

1. 29-30 January 2018

From: [REDACTED]@actionforme.org.uk]
Sent: 30 January 2018 11:07
To: [REDACTED]
Cc: [REDACTED]
Subject: RE: Tomorrow's invite

[REDACTED]
Thanks for getting back to me. Gail Ross MSP will be hosting an event for us during M.E. Awareness Week (Wed 9th of May) so perhaps you'll have the opportunity to join us then. I will be sure to send you an invite.

Kind Regards
[REDACTED]

From: [REDACTED] Scottish Government
Sent: 29 January 2018 22:10
To: [REDACTED] Action for ME
Cc: [REDACTED] Action for ME
Subject: RE: Tomorrow's invite

Hello [REDACTED]

Thank you for the invite. Unfortunately, I am in Glasgow for meetings during the day tomorrow and unable to attend the event in the evening in Edinburgh.

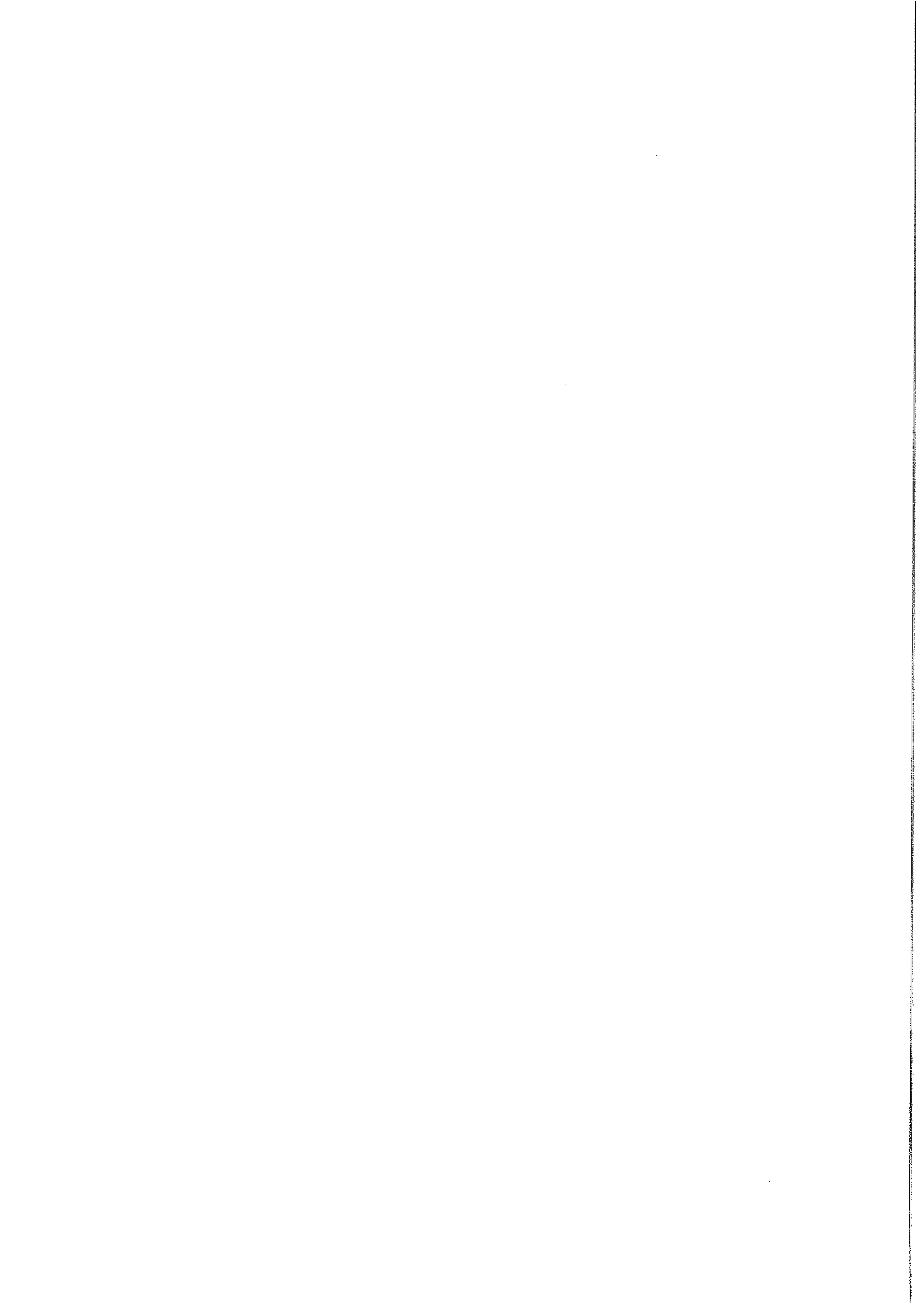
Best wishes
[REDACTED]

From: [REDACTED] Action for ME
Sent: 29 January 2018 14:09
To: [REDACTED] Scottish Government
Cc: [REDACTED] Action for ME
Subject: Tomorrow's invite

[REDACTED]
I wondered if you might be going along to tomorrow evening's event by MEAction in the Scottish Parliament? Just in case you are, I thought I'd introduce you to my colleague Clare Ogden, Head of Communications, who is attending and would welcome to opportunity to say hello. Unfortunately I am unable to attend myself (tomorrow evening we are delivering a webinar for HPs in Scotland) but it might be good opportunity to chat with Clare about some of the work we are involved in.

Best Wishes
[REDACTED]

[REDACTED]
Action for M.E.
Mobile: [REDACTED]
Monday to Friday 9am – 2pm.



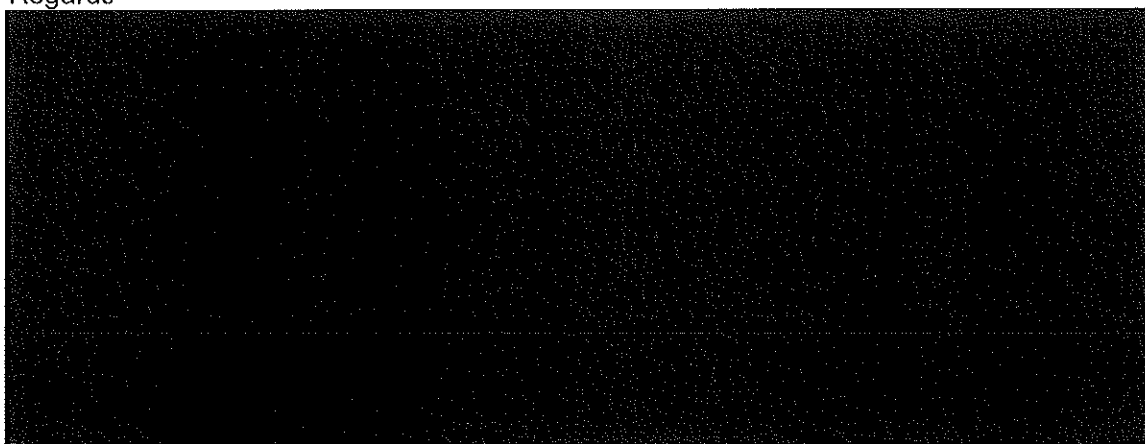
2. 23-24 January 2018

From: [REDACTED] Scottish Government
Sent: 24 January 2018 11:34
To: 'Sonya Chowdhury'; [REDACTED] Scottish Government
Cc: 'Tom Owen'; 'Ian Jess'; [REDACTED] Action for ME
Subject: RE: [REDACTED] Scottish Government

Sonya

Thanks for your email and contact/organisation details. I look forward to hearing about your project in due course.

Regards



From: Sonya Chowdhury [mailto:Sonya@actionforME.org.uk]
Sent: 24 January 2018 11:23
To: [REDACTED] Scottish Government
Cc: [REDACTED] Scottish Government Tom Owen; Ian Jess; [REDACTED] Action for ME
Subject: [REDACTED] Scottish Government

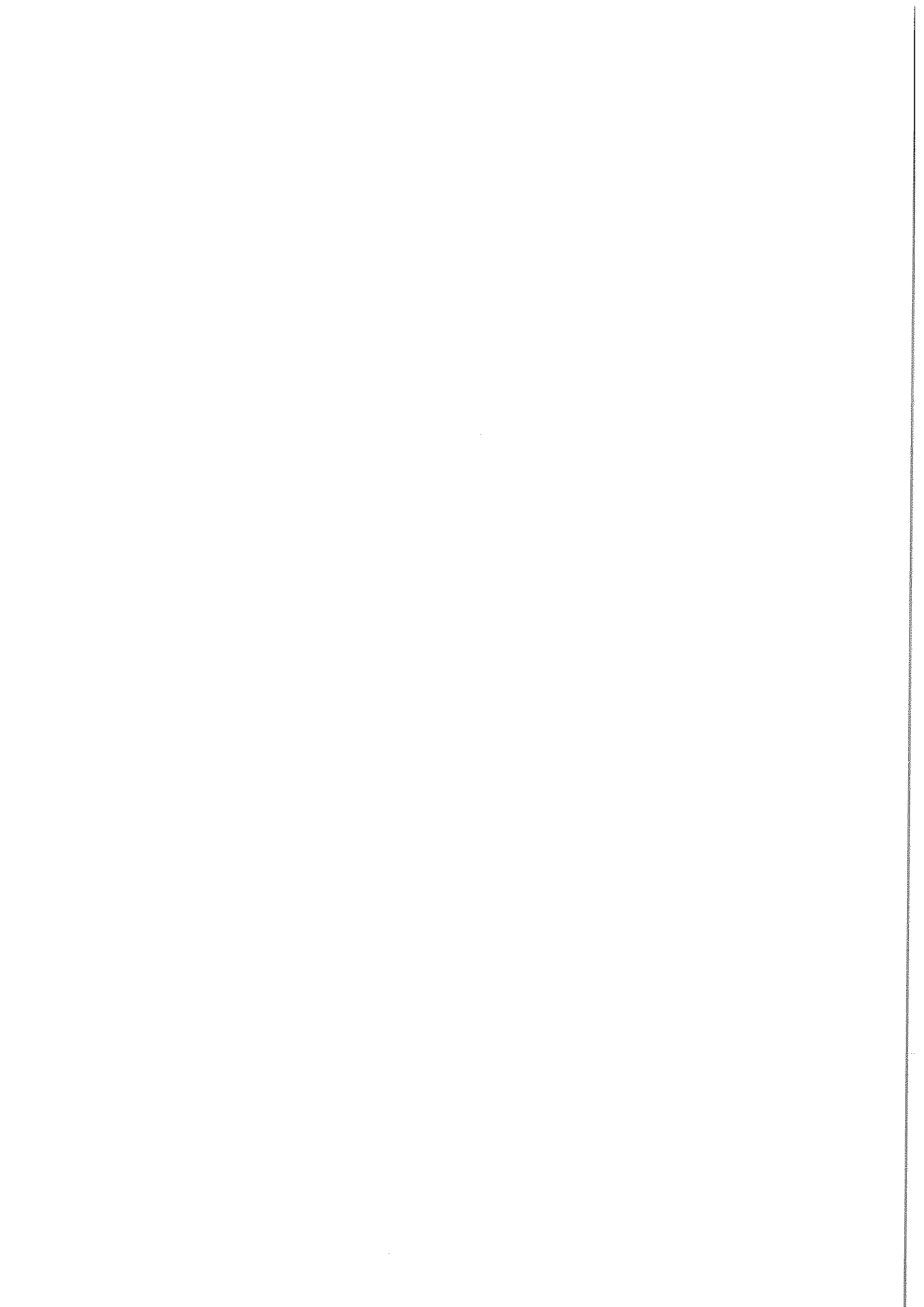
[REDACTED]

[REDACTED] – congratulations on your new role and I hope you have had a good start! I'm cc'ing in my colleagues who are leading the project you are funding so that you have a sense of how we all 'fit' together here!

- Ian Jess – Chief Operating Officer, line manages Tom
- Tom Owen – Director of Services and Development, line manages [REDACTED] Action for ME
- [REDACTED]

Look forward to meeting you at some point in the not too distant future!

Sonya



Sonya Chowdhury, Chief Executive, Action for M.E.

✉ 42 Temple Street, Keynsham BS31 1EH | 📧 sonya@actionforme.org.uk | 🌐 www.actionforme.org.uk /

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From: [redacted] Scottish Government

Sent: 23 January 2018 14:26

To: [redacted]
[redacted]
[redacted]
[redacted] Sonya Chowdhury

<Sonya@actionforME.org.uk>; [redacted] Action for ME

Cc: [redacted]

Subject: [redacted]

Hi all

Just wanted to drop you a note to introduce [redacted] who has joined my team as Senior Policy Manager, covering neurological conditions amongst other things.

When [redacted] gets up to speed it's our intention that she becomes the first point of contact for neurological – with the exception being the NACNC / National Action Plan work which [redacted] and I are leading on.

