Correspondence between the National Services Division, University of Dundee and NHS Tayside regarding essential tremor treatment including discussions about MRI-guided focused ultrasound going back to 2017, or in line with data retention policies, whichever one goes back furthest.

## **Email Records:**

# Emails to and from Dr. Tom Gilbertson (NHS Tayside) 13th May 2022

Hi Tom,

Thanks very much for catching up just now. As discussed I think there would be some merit in us catching up with some of the team in the DBS service in Glasgow to determine whether a collaborative approach to the development of movement disorder services would be useful. I've copied in Cheryl who can put some time in diary once you have linked in with Vicki and Trish in Glasgow. It would probably be helpful to include Amy who is the NSD Programme Manager for this service.

Have a nice weekend and hope you feel much better soon.

Kind Regards,

Craig

Dr. Craig Wheelans

National Medical Advisor for Specialist Healthcare Commissioning & National Networks

Hi Tom,

How are you placed around lunchtime today? I'm about to go into a meeting until 12.30 and then have another meeting with Scottish Government at 2. Want to send me a MS Teams invite for a wee 15 minute catch up if that works for you between 12.30 and 2?

Craig

Dr. Craig Wheelans

National Medical Advisor for Specialist Healthcare Commissioning & National Networks

From: Thomas P. Gilbertson Sent: 13 May 2022 10:41 To: Craig Wheelans < > Subject: MRgFUS

Hi Craig,

Would it be possible for a quick phone call or teams catch up soon? There has been a development with respect to the MRgFUS service that may be relevant to the NSD dialogue ongoing, it would be useful to get you feedback on this.

bw Tom

Email to NHS Tayside from Dr. Craig Wheelans 25th November 2021

Hi Pamela,

I hope that all well with you and that you are still living the dream of NHS Medical Leadership in a Covid pandemic – who would have thought we would be at nearly 2 years of the nightmare.

I've had another enquiry from Scottish Government today regarding this service so I think there is clearly an appetite for it. We wouldn't be planning to establish another service elsewhere in Scotland therefore it might make sense for us to think about how to move things forward.

NSD are still in a pause for establishing new applications as well as undergoing a service redesign and reorganisation however I think it would be useful for us to catch up sometime to discuss next steps.

I will ask Ruth to set up a meeting with Colin, Tom and I to discuss.

Kind Regards,

Craig

Dr. Craig Wheelans

National Medical Advisor for Specialist Healthcare Commissioning & National Networks

# Email from NHS Tayside 23rd November 2021

From: Pamela Johnston

**Sent:** 23 November 2021 12:17

**To:** Craig Wheelans **Cc:** Colin Fleming

Subject: MRI focussed Ultrasound

Hi Craig

In our last chat, you briefly mentioned this service which we are still running in Tayside. Can you tell me if NSS is reconsidering developing this service more widely? I ask as Colin Fleming was talking to me about it. If you would like any more info about it. Colin would be happy to speak to you.

Pamela

#### **Dr Pamela Johnston**

Consultant Anaesthetist Operational Medical Director

Ninewells Hospital and Medical School | Dundee | DD1 9SY (Postal) DD2 1UB (Sat Nav)

#### Email from NHS Tayside 25th October 2021

**From:** Thomas P. Gilbertson **Sent:** 25 October 2021 15:28

To: Craig Wheelans

Subject: Re: MRI Focused Ultrasound for Tremor

Hi Craig,

Thanks for getting in touch. We have treated 5 patients and are continuing to treat 1 patient a month. All patients have been assessed for DBS by our colleagues in Glasgow and are either ineligible or have chosen ultrasound on the basis of the higher risk profile of DBS. Its probably worth feeding back at this point that the overall saving is around 80k (sssuming ~10k treatment for ultrasound ~30k DBS).

Our waiting time is around 6 months and we have 80 referrals so far with a conversion rate of 25%. We have als had individual patients funding approved by both NHS Lothian and NHS GG&C.

The main issue for me at the moment is that all the patients are being assessed and treated during my university time (which the uni are happy with) but ET assessments will be challenging to fit in when the clinical trial for Parkinson's patients starts in the new year.

An established NSD mechanism for the ET patients would allow us to keep up the ET treatment rate as it stands and deliver on the clinical trial work in parallel.

