and the independent review and objective health check which have been undertaken on the project, explaining that these will be considered by the HIAL board on 24 February.

15. HIAL assured the Committee, however, that it would provide more information regarding these reports following their consideration by the Board.

16. In relation to staff engagement, HIAL stressed that is has been engaging with its workforce throughout the project. The organisation highlighted action it was taking in response to concerns and suggestions such as—

    - updating its re-location and commuting policies; and

- creating an Aerodrome Flight Information Service Officers (AFISO) training facility on Benbecula.

17. Concerns have been raised that the change from Air Traffic Control to Aerodrome Flight Information Service at Wick and Benbecula will mean that these airports are no longer able to handle several aircraft simultaneously.

18. In response to this, HIAL explained that it anticipates no impact on the ability to manage current traffic levels, or even greater numbers as a result of this change.

19. Furthermore, HIAL noted that the AFISO teams at Wick and Benbecula will have enhanced situational awareness as a surveillance-based flight information display system is being installed. Both airports will also retain their full suite of instrument approach services and air traffic control systems.

20. HIAL highlighted that, as a result of the ATMS, airspace from approximately 15 miles from Wick will be controlled by a new radar service, operating from Inverness. HIAL explained that this will allow greater flexibility at Wick.

21. Concerns have been raised that changes at Wick and Benbecula will reduce access to only those operators 'approved' by HIAL. In its evidence, HIAL stated that it was in the process of removing the need for 'approved operators'. Access will therefore not be restricted.

22. A robust communications infrastructure is critical to the project. When asked whether each airport will be supported by multiple connections, HIAL responded that it would, although agreed to provide more detail to the Committee on this point.

23. The organisation did highlight that it is currently undertaking a project at Sumburgh to prove the feasibility of its communications plan there. If successful, it intends to roll out similar plans at its other airports.

24. HIAL stressed that the regulatory framework for remote towers has been in place since 2015, and that it will conform to that framework.

Action

25. The Committee is invited to consider what action it wishes to take on this petition. Options include–

    - To continue this petition and include it in its legacy paper for its successor Committee, along with a suggestion to seek an update from the Scottish Government on any issues of concern raised during the evidence session;

    - To take any other action members consider appropriate.

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting—

- PE1804/J: Highlands and Islands Airport Ltd submission of 29 October 2020 (98KB pdf)
- PE1804/T: Cabinet Secretary for Transport, Infrastructure and Connectivity submission of 5 November 2020 (59KB pdf)
- PE1804/FF: Highlands and Islands Airport Ltd submission of 10 December 2020 (117KB pdf)

All written submissions received on the petition can be viewed on the petition webpage.

PE1804/J
Highlands and Islands Airport Ltd submission of 29 October 2020

Thank you for your email of 2 October. HIAL appreciates the opportunity to provide more detail on the project whilst correcting misleading and inaccurate information presented by the petitioners.

HIAL provide lifeline and essential services to remote communities in the North and West of Scotland. Accordingly it must have resilient air traffic provision to ensure that lifeline services continue and importantly, are future proofed.

Since announcing the project in 2018, HIAL has presented the challenge of maintaining lifeline links in remote areas to a number of organisations and welcomes this further opportunity.

Notwithstanding the challenges of COVID, the original reasons for introducing the Air Traffic Management Strategy (ATMS) remain: the opportunity to enhance safety, improve resilience, a changing legislative framework, ageing operating models, staff recruitment and retention issues.

The impact of COVID in the short term, is recognised. However, over the medium to long term the issues remain.

To be clear, our first priority is - and will always be - safety. Neither HIAL, nor the CAA as regulator, would permit the installation of an air traffic management system that was not safe or fit for purpose. HIAL encourages the Committee, if not already done so, to seek the views of the CAA, the regulatory body with responsibility for aviation safety within the UK.

For petitioners to portray remote digital tower technology as unsafe and untested is uninformed and misleading. This technology has been operational since 2015. There are currently four other multiple airport digital tower operations in service or development, including two in Sweden, one in Norway and one in the United States.

Currently, Swedish, Norwegian, German, Dutch, Danish, Belgian, Irish and UK national Air Navigation Service Providers have either implemented, or are in the process of implementing, this technology, including one for London City, one of the busiest sections of managed airspace in Europe.

There is consensus across some MSPs, Prospect Trade Union and members of staff that doing nothing is not an option, the differing opinion centres on the chosen option. Responding to the petitioners' assertion that the HELIOS scoping study contained numerous errors and that the chosen solution was the most complex, we note that the petitioners did not present the errors. However, we agree that the best suited solution is the most complex and to overcome issues of complexity HIAL has employed in-house technical experts from remote locations, and specialists from elsewhere in the country to help design the system.