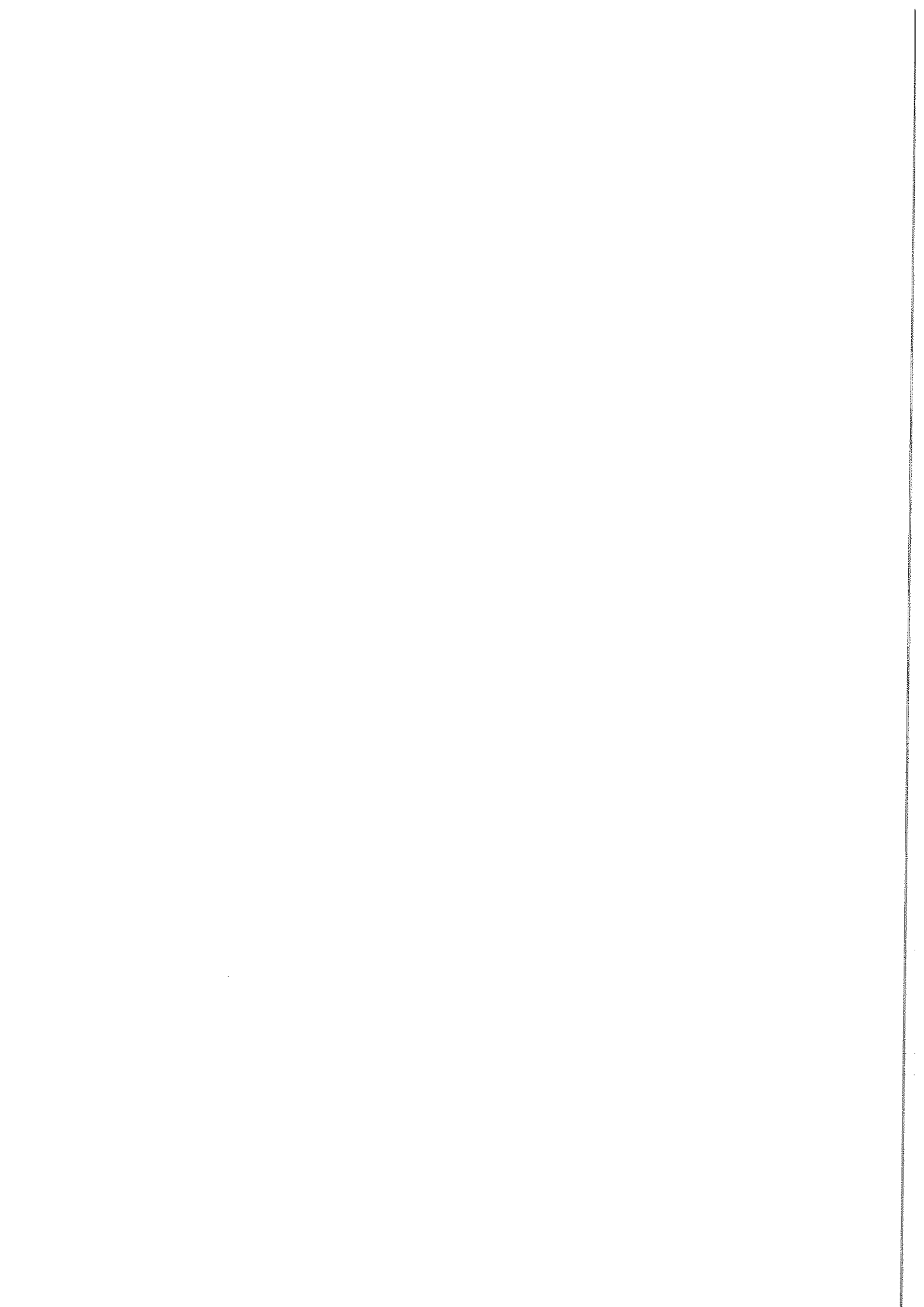
Grateful if you could share this note with any relevant colleagues in the sector who I may have missed.

Thanks

[redacted signature block]



St Andrew's House
Regent Road
Edinburgh EH1 3DG



3. 23 February 2018

From: [REDACTED] Scottish Government
Sent: 23 February 2018 13:53
To: Sonya Chowdhury
Subject: Re: PhD

Thanks Sonya

That's great news
I'll keep you updated as applications come in

Kind regards
[REDACTED]

Sent from my BlackBerry 10 smartphone.

From: Sonya Chowdhury
Sent: Friday, 23 February 2018 12:54
To: [REDACTED] Scottish Government
Subject: PhD

Hi – I just wanted to email to say 'wow'! I hadn't anticipated so much interest in the PhD announcement. We have just heard through our news tracking company that the announcement has featured over 125 times already and we know that there is radio coverage and other press/online coverage to come. There has also been a lot of social media activity for which I don't yet have the stats.

Not a bad way to end the week! Thank you for all your support

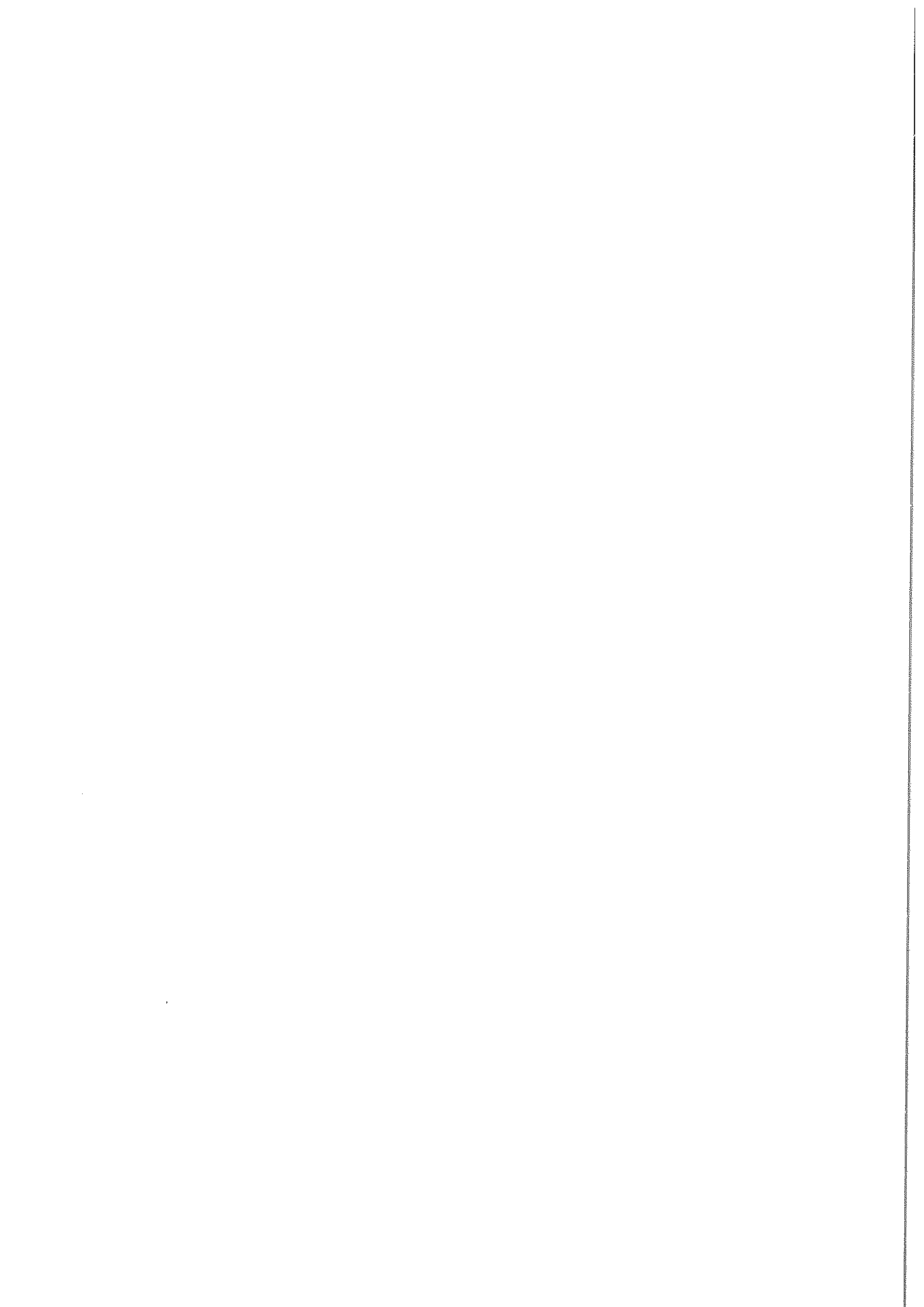


Sonya Chowdhury, Chief Executive, Action for M.E.

✉ 42 Temple Street, Keynsham BS31 1EH | sonya@actionforme.org.uk | [REDACTED]
[REDACTED] www.actionforme.org.uk

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4. 19-22 February 2018

From: [REDACTED] Scottish Government
Sent: 22 February 2018 09:17
To: Clare Ogden
Cc: [REDACTED] Scottish Government
Subject: Call published

Clare

I have just published the call - <http://www.cso.scot.nhs.uk/me/>

Which links to this page - <http://www.cso.scot.nhs.uk/mephd/>

Thanks for getting back to [REDACTED] yesterday.

Best wishes

[REDACTED]

[REDACTED]

[REDACTED]

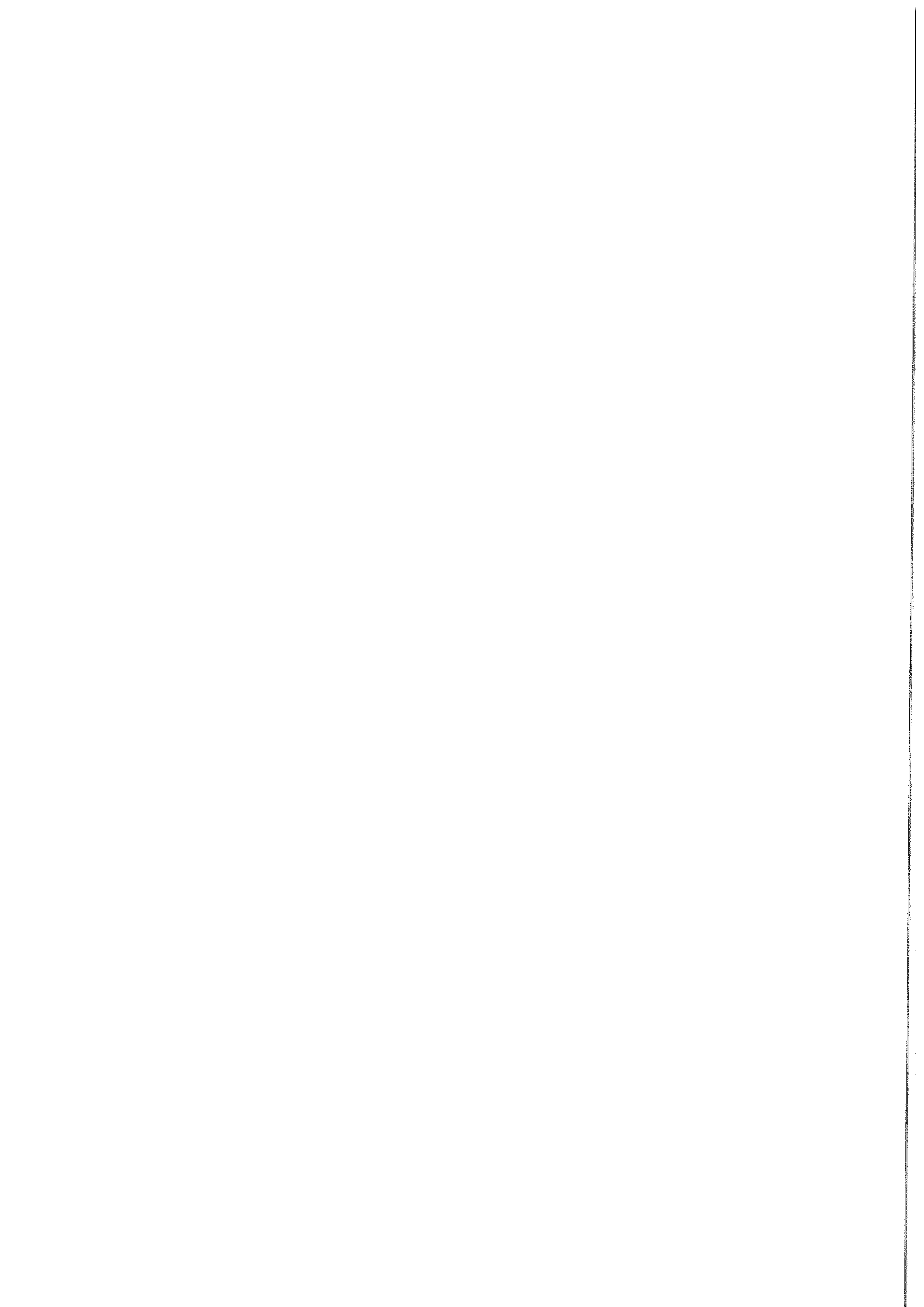
[REDACTED]

From: Clare Ogden [mailto:clare@actionforme.org.uk]
Sent: 21 February 2018 14:15
To: [REDACTED] Scottish Government
Cc: [REDACTED] Scottish Government
Subject: Re: CSO - Action for MN call - suggested text and application form

Will do, thank you both!

Clare

From: [REDACTED] Scottish Government
Sent: 21 February 2018 14:12
To: Clare Ogden



Cc: [REDACTED] Scottish Government

Subject: RE: CSO - Action for MN call - suggested text and application form

Clare

I will send you an email with the link to our page when I publish it tomorrow.

I am about to head for the day – so can you send back your comments on the press release to my colleague – [REDACTED] who is copied into this email.