Best wishes,

Tom

#### Email to NHS Tayside 20th October 2021

From: Craig Wheelans
Sent: 20 October 2021 12:17
To: Thomas P. Gilbertson

Subject: MRI Focused Ultrasound for Tremor

Hi Tom,

I hope that all is well with you. I am due to provide an update to our sponsors in Scottish Government shortly and I just wondered how your new service is getting on as it is some time since we last spoke.

How are things?

Craig

Dr. Craig Wheelans

National Medical Advisor for Specialist Healthcare Commissioning & National Networks

#### Email from Dr. Tom Gilbertson NHS Tayside 9th August 2021

Dear Craig,

I was just following up on this email. We have treated of first 3 patients with good results so far and have a had a further 30 referrals since we last spoke.

Let me know if there is any more information I can help with here.

Best Wishes,

Tom

From: Craig Wheelans Sent: 26 May 2021 07:03

To: Alan Burns Cc: Susan Buchanan; Roseanne McDonald; Anna Lamont; Thomas P.

Gilbertson

**Subject:** RE: MR-guided focus ultrasound (MRgFUS)

Hi Alan.

I just wanted to give you an update regarding the service in Dundee. I spoke yesterday with Dr. Tom Gilbertson who is the Lead Clinician for the new service in Dundee.

Tom informed me that things have moved on somewhat since when I caught up with him earlier this year. If you recall when this was last considered there were some issues from an NHS Scotland point of view in that NPPPRG/NSSC were of the opinion that there was still some need to gather evidence of the efficacy and safety of the treatment and in addition there were capital requirements to purchase the specific equipment required to run the service. It was therefore pushed back and we then sought to see whether NHS England might look at commissioning the service as their 2<sup>nd</sup> national centre however this did not fit with the needs of their population and they therefore declined.

Yesterday Tom was extremely upbeat in confirming that the team in Dundee were now in place to deliver the treatment and that they were anticipating that they would treat their first patient before the summer in Dundee. They have fostered a good working relationship with the National DBS MDT in Glasgow to allow peer scrutiny of patient selection and treatment planning. In addition this would allow the flux of appropriate patients each way as felt was most clinically appropriate.

Tom informed me that since the beginning of the year they had received approximately 30 patients for assessment in Dundee of which around 1/3<sup>rd</sup> were known local patients, 1/3<sup>rd</sup> referred from their GP across Scotland via patient awareness and the final 1/3<sup>rd</sup> by referral from other neurologists/movement disorder specialists. The rate of conversion to suitability following assessment is approximately 50%.

Via charitable funding they expect that around 1 patient per month to be able to be funded however this does not appear to be a long term sustainable solution as it appears that the need is significant in that at the present time whilst the indication is the use of the treatment for benign essential tremor plans are also afoot to undertake clinical trials for the use in the treatment of Parkinson's disease.

As you are aware funding within the NHS envelope is extremely tight at present and I think the team in Dundee would greatly appreciate the support of ministers in developing a national service with appropriate funding to match.

So far we have seen 1 funding application for access to the service in NHS England however the clinical team in Scotland now seem less keen to refer knowing that there is the potential that their patient could be assessed /treated within Scotland.

I have copied in Tom to this email should you require further information. My own plan is to discuss further with NSD colleagues as my concern is that whilst there is a need and certainly demand for the service I am not sure how easy it will be to get the service application through NPPPRG/NSSC whilst the recovery from Covid-19 is still very much in the minds of the boards.

If you wish to catch up drop me an email.

Craig

Dr. Craig Wheelans

National Medical Advisor for Specialist Healthcare Commissioning & National Networks

## Email to NHS Tayside 14th December 2020 from Dr. Craig Wheelans

Hi Tom.

I am sorry to be the bearer of bad news but NHS England have come back and said that at the present time they do not see Dundee as a potential centre within their future plans to offer this treatment to the population which they commission for. It was felt that Dundee would not be easily accessible for many patients and therefore they do not wish to take forward at present.