The decision by the HIAL Board to revise the level of air traffic provision at Benbecula and Wick followed a comprehensive evaluation process of all requirements. The proposal for an Air Flight Information Service (AFIS) at these airports is not based purely on volume of traffic and is certainly not a cost-saving exercise. It is based on the volume and complexity of air traffic that operates at, and in the environs of, each aerodrome and providing a

proportionate level of service. HIAL has safely and effectively provided AFIS services at four of its airports for a number of years, just as other aerodromes do elsewhere in the UK.

As with any change in service a full safety case will be prepared in conjunction with the CAA before any approval is granted.

Much has been made of the independence of the island impact assessment commissioned by HIAL, which the petitioners' described as a 'tick box' exercise. To be clear - it is not.

The ATMS strategy was approved in January 2018 with the Bill for The Islands (Scotland) Act 2018 being passed by the Parliament on 30th May 2018, receiving Royal Assent on 6th July 2018.

Accordingly, HIAL is not required to undertake an island impact assessment. Notwithstanding, to ensure transparency and objectivity, we commissioned an independent consultant, Reference Economic Consultants (REC), to undertake a retrospective island community impact assessment on our behalf.

As no guidance existed on how island impact assessments should be undertaken, the Scottish Government Islands Team was consulted by REC for guidance before starting the process. As a result, the approach the independent consultant is taking reflects the Islands Act's requirement that an islands impact assessment should '*describe the likely significantly different effect of the policy, strategy or service compared to its effect on other communities (including other island communities) in the area in which the authority exercises its functions'*. Rather than recommend whether the programme should or should not go ahead, the assessment process underway will assess '*the extent to which the authority considers that the policy, strategy or service can be developed or delivered in such a manner as to improve or mitigate, for island communities, the outcomes resulting from it'*.

HIAL absolutely refutes the petitioners' allegations of poor engagement with staff and stakeholders, and would caution against conflating objection to the project with a lack of engagement. HIAL has undertaken over 150 meetings since announcing the project, with staff and politicians, local and national, and will continue to do so.

The current COVID pandemic has emphasised the important role HIAL's airports plays in our communities, but it has also highlighted the vulnerability of our current air traffic service provision and resilience. For example, losing two ATCOs at an island airport will likely result in closures whereas this is highly unlikely in a combined surveillance centre.

HIAL would welcome the opportunity to present more detailed information directly to the Petitions Committee.

Inglis Lyon
Managing Director, HIAL

PE1804/T
Cabinet Secretary for Transport, Infrastructure and Connectivity submission of 5 November 2020

Thank you for your letter of 6 October 2020 following the Public Petitions Committee's consideration of Petition PE1804 about Highlands and Islands Airports Limited's (HIAL) Air Traffic Management 2030 Strategy (ATMS). I welcome the opportunity to comment on this important issue.

I recognise the need to modernise Air Traffic Control to ensure more sustainable and reliable air services in the Highlands and Islands. HIAL has been tasked with taking this process forward to find the safest and most sustainable solution. HIAL need to future-proof their operations in Scotland against a background of issues including increasing regulation, future operational safety and staff recruitment and retention.

The Scottish Government subsidises the operation of airports in our remote communities to ensure that these communities stay connected with the rest of Scotland and beyond. We need to ensure that air services are maintained into the future with safety at the heart of operations. As with all public bodies in Scotland, HIAL should engage with its staff, stakeholders and those that use its services in relation to how it delivers those services. I am aware that HIAL has engaged extensively with all interested parties throughout the duration of the ATMS project to date and this will continue as the project progresses. This includes undertaking a retrospective Islands Impact Assessment even though there is no legal requirement for them to do so as the decision to proceed was taken before the Islands Bill was passed.

HIAL is responsible for the operation of airport services at its 11 airports. Scottish Ministers appoint a Board to represent their interests, to oversee the management of the company and to ensure that it operates in line with Ministerial expectations. The HIAL Management Team is responsible for operational issues and the Board is responsible for overseeing this. Part of the Board appointment process is ensuring that, collectively, the Board has the requisite skills and knowledge to carry out its duties. I am satisfied that the HIAL Board has taken its decisions based on the best available information and analysis of the different options available.