Many thanks

[REDACTED]

From: Clare Ogden [mailto:clare@actionforme.org.uk]

Sent: 21 February 2018 13:00

To: [REDACTED] Scottish Government

Subject: Re: CSO - Action for MN call - suggested text and application form

Lovely to speak to you [REDACTED], and thank you for your patience!

Agree with Sonya's amendment, and understand that you will post this on your website tomorrow - would that be first thing? We will publish our own website story, linking to yours, just afterwards.

Re the press release, I will get back to you ASAP on this.

Thanks

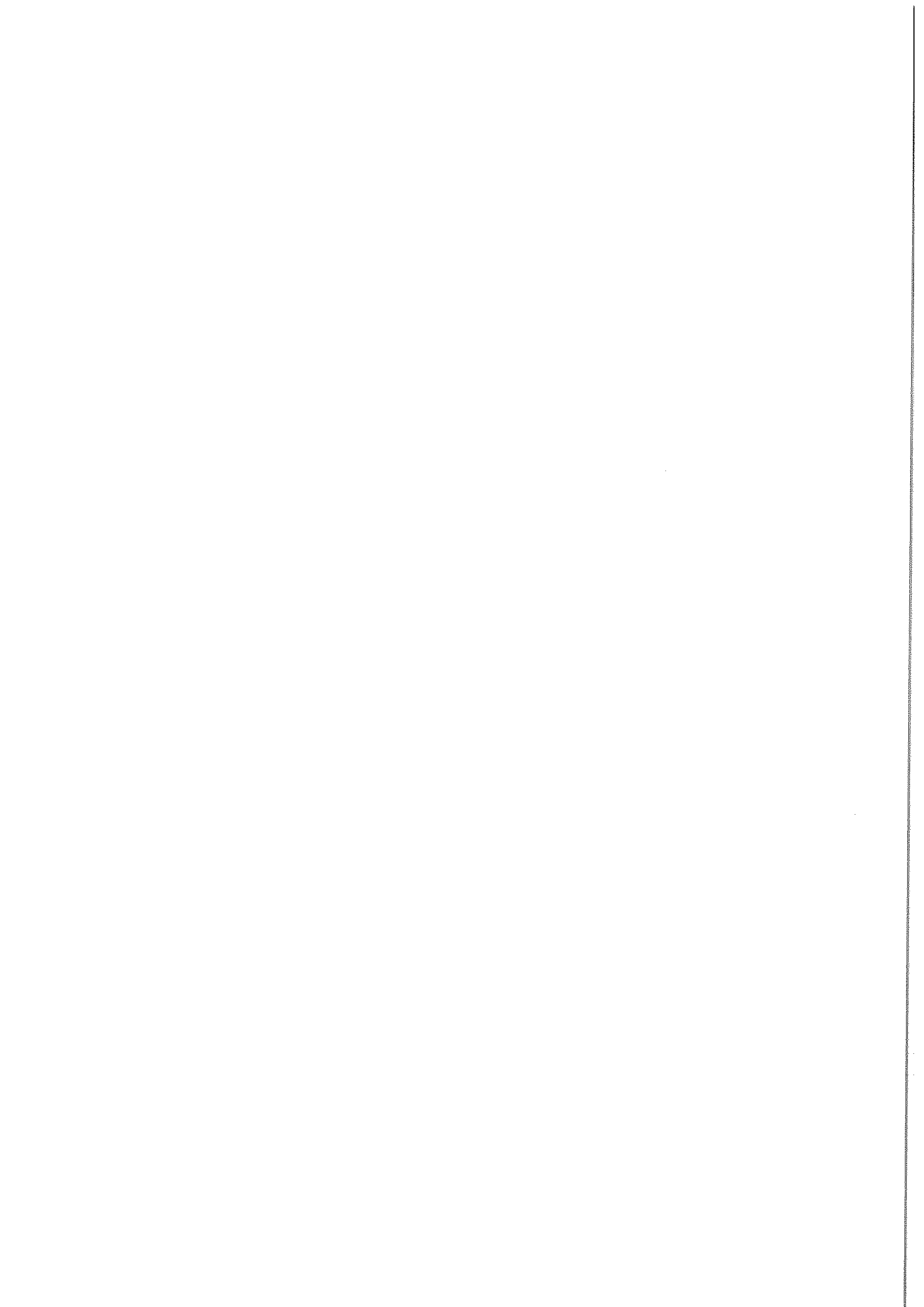
Clare

Clare Ogden
Head of Communications and Engagement
Action for M.E.

Office: [REDACTED]

Mobile: [REDACTED]

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From: Sonya Chowdhury
Sent: 19 February 2018 16:03
To: [REDACTED] Scottish Government
Cc: [REDACTED] Scottish Government [REDACTED]; Action for ME [REDACTED] Action for ME
Subject: RE: CSO - Action for MN call - suggested text and application form

Hi – this looks great. Please can you make one small amendment as highlighted:

In terms of research into M.E., the Chief Scientist Office (CSO) and the patient support and health research charity Action for M.E. have

Clare and I are both in meetings in London tomorrow so please can you also cc in [REDACTED] (address above) so that he can post on our webstie/social media once live.

Thanks



Sonya Chowdhury, Chief Executive, Action for M.E.
✉ 42 Temple Street, Keynsham BS31 1EH | sonya@actionforme.org.uk | [REDACTED] /
[REDACTED] www.actionforme.org.uk

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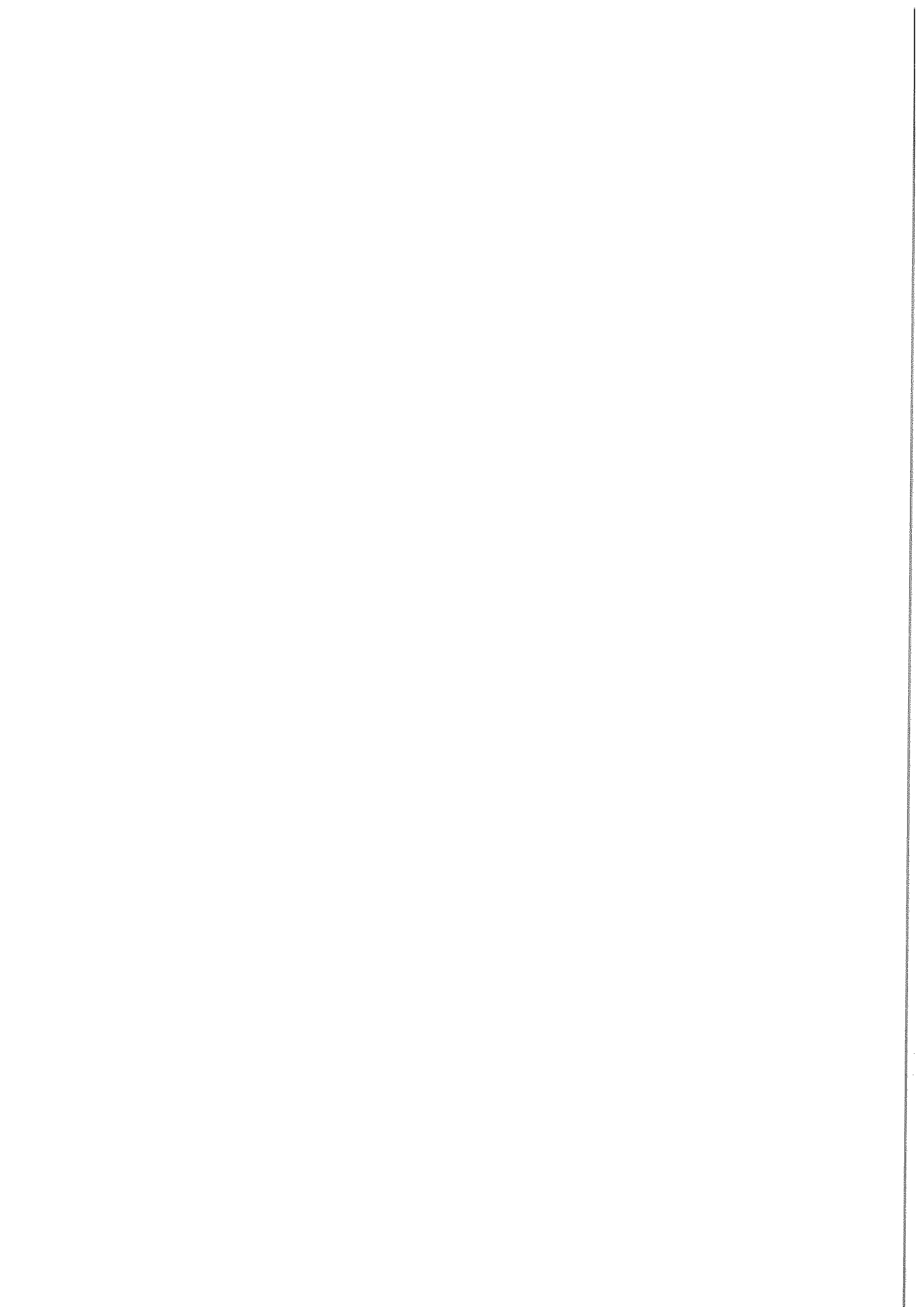
From: [REDACTED] Scottish Government
Sent: 19 February 2018 14:16
To: Sonya Chowdhury <Sonya@actionforME.org.uk>
Cc: [REDACTED] Scottish Government
Subject: CSO - Action for MN call - suggested text and application form

Dear Sonya

Please find below the suggested text for the call to go on our respective websites – this then links to a brief summary, that in turn links to the application form that interested Universities can fill in – on your approval we can go live I'd put a deadline of 6 weeks after the announcement. We'll also distribute by email to all of the Scottish University Research Offices. I'm In London Tues / Wed so we could go live on Thursday at the earliest

Kind regards





Text for CSO website, NHS Research Scotland website – adapted for Action on M.E. website

<<

Ph.D. Studentship in biomedical research in Myalgic Encephalomyelitis.

The Chief Scientist Office is pleased to announce a funding collaboration with Action for M.E. Applications are invited from Scottish Universities to bid for funding to host a Ph.D. in biomedical research into the underlying aetiology, diagnosis or treatment of Myalgic Encephalomyelitis.

The deadline for receipt of applications is XXXXX

Full details of the scheme are available [here](#)

>>

Links to

Ph.D. Studentship in biomedical research in Myalgic Encephalomyelitis.

The Scottish Government is committed to ensuring that people in Scotland living with Myalgic Encephalomyelitis (M.E.) are able to access the best possible care and support. This commitment includes recognition of the importance of research in increasing our understanding of M.E., and in the development of new and effective approaches to diagnosis and treatment of the condition.

The Scottish Government Chief Scientist Office and Action for M.E. are pleased to announce a joint funding call for Scottish Universities to host a Ph.D. studentship in biomedical research into the underlying aetiology, diagnosis or treatment of Myalgic Encephalomyelitis. Funding of up to £90,000 for a 3 year studentship. It is expected that this will cover the student's stipend, Ph.D. registration fees, research costs and a modest travel budget for attending scientific symposia.

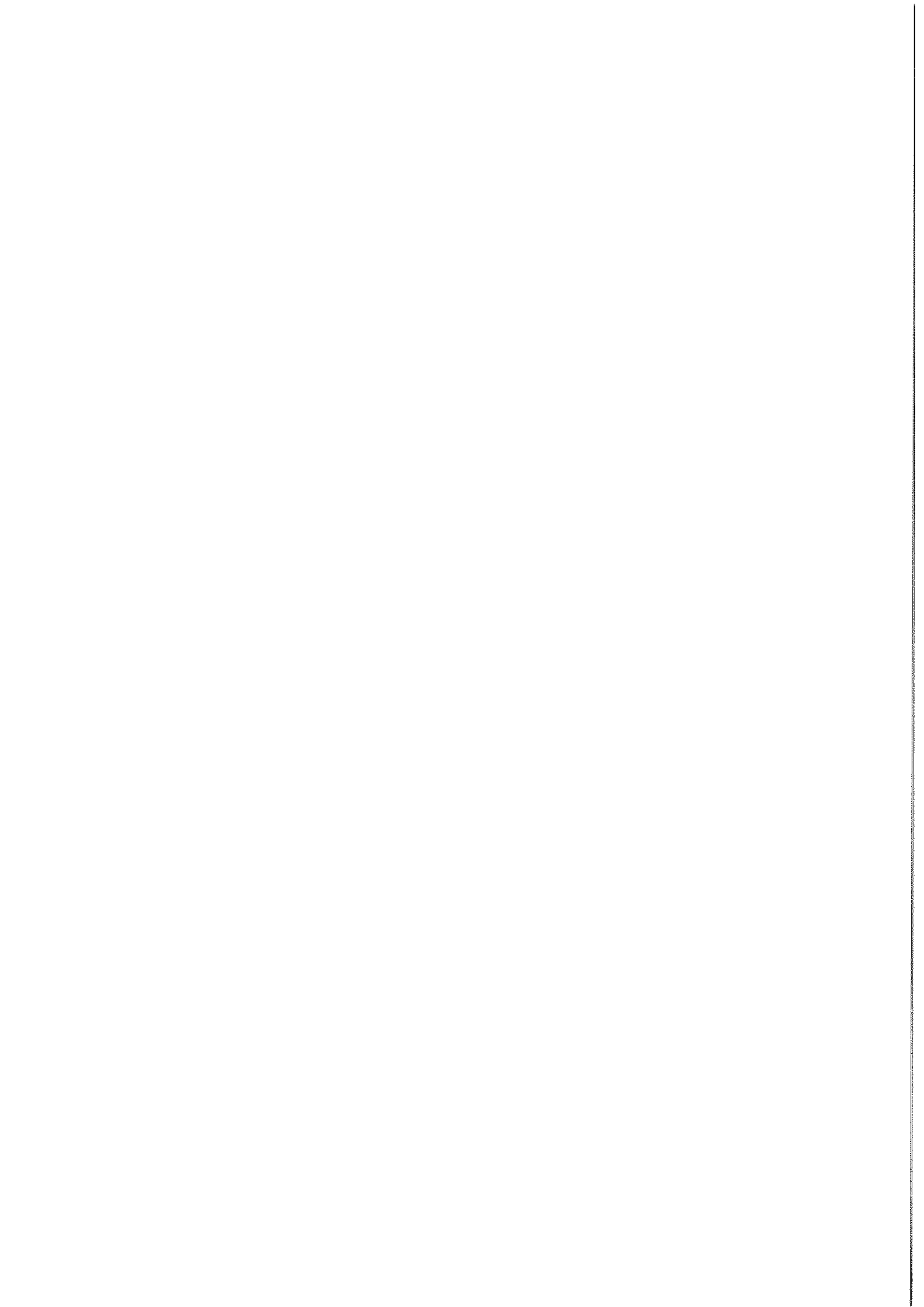
The proposal should be completed using the headings provided on the [application form](#) and should be no longer than a total of 4 pages of text completed in Calibri font at font size 11 with no changes to the line spacing or the margins of the form.