As you will recall when a previous application to the NSSC was considered it was felt that the evidence base for a such a service was somewhat lacking, that there was still a need for clinical research and in addition for the potential number of patients likely to require this treatment it would not be cost effective to commission a Scottish national service and were there to be a need it would be less costly to buy on a case by case basis from a provider elsewhere in the UK. We had hoped that if you were commissioned by NHS England that Scottish patients could access by a reverse funding mechanism where any costs could be recharged to Health Boards on a case by case basis.

Karen has moved on from NSD to work within Scottish Government leading on Covid-19 vaccination and our new Director Susi Buchanan is currently on sick leave. At present due to Covid-19 the application process for new services is on the backburner somewhat and I cannot see such a service being prioritised at the present time as many of the previous challenges are still present.

Could we maybe catch up for a chat via MS Teams either this week or next?

Craig

Dr. Craig Wheelans

Specialist Healthcare Commissioning, National Screening, Procurement & Facilities

#### Email from NHS Tayside 11th December 2020

From: Thomas P. Gilbertson > Sent: 11 December 2020 12:13

To: Craig Wheelans

Subject: Re: Email to NSD

Dear Craig,

I have just presented our MRgFUS proposal at the Neurosurgical MSN. There was general support for the referral pathway that we have proposed in principle. They have asked me to submit a proposal to the NSSC via Karen Grieve.

I am naïve to the remit/overlap of NSD versus NSSC so wanted to keep you in the loop in this regard.

Best wishes,

Tom

## Emails to and from NHS Tayside 19th November 2020

**From:** Thomas P. Gilbertson **Sent:** 19 November 2020 15:46

To: Craig Wheelans

Subject: Re: Email to NSD

Dear Craig,

Many thanks for getting back to me. I was emailing to update Nicola regarding MRI focused ultrasound project in Dundee. We had a series of telephone meetings pre-pandemic to discuss NHS Scotland's position regarding future reimbursement for patients with ET. We have completed our fundraising and are due to purchase the system required for the treatments by the end of this year. The aim would be to treat patients both as part of clinical research, but also NHS eligible patients as part of routine care.

NHS England have recently approved reimbursement for patients south of the boarder from April 2021, so it would be useful get feedback on NHS Scotland position in view of this. Nicola had thought that the NHS England commissioning policy would most likely be adopted UK wide, but this had not been confirmed and was dependant upon their final decision published this month.

Grateful for any guidance you can offer, Best wishes, Tom

https://www.england.nhs.uk/publication/transcranial-magnetic-resonance-guided-focused-ultrasound-thalamotomy-for-treatment-of-medication-refractory-essential-tremor/

From: Craig Wheelans

**Sent:** 19 November 2020 13:09 **To:** Thomas P. Gilbertson **Subject:** Email to NSD

Dear Tom.

Thanks for your email which has been passed to me. At the present time I am covering for Nicola while she is working with Scottish Government. Is your enquiry in relation to the MRI guided focussed ultrasound for tremor? What can I do to help?

Craig

Dr. Craig Wheelans

Interim Medical Director (GMC: 4506737)

Specialist Healthcare Commissioning, National Screening, Procurement & Facilities

From: Thomas P. Gilbertson Sent: 19 November 2020 10:57

**To:** nss.nsd-enquiries@nhs.net

Subject:

This message originated from outside of NHSmail. Please do not click links or open attachments unless you recognise the sender and know the content is safe.

Dear NSD,

I am a neurology consultant who had been liaising with Dr Steedman earlier this year regarding a new neurology treatment.

I note that she has been seconded to the Scottish government and would be grateful if you could let me know who here replacement is so I can make contact.

Best wishes,

Tom Gilbertson.

# Emails from and to NHS Tayside 12th May 2020

Hi Kismet.

Thanks for your email. I was aware of the proposal as was looking at some of the papers last week.

Unfortunately as a result of Covid-19 much of the routine commissioning work in NHS England for services is currently in limbo as the commissioners are supporting pandemic surge capacity in critical care, diagnostics etc. The next work will be planning for resumption of normal services after prioritisation on the grounds of urgency and need. I would doubt therefore that this work would progress until September at the earliest.

We don't think this year we will be able to take forward any proposals until the post Covid dust settles but will update you if I hear anything.

Hope you keep safe and well.