I am aware that the Committee has written to HIAL separately. I have asked HIAL to address the operational issues raised by the Committee in their response and to offer to present more detailed information directly to the Committee. The Committee may also wish to consider taking evidence from others in the field. In particular, the Committee may wish to consider engaging with the Civil Aviation Authority (CAA), as the industry regulator, given their role in ensuring that the new system will be as safe or safer than existing arrangements.

Best wishes
Michael Matheson

PE1804/FF
Highlands and Islands Airport Ltd submission of 10 December 2020

We are aware that the Committee will sit again on 16 December to consider the further submissions relating to the above.

Having read all of the submissions we feel that further clarification will assist the committee with its deliberations.

In the first instance, the modernisation programme is not something that HIAL has gone into lightly. The fundamental purpose of air traffic control is safety and our number one priority in making these changes is also safety.

New technology is improving the resilience and safety of air traffic management systems around the world and we must act now to modernise our operations to ensure they are safe and sustainable for passengers for decades to come. The investment in new systems is absolutely critical to a viable future for our network and the lifeline transport services that rely upon it.

There has been a detailed programme of studies, reviews, and independent approvals since December 2017 and we include a summary of these below for your information:

- December 2017: Air Traffic Management Technical Scoping study undertaken by Helios Consultancy group presented to HIAL Board. HIAL Board authorise recommendation for next stage approval.
- January 2018: HIAL receive approval to proceed with the Air Traffic Management Strategy (ATMS) Programme from the Transport Minister.
- July 2018: ATMS Programme Board established. Board membership includes Transport Scotland, Non-Executive member from the HIAL Board and the full-time Prospect Union Officer.
- July 2018: Consultancy group Ekos study on the optimal location for the centralised facility published. Having been consulted, staff expressed a preference for Inverness – were they to relocate.
- September 2018: ATMS Programme Director appointed.
- January 2019: The ATMS Programme delivery team in place.
- July 2019: FarrPoint Study to explore HIAL ATC airport digital connectivity status completed and published.
- October 2019: ATMS feasibility and options process to validate Helios conceptual study completed and ATMS Business Case approved by HIAL Board for decision by Transport Scotland Investment and Decision-Making Board.
- December 2019: ATMS Business Case approved by Transport Scotland Investment and Decision-Making Board.
- December 2019: HIAL Board approval to proceed with ATMS Programme delivery.
- June 2020: Detailed review of ATMS programme undertaken by new HIAL Board, who endorse previous decisions.

As a further independent review, we are currently working with the Digital Assurance Office Directorate of Internal Audit and Assurance and have time scheduled in January 2021 for an objective ‘health check’ on the programme.

Our extensive consultation with the various local authorities and stakeholders has raised the issue of reliable air connectivity in the context of Highlands and Islands air services as essential elements of the Scottish transport infrastructure, facilitating essential lifeline island activities.

HIAL's Air Traffic Management Strategy aims to provide a foundation stone to address a number of industry wide structural deficits which, if left unaddressed, will compromise these lifeline activities.

As other contributors have noted, there is general agreement between our air traffic teams and their Trade Union Representatives on the need for a modernisation programme, and there are no alternative proposals for air traffic services which provide the all-encompassing solution of HIAL's current strategy.

The structural deficits were detailed in our earlier submission dated 29 October 2020, and include ageing operating models and infrastructure, the need to improve resilience, staff recruitment and retention and a changing legislative framework. Our modernisation programme seeks to address all of these issues, not least the resilience challenge. The current pandemic has highlighted this fundamental fragility of the current model of operation.

Once again we absolutely refute any allegation of a reduction in safety. Very simply, our Board, Transport Scotland, or indeed the CAA as industry regulator would not permit any development which compromised safety. We would once again encourage the Committee to seek the views of the CAA in this regard.

We absolutely recognise the personal impact of the programme on those affected and profoundly regret any disruption or distress this may cause. We are working with our teams to provide the best possible mitigations to the concerns that have been raised.

The submissions from those opposing the modernisation programme are heartfelt and passionate and we expect nothing else having discussed the matter extensively with the local teams. However, ATMS is not something that HIAL 'wants' to do – it is something that HIAL 'must' do. Unless we modernise and move forward with the programme, we cannot guarantee air connectivity for the Highlands and Islands into the future.

Finally, once again as part of our consultation, various parties have indicated their belief that this is a cost saving centralisation. It is not, our manning levels will not drop and the costs involved to future-proof service provision will exceed the standstill position.

We know all too well that this is a complex and emotive issue. We have no doubt that the Petitions Committee will consider the matter thoroughly, but having made the offer to present our case to you directly, we make that offer again. In the event that you are unable to meet with us, we make the same offer to the Rural Economy and Connectivity Committee.