The deadline for receipt of applications is XXXXX

Applications should be submitted electronically to **CSO Grant applications**

Any specific queries should be addressed to XXXXXXXXXX

(application form attached)



Attachment to email 19 February 2018 14:16

Chief Scientist Office / Action for M.E. funded Ph.D. in biomedical research into Myalgic Encephalomyelitis

The proposal should be completed using the headings provided and should be no longer than a total of 4 pages of text completed in Calibri font at font size 11 with no changes to the line spacing or the margins of the form. Please delete the background note before submitting the application. The deadline for receipt of applications is 5 pm on xxxxxxx. Applications should be submitted electronically to CSO_Grant_Applications@gov.scot.

Background

The Scottish Government is committed to ensuring that people in Scotland living with Myalgic Encephalomyelitis (M.E.) are able to access the best possible care and support.

We have published guidelines to assist health care practitioners in providing better M.E. care. The Scottish Good Practice Statement (SGPS) on M.E. for GPs, is just part of the process of ensuring that people receive better and more consistent standards of care (including a quicker and more reliable diagnosis).

In terms of research into M.E., the Chief Scientist Office (CSO) and the health research charity Action for M.E. have met to discuss possible areas of collaboration in research. Both organisations agree that research is essential if new and effective approaches to the diagnosis and treatment of M.E. are to be developed. CSO and Action for M.E. are therefore pleased to announce a joint funded call for research in M.E. Funding will be made available for a PhD on biomedical research into the underlying aetiology, diagnosis or treatment of M.E. – the maximum available will be in the region of £90,000 for a 3 year studentship. It is expected that this will cover the student's stipend, Ph.D. registration fees, research costs and a modest travel budget for attending scientific symposia.

Application

Organisation Details

Please include details of the institution applying for the award, and the departmental address of the primary training environment.

Primary Academic lead for Research into M.E. Ph.D.

Please include the name, position and contact details of this individual.

Administrative lead for Research into M.E. Ph.D.

Please include the name, position and contact details of this individual.

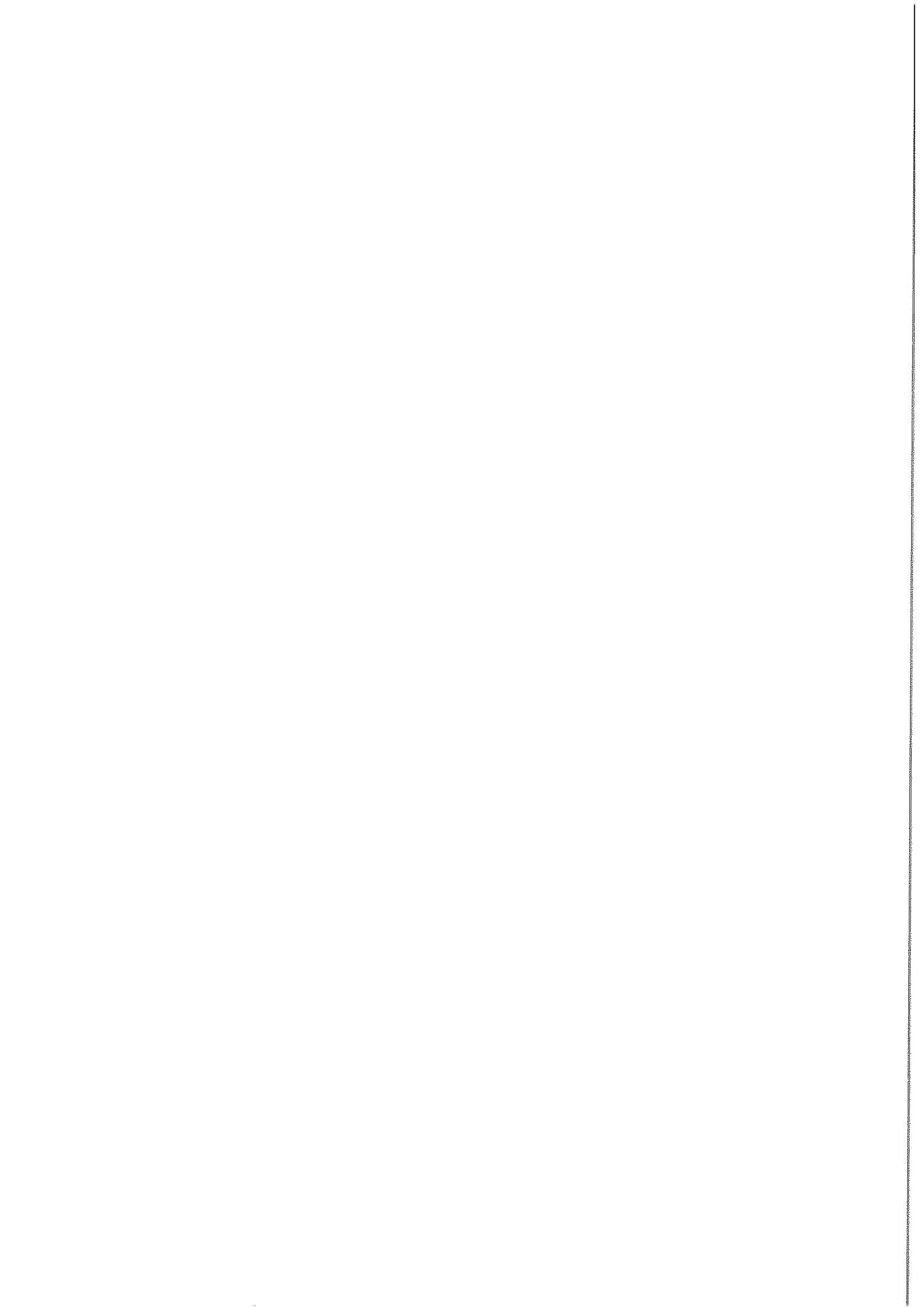
Academic team for Research into M.E. Ph.D.

Please provide the names, positions and contact details of up to 2 individuals (not including the primary academic lead) who will provide academic training and support for the PhD student appointed under this scheme.

Specific points for response

Training Environment

- *Outline specific benefits of the training environment including the methodologies and technologies available to Ph.D. students.*



- *Provide a list of up to five recent publications from the Primary Academic Lead and/or members of the Academic Team that illustrate the strength of research in this area.*

Professional Development / Career Support

- *Indicate the breadth of professional development training available to Ph.D. students.*
- *Detail how Ph.D. students are supported to make timely, informed career choices and helped with career management.*

Networking

- *Outline the current and planned opportunities for constructive networking. This may include links with Scottish, UK-wide and international 3rd sector organisations, patient groups, UK and international academic collaborators etc.*

Selection of Students

- *Detail the policy for student recruitment (including policies to ensure equality and diversity).*
- *Policy for supervisor selection / training and arrangements of developing supervision skills for academic and postdoctoral staff.*

Supporting statement

Please provide a brief summary of the strategic case and unique selling points of your Biomedical Research in Myalgic Encephalomyelitis Ph.D. proposal.

Signature of University Vice-Principal or equivalent

I confirm that I have read and support this application to the CSO / Action for M.E. funded Ph.D. studentship on biomedical research into Myalgic Encephalomyelitis.