Kind Regards,

Craig

Dr. Craig Wheelans Interim Medical Director (Specialist Healthcare Commissioning, National Screening, Procurement & Facilities) NHS National Services Scotland

On 12 May 2020, at 16:17, IBRAHIM, Kismet (NHS TAYSIDE) wrote:

Dear Craig,

Did Nicola mention a plan for a MRI-guided focused ultrasound service for Scotland before she was seconded to the SG? If so, do you know if the consultation meeting planned for NHS England this month is still going ahead?

Thank you,

**Kismet** 

<u>Kismet Hossain-Ibrahim (FRCS (SN), PhD)</u> Consultant Neurosurgeon Ninewells Hospital, Dundee

# Email from NHS Tayside 8th January 2020

From: IBRAHIM, Kismet (NHS TAYSIDE) Sent: 08 January 2020 16:17

To: GILBERTSON, Thomas (NHS TAYSIDE) >; WINTER, Mike (NHS TAYSIDE)

Cc: STEEDMAN, Nicola (NHS NATIONAL SERVICES SCOTLAND)

Subject: Re: MRI guided HF USS

Dear Dr Steedman,

Please find below an email from Tom Gilbertson, updating NSS on Dundee's near-closure on purchasing an MRI-guided high frequency Ultrasound system to treat essential tremor. Tom did not realise that you had taken over Mike's role.

I have attached the document to 2018 that I sent to NSS to ask if NHS Scotland would be able to fund treatment of Scottish patients suffering from essential tremor with MRI guided HF USS. At the time, it was thought that more research was required but a lot more evidence has been acquired since then with an excellent safety record (e.g. no stroke in 1100 treatments worldwide compared to 1-2% risk of stroke with the alternative treatment of deep brain stimulation and an estimated £9700 per patient cost saving over DBS). Moreover, NHS Tayside has offered support for the treatment (though not cost of treatment) after discussion with their executive committee in 2019.

Please do not hesitate to contact Tom and with any questions regarding this novel treatment for a currently underserved population in Scotland.

Regards,

Kismet Hossain-Ibrahim (FRCS (SN), PhD)
Consultant Neurosurgeon
Ninewells Hospital,
Dundee

From: GILBERTSON, Thomas (NHS TAYSIDE)

**Sent:** 20 December 2019 13:34

**To:** IBRAHIM, Kismet (NHS TAYSIDE); WINTER, Mike (NHS TAYSIDE)

Subject: Re: MRI guided HF USS

Dear Mike,

I am the neurologist in Dundee involved with the MRgFUS project. I wanted to update you with our current position on this. We have completed our local procurement process are expecting responses to this from the supplier at the end of January. Assuming that the bid is in line with what we have fundraised then purchase is likely to happen in the spring.

As it stands, the first patients in Scotland will be treated as part of a clinical trial. I have been recently informed by my colleague Peter Bain in London that NHS England have drafted a commissioning document to be published in May which is likely to approve reimbursement of for NHS England patients.

This will potentially place us in a tricky situation as I don't think given the significant financial commitment made here that we will be in a position to turn down referrals from the north of England which would be reimbursed by NHS England from May onwards. Equally, it could lead to a lack of parity in terms of access to treatment for Scottish patients if they are treated under the much narrower remit of a clinical trial.

I would emphasise that this remains a hypothetical scenario until we have officially purchased the system, but thought it pertinent to raise this with you sooner rather than later.

With best wishes,	
Tom Gilbertson.	
Consultant Neurologist,	
Ninewells Hospital,	
Dundee.	

#### **Informal MS Teams Meetings Date & Times**

A number of MS Teams meetings took place between Dr. Craig Wheelans (National Medical Advisor, NHS National Services Scotland) and NHS Tayside colleagues as follows:

- 1. 15<sup>th</sup> December 2020 from 13.30 to 14.00
- 2. 25<sup>th</sup> May 2021 from 13:30 to 14.00
- 3. 26<sup>th</sup> January 2022 from 13.30 to 14.30
- 4. 28<sup>th</sup> March 2022 from 11.00 to 11.30
- 5. 14<sup>th</sup> June 2022 from 13.00 to 14.30 (This meeting included representatives from National Deep Brain Stimulation Service in Glasgow as they also specialise in the management of movement disorders and have been working closely with the Dundee clinicians).

These minutes were not formally recorded in the form of minutes as they were informal peer to peer clinical discussions.