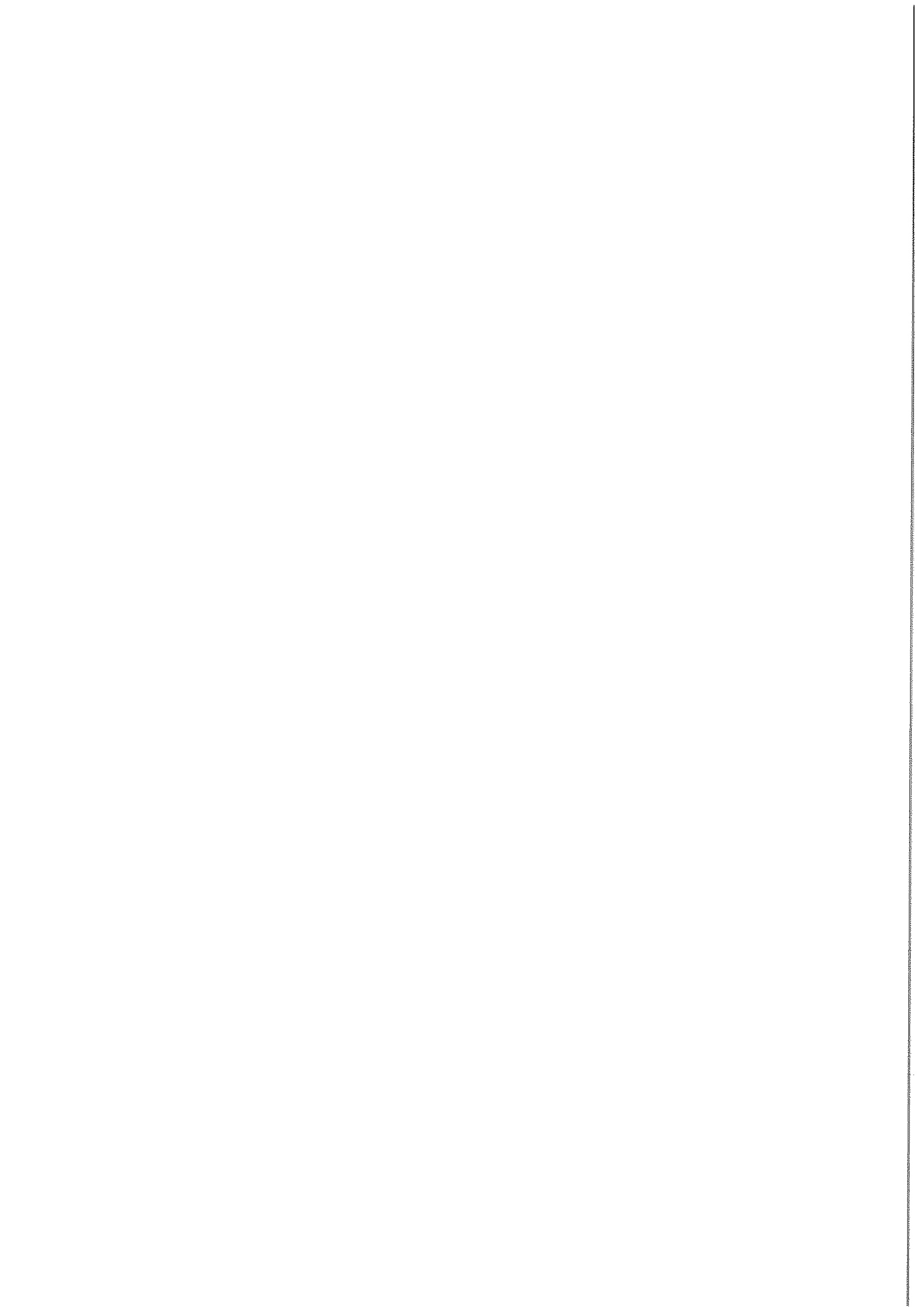
Name	Signature	Date

Signature of Primary Academic Lead

Name	Signature	Date

Signature of Administrative Lead

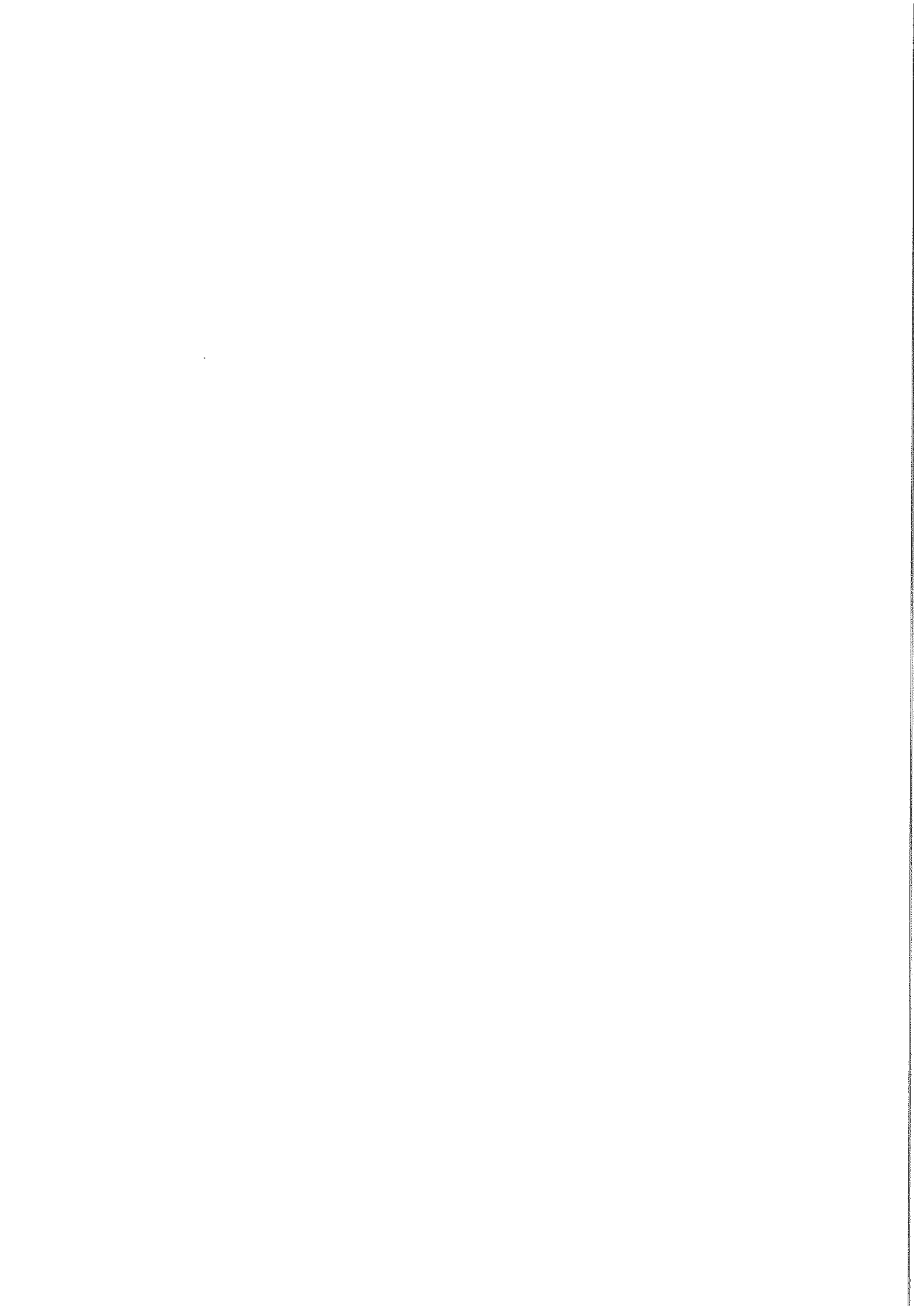
Name	Signature	Date



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Signatures of Academic Team

Name	Signature	Date



5. 9-16 February 2018

From: [REDACTED] Scottish Government
Sent: 16 February 2018 13:56
To: Sonya Chowdhury
Subject: RE: PhD call

Hi Sonya

Could you have a look at the attached MoU – I've amended it to put the correct costings in and the 6 month reporting schedule – once this is agreed I'll finalise the draft of the call text for your approval

Have a great week end

[REDACTED]

From: Sonya Chowdhury [mailto:Sonya@actionforME.org.uk]
Sent: 09 February 2018 13:21
To: [REDACTED] Scottish Government
Subject: PhD call

Hi – My colleague has just told me that there is a possibility that BBC Scotland want to run a piece on recent activity that we have been involved in and making some comment about the PhD and how we are working to stimulate research funding would be great. If there's a way of working that in to the timings/announcement, that would be great but no worries if not, we can just leave it out!

Thanks

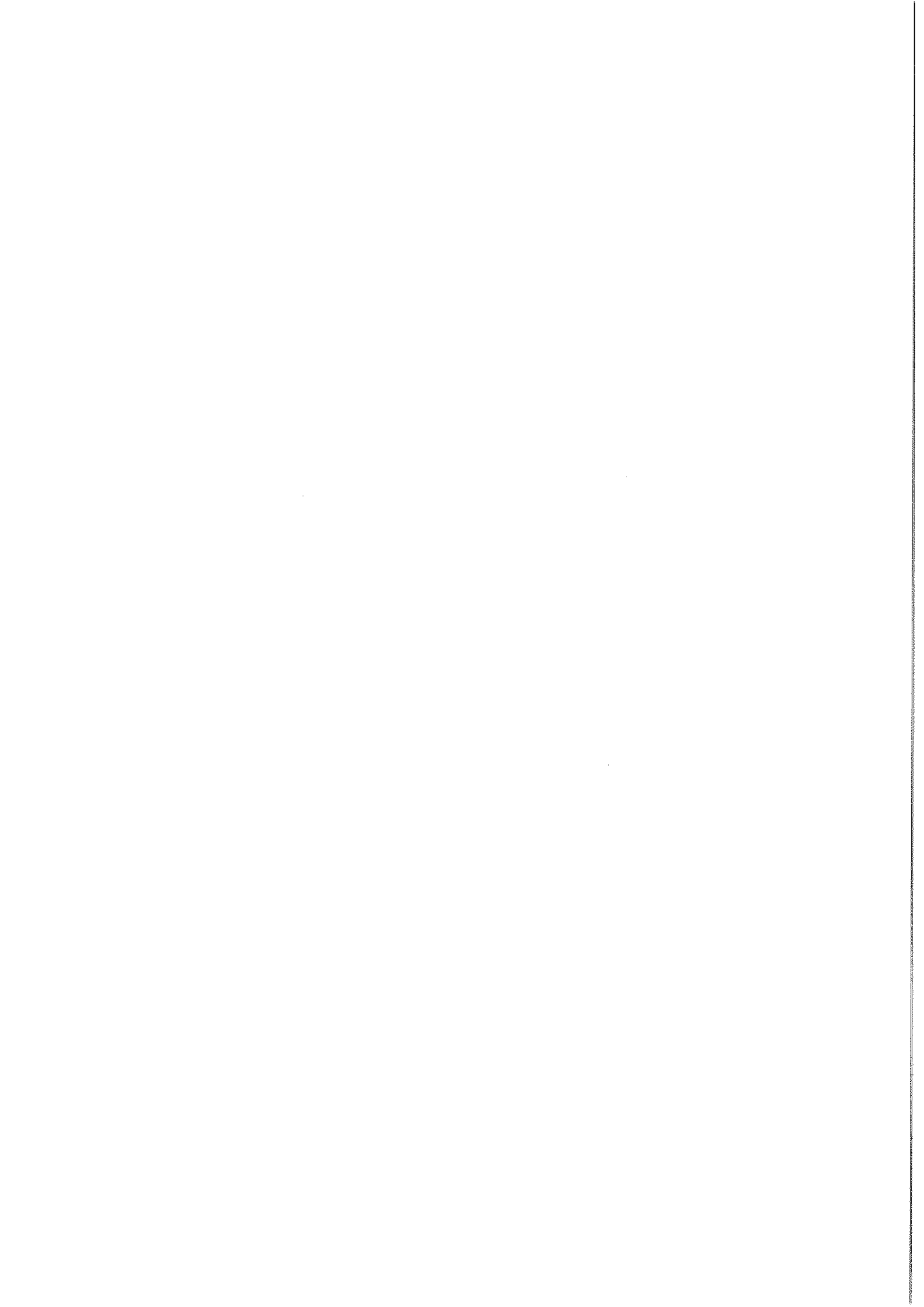


Sonya Chowdhury, Chief Executive, Action for M.E.

✉ 42 Temple Street, Keynsham BS31 1EH | 📧 sonya@actionforme.org.uk | 📞 [REDACTED] /
[REDACTED] www.actionforme.org.uk

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MEMORANDUM OF AGREEMENT
The Chief Scientist Office and Action for M.E.

Overview

Agreement: The Scottish Government Chief Scientist Office and Action for M.E. Ph.D. Fellowship in Myalgic Encephalomyelitis.

BETWEEN

(1) Action for M.E., a company limited by guarantee (registered in England no. 2906840) and a registered charity (Charity Number SC040452) whose registered office is 42 Temple Street Keynsham BS31 1EH (herein after referred to as "Action for M.E.");

(3) The Scottish Ministers acting through the Chief Scientist Office of The Scottish Government Health and Social Care Directorate, whose registered office is St Andrew's House, Regent Road, Edinburgh, EH1 3DG (herein after referred to as "CSO").

BACKGROUND

(A) Action for M.E. and CSO have agreed to support one Ph.D. Fellowship limited to biomedical research on Myalgic Encephalomyelitis at a total annual cost not exceeding £30,000 and a duration not exceeding 3 years (the "Ph.D."). Details of the relevant Award Letter and the Term and Conditions are appended as Annex 1 and Annex 2 respectively.

(B) This Agreement sets out the terms on which Action for M.E. and CSO will support the Ph.D. Fellowship.

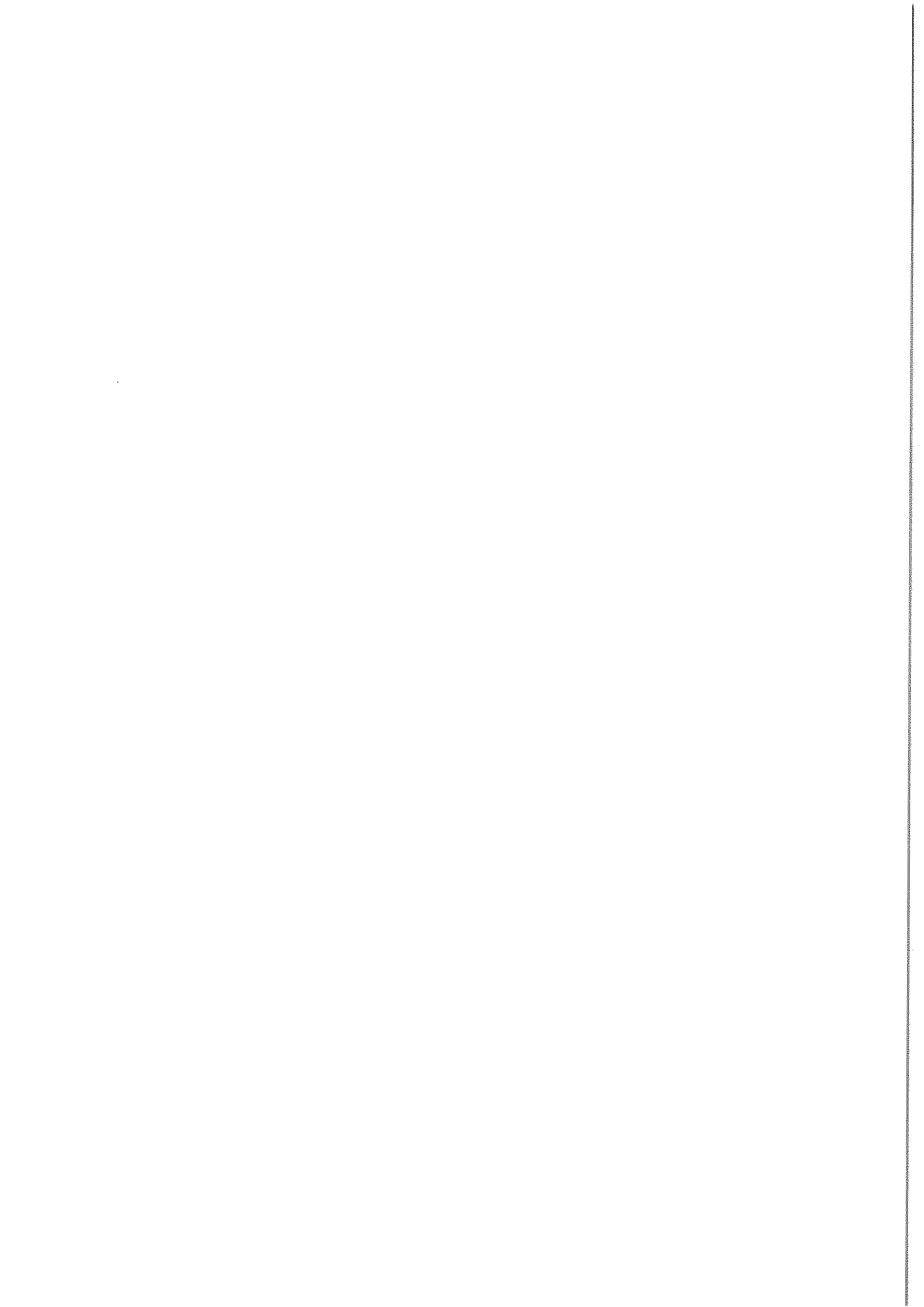
(C) The cost of the Ph.D. will be apportioned as follows:
Action for M.E. and CSO will each contribute up to a maximum of £15,000 per annum for a period of 3 years.

(D) CSO will administer the application and interview process of the Ph.D., with input required from Action for M.E. as outlined in section 2 below.

(E) CSO will administer the post-award management of the Ph.D., and will invoice Action for M.E. on an annual basis for the duration of payment of the Ph.D. Fellowship.

Duration

1. The Agreement shall be deemed to have commenced on the date the Agreement is made, as stated on the first page of the Agreement and shall be completed at the end of the Ph.D. Fellowship, save for the provisions contained in clauses 12 to 16 which shall continue for so long as there is any intellectual property arising from the Ph.D. Fellowship.



Grant Administration Responsibility

2. Except as specifically described otherwise in this agreement, CSO will administer the Ph.D. award made under this agreement in accordance with CSO's normal terms & conditions, as attached to this Agreement
3. CSO will consult Action for M.E. should there be any issues related to the Ph.D. award made under this agreement and will annually update Action for M.E. on research progress on such award.

Payment Arrangements

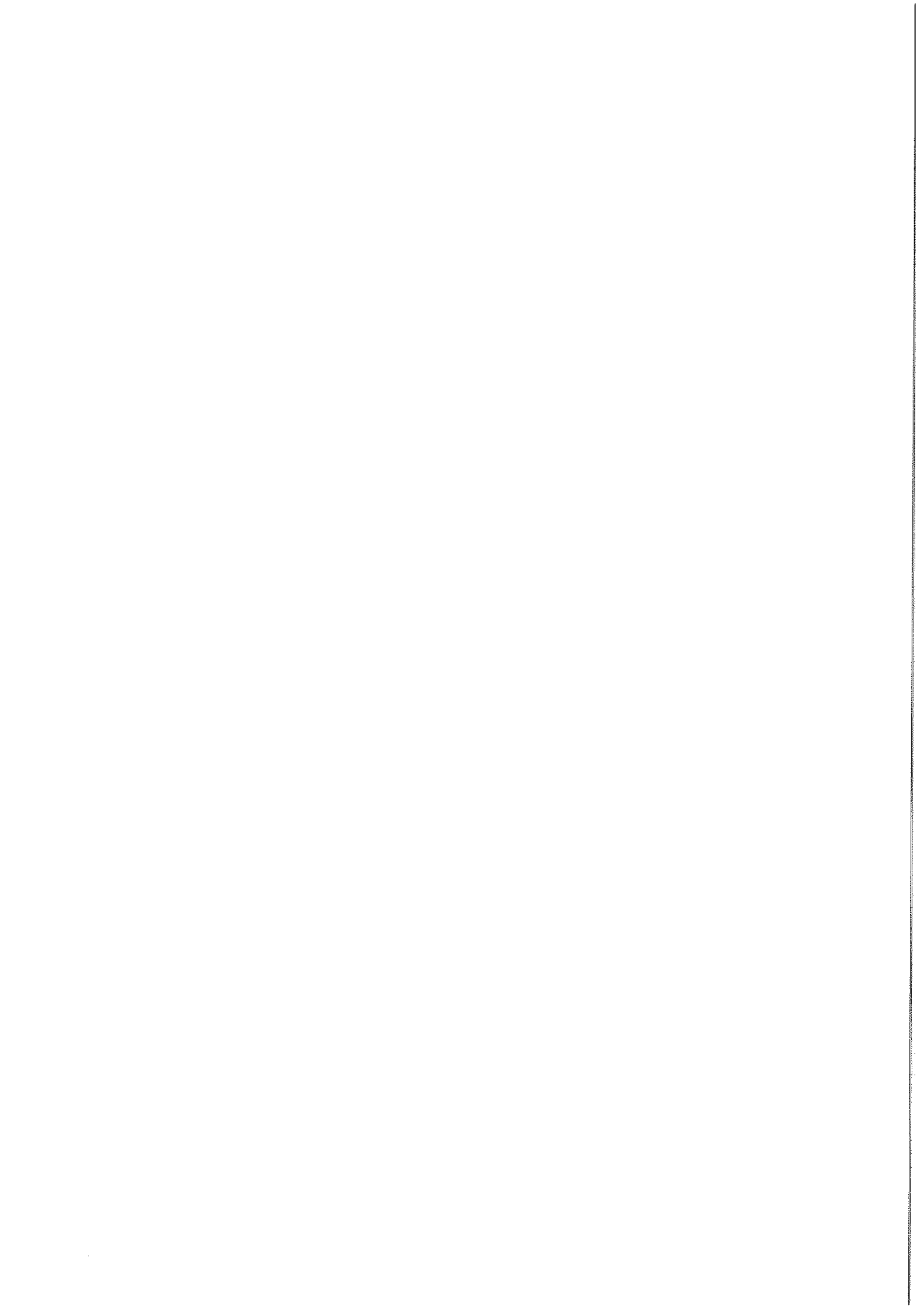
4. CSO will invoice Action for M.E. for their financial contribution to the Ph.D. Fellowship awarded under this agreement in accordance with the payment profile set out in Recital C, with the first such payment to be due at a date to be specified but within 6 months of the award being made and subsequent payments to be due annually thereafter following receipt and satisfactory review of the annual update in accordance with clause 3.
5. Action for M.E. reserves the right to withhold the final payment until final scientific reporting arrangements have been completed by the organisation awarded the Ph.D. Fellowship.

Communication/Dissemination Activities

6. CSO and Action for M.E. shall have the right to advertise the Ph.D. Fellowship award via normal CSO and Action for M.E. channels, respectively.
7. Publicity for all outcomes arising from the Ph.D. Fellowship should be jointly coordinated by CSO and Action for M.E.. Neither party shall carry out any publicity activities relating to the Ph.D. Fellowship without the prior agreement of each other party.
8. The holder of the CSO / Action for M.E. award will be required to acknowledge both parties' support in all publications and presentations/posters directly resulting from such award. In addition, holders of such awards will be required to forward, via CSO, copies of such publications to the parties.

Reporting Arrangements

9. Under CSO standard terms and conditions, CSO requires award holders to complete an annual report via ResearchFish. Details about ResearchFish can be found on the CSO website (<http://www.cso.scot.nhs.uk/outputs/evaluation-of-outputs/>)
10. CSO will make the ResearchFish submission available to Action for M.E. following annual completion.
11. The Fellow is responsible for providing progress reports to CSO as described in the CSO Standard Conditions of Award . Any change of objective must be agreed with CSO and approved by Action for M.E.. Progress reports are required at 6, 12, 18, 24 and 30 months from the start of the Clinical Fellowship. A final report is to be submitted within 4 months of the end date of the Fellowship.



IPR & Copyright, Technology Transfer

- 12. CSO will not claim ownership of intellectual property arising from the CSO funding for the CRF made jointly under this agreement. CSO policy is that responsibility for the protection and exploitation of CSO-funded research rests with the host institution responsible for the Fellow funded by the Ph.D.
- 13. The Fellow must advise CSO of the nature of any proposed exploitation, identifying partners and proposed sharing of royalties. If a third party is used in this process then the Fellow must provide details of the proposed third party to CSO and obtain CSO's prior written approval.
- 14. All intellectual property created or acquired out of the Ph.D. belongs to the host institution. However, no intellectual property, created or acquired, as a direct result of the funding may be exploited commercially without the prior written consent of CSO. CSO will obtain the written agreement of Action for M.E. before authorizing such exploitation. Exploitation includes the use for any commercial purpose or any license, sales, assignment, materials transfer or any transfer of rights.
- 15. If the host institution does not exploit or protect any intellectual property to the CSO's reasonable satisfaction, CSO shall have the right, but not a duty, to protect and exploit such intellectual property. Any commercial benefit will be shared between the relevant institution, CSO and Action for M.E. in such proportion as may be equitable, taking into account their respective contribution to the Intellectual Property. Any such action by CSO will not proceed unless agreed to in writing by Action for M.E..
- 16. CSO will provide detailed accounts to Action for M.E. of any royalty income and relative costs arising from the intellectual property created out of the Ph.D. as required from time to time by Action for M.E., and in any case not less than once per year.

General

- 17. Nothing in this Agreement shall constitute or shall be deemed to constitute a partnership or joint venture or the relationship of employer and employee between the parties and any sponsors; and no officer, employee or representative of one party shall act or be deemed to act as an agent of the other party.
- 18. This Agreement sets out all matters which have been agreed by the parties in relation to the funding of the Ph.D..
- 19. This agreement and all matters arising in relation to it shall be governed by and construed in all respects in accordance with the laws of Scotland and each party hereby submits to the non-exclusive jurisdiction of the Scottish Courts.

On behalf of Action for M.E.

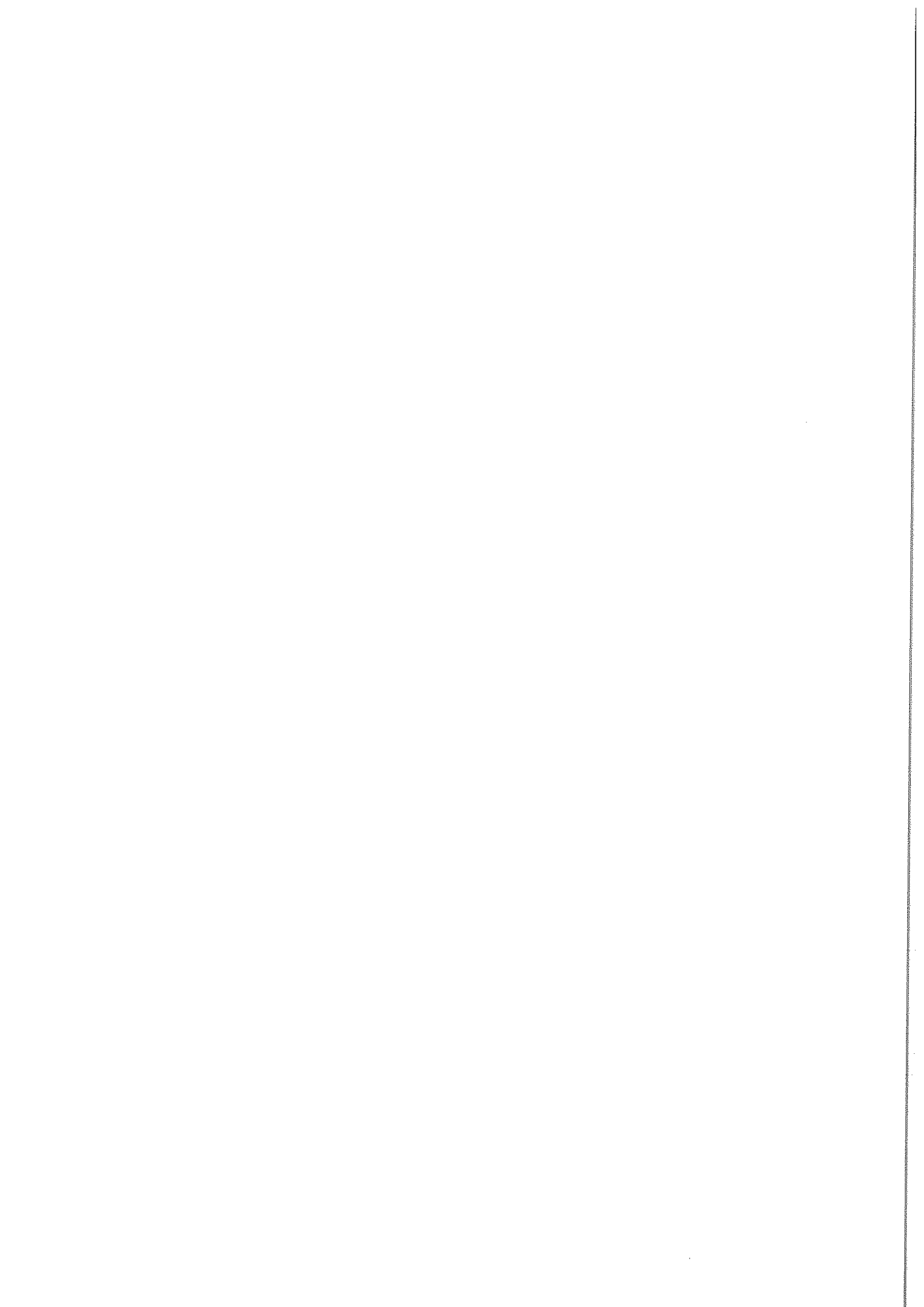
On behalf of CSO

Signed:

Signed: 

Name:

Name: 

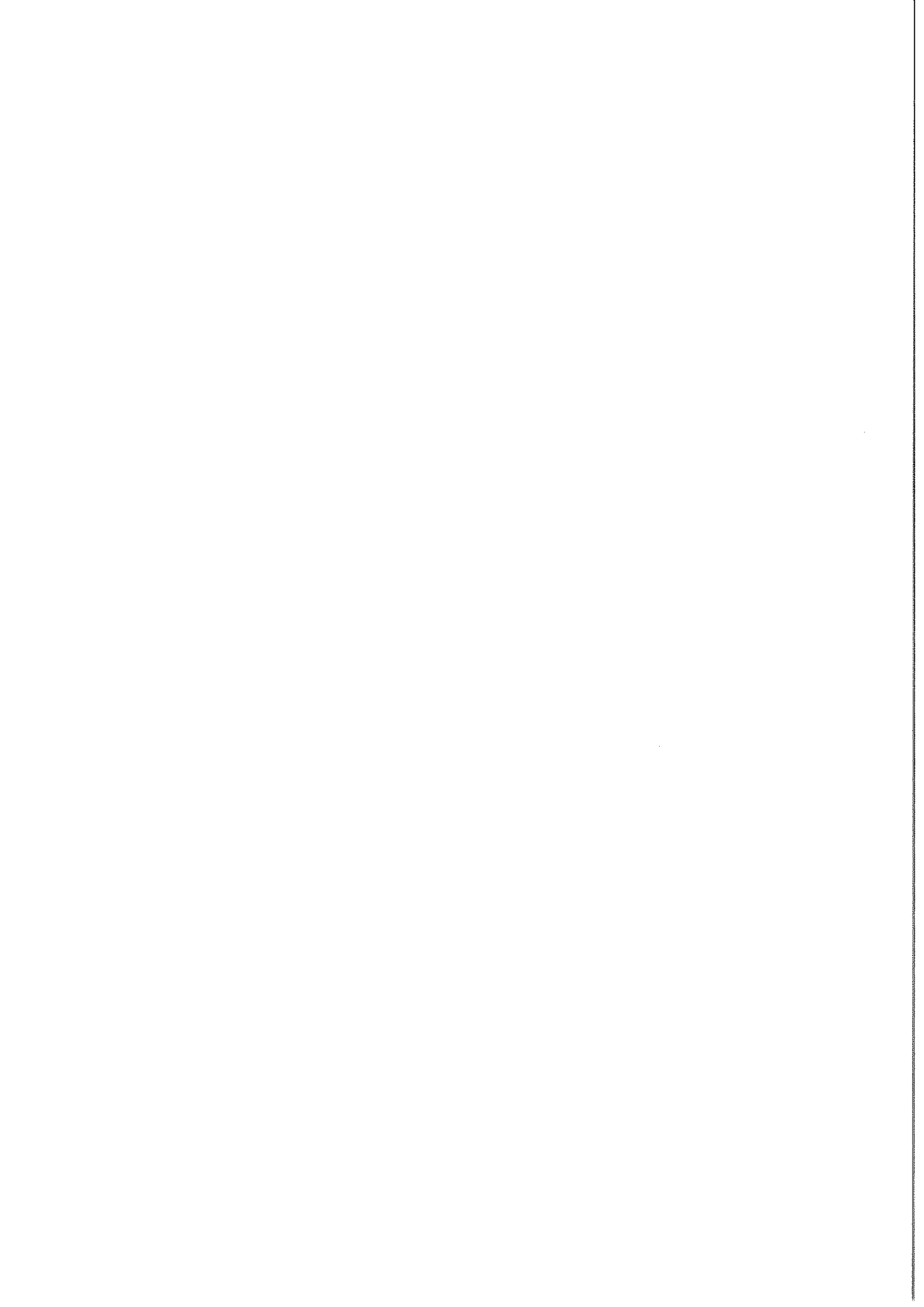


Position:

Position: [REDACTED]

Dated:

Dated: 16/02/2018



6. 13 February 2018

From: [REDACTED] Scottish Government
Sent: 13 February 2018 15:13
To: Sonya Chowdhury
Subject: RE: PhD call

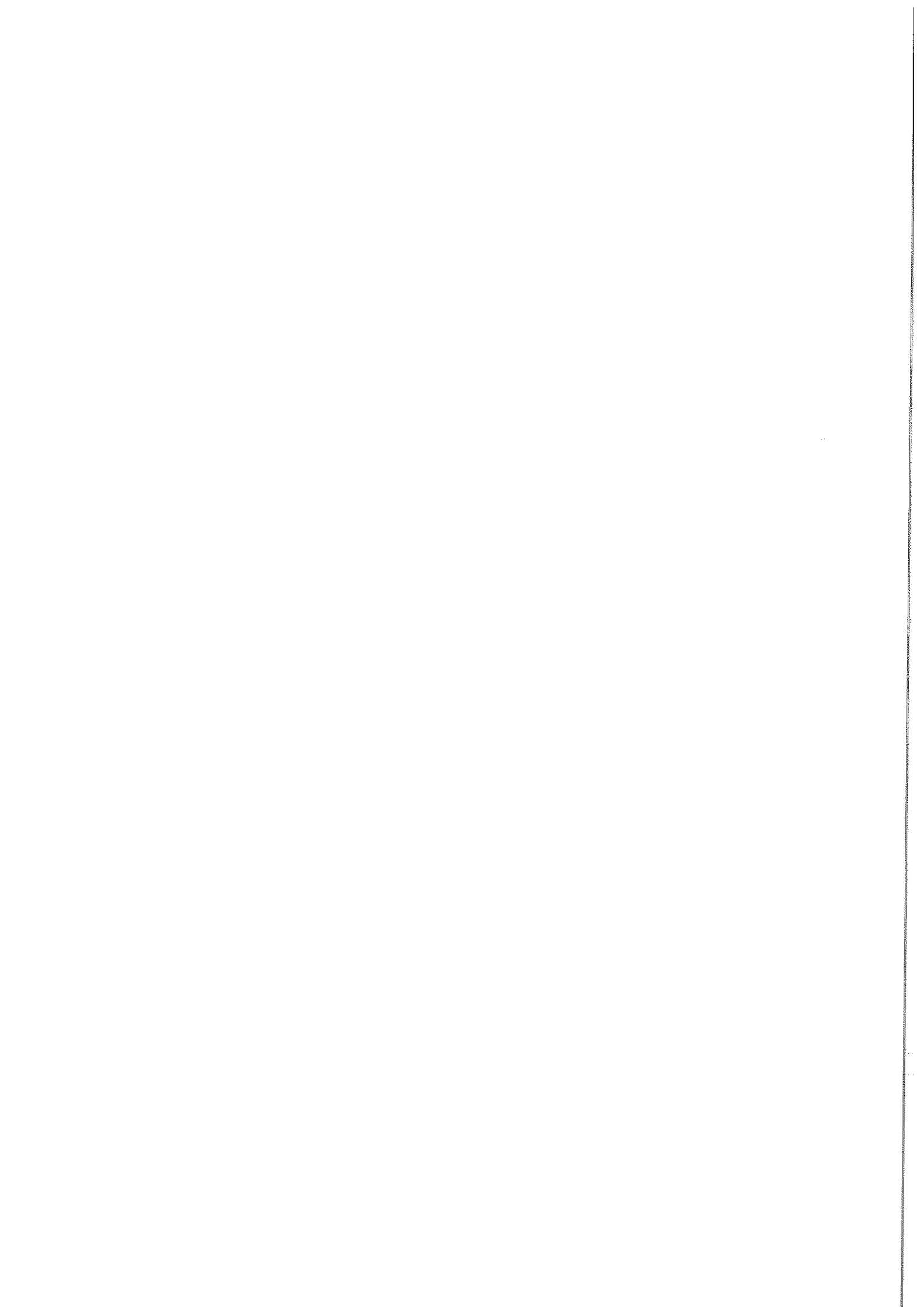
Thanks Sonya

Happy to work with you to facilitate this

I've been caught up with Ministerial business and I'm taking tomorrow off – I'll get the MoU and proposed text for the call to you by the end of the week

Kind regards

[REDACTED]



7. 22-24 January 2018

From: [REDACTED] Scottish Government
Sent: 24 January 2018 11:27
To: Sonya Chowdhury
Cc: Anna Whitson
Subject: RE: MOU

Thanks Sonya

I agree and we could put in £15 K to strengthen the consumables component

I'm just about to head off to Glasgow but could do a call as suggested on February 9th

Kind regards

[REDACTED]

From: Sonya Chowdhury [mailto:Sonya@actionforME.org.uk]
Sent: 24 January 2018 11:20
To: [REDACTED] Scottish Government
Cc: Anna Whitson
Subject: RE: MOU

Hi – I was a little surprised by the £25k as we normally provide £15.5k per year so had to do some scrabbling around to work out how we could do this! Is it possible that we could provide a little extra towards the research project costs and both put in £15k? We could then explore a further project if things go well or we get more than one good, fundable application?

A call would be great. I'm about to go on leave until 5 Feb so copying in my PA who can confirm something for us if I'm away when you respond.

I could do 5th Feb at either 2 or 3pm or in the afternoon of the 9th. If you would like to speak today, before I go so that we can move forward quicker, let me know and I will try and fit something in.

Thanks

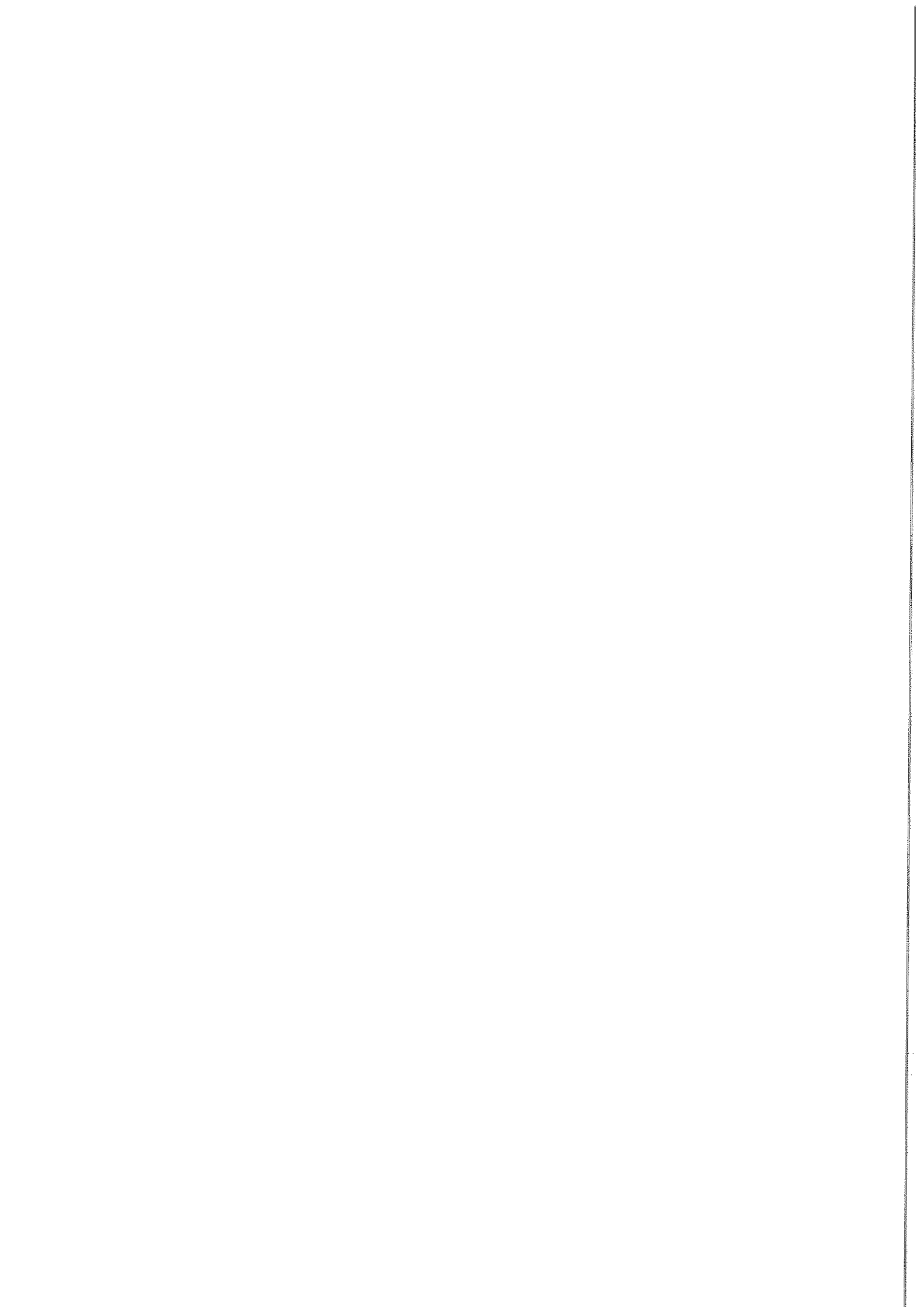


Sonya Chowdhury, Chief Executive, Action for M.E.

✉ 42 Temple Street, Keynsham BS31 1EH 📞 sonya@actionforme.org.uk | 📠 [REDACTED]
[REDACTED] www.actionforme.org.uk

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From: [REDACTED] Scottish Government
Sent: 23 January 2018 15:41
To: Sonya Chowdhury <Sonya@actionforME.org.uk>
Subject: RE: MOU

Dear Sonya

Thank you for getting back to me and I hope that you are feeling better – I'm happy to go with the 6 month reporting schedule as suggested

Could we schedule a brief call to run through the text for the announcement and timelines for the call – in addition, I over-estimated the likely cost (I must have been thinking about a clinical fellowship). The annual cost to each of us for a PhD is more in the region of £12.5 K – if you have £25 K p.a. available then we could look to match this and fund 2 PhD's – happy to discuss

Kind regards
[REDACTED]

From: Sonya Chowdhury [<mailto:Sonya@actionforME.org.uk>]
Sent: 22 January 2018 08:41
To: [REDACTED] Scottish Government
Subject: MOU

Hi – sorry for the radio silence here. I have unusually been off ill.

The MOU looks fine to us albeit with one requested amendment. We would like a six-monthly update report from the awardees. As a small charity, the small amounts of money we invest in research are actually quite large to us and the Board like to keep updated on progress. Could we therefore build in a request for a six monthly update report (we use a one page summary, attached) and a more detailed annual report?

Thanks



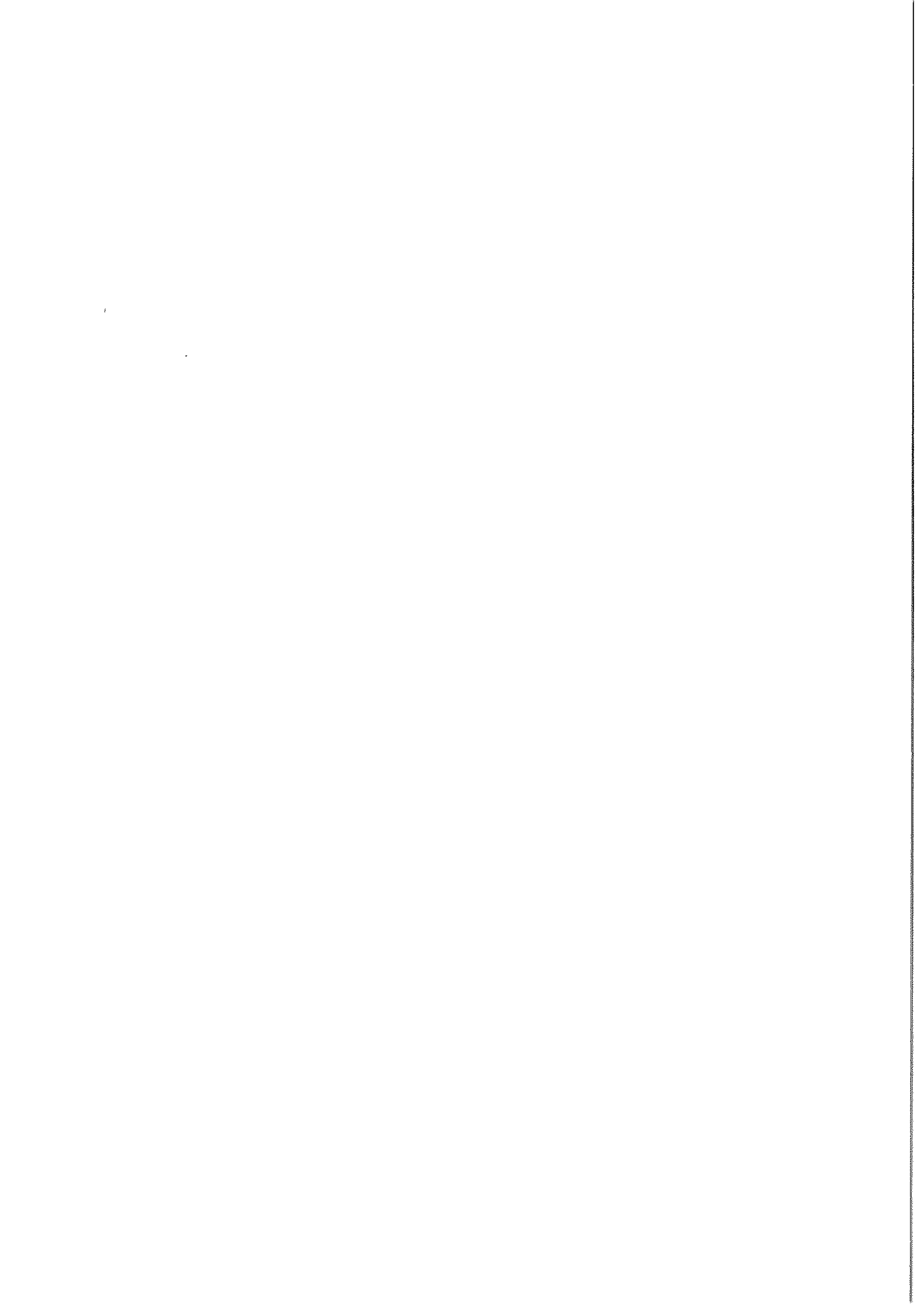
Sonya Chowdhury, Chief Executive, Action for M.E.

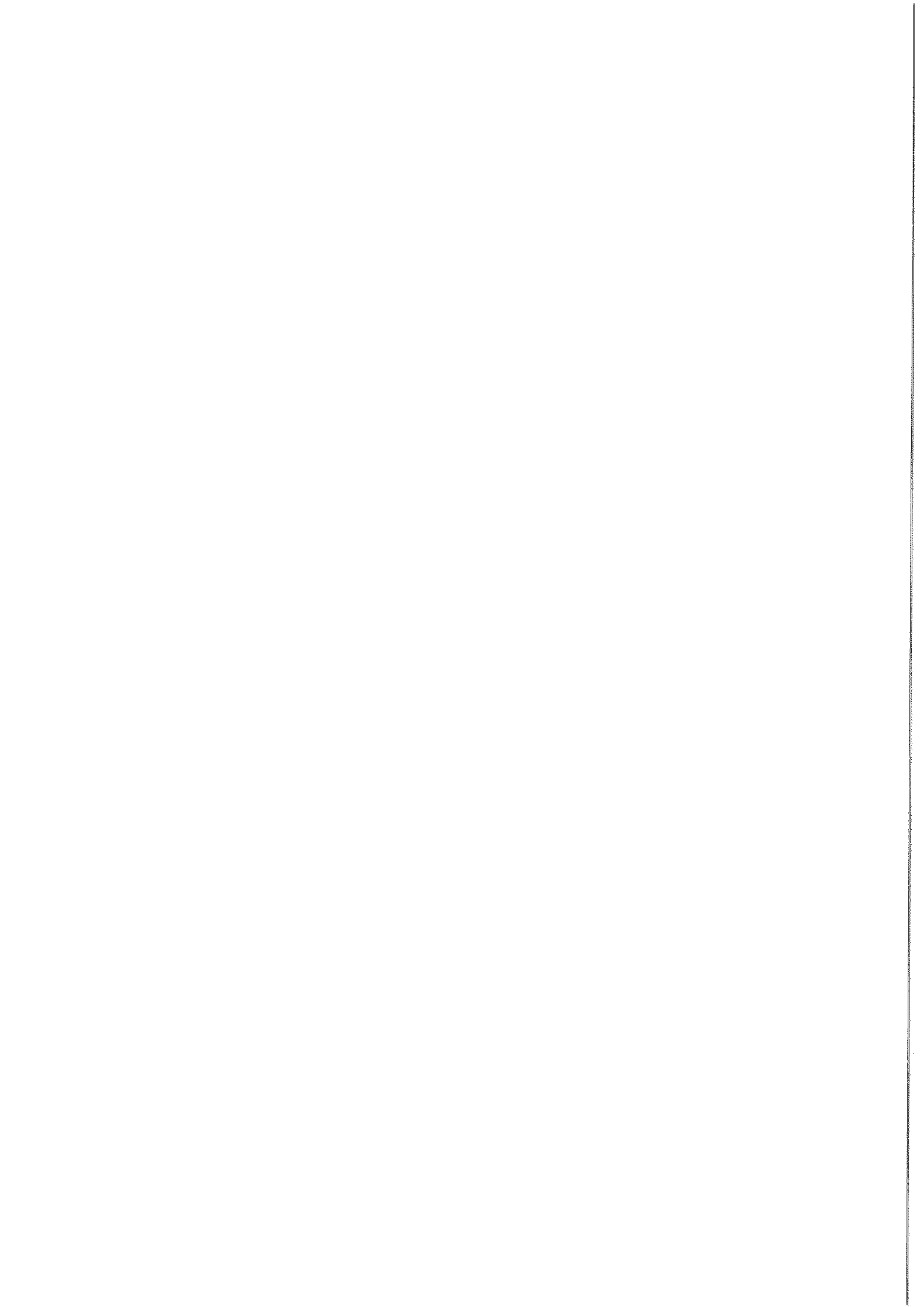
✉ 42 Temple Street, Keynsham BS31 1EH | 📧 sonya@actionforme.org.uk | 📞 [REDACTED]

[REDACTED] www.actionforme.org.uk

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Finance

Please insert/append budget summary and claim

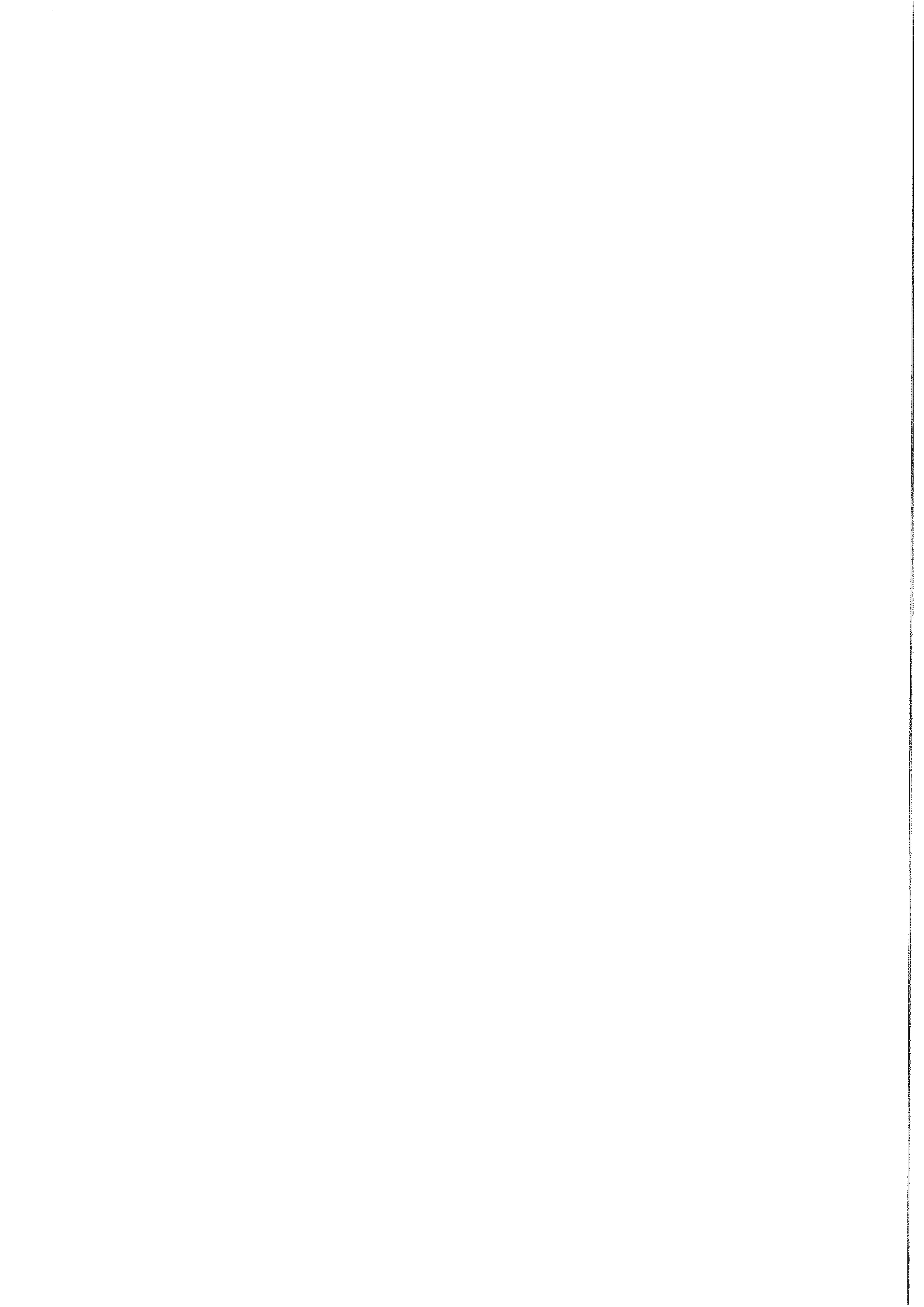
Is the budget on target?	Yes / No (please delete as appropriate)
Provide details of any difficulties/issues and identify action required to mitigate against them	

Emerging Findings

Please provide any details of emerging findings (as appropriate)	
--	--

Any Other Comments / Issues / Difficulties / News

Please provide details	
------------------------	--



8. 18 December 2017- 23 February 2018

From: [REDACTED] Scottish Government
Sent: 23 February 2018 17:26
To: [REDACTED] Scottish Government
Subject: FW: Approval request

From: [REDACTED] Action for ME
Sent: 22 December 2017 09:53
To: [REDACTED] Scottish Government
Cc: Tom Owen
Subject: RE: Approval request

[REDACTED]
Just collating some of the feedback from our first webinar and will be finished by lunchtime
...Yippee.

I appreciate your support in being able to respond flexibly to what is needed and its very satisfying to be making good progress with the engagement of HPs. The first webinar was really well received and we reached our target audience that included lots of GPs, "The webinar was most informative, and I now understand more fully, the prevalence and range of symptoms of ME/CFS, will more readily consider it when a patient presents with such symptoms and will know where best to direct them for appropriate treatment and care."

Have a lovely break too and enjoy the festive season and break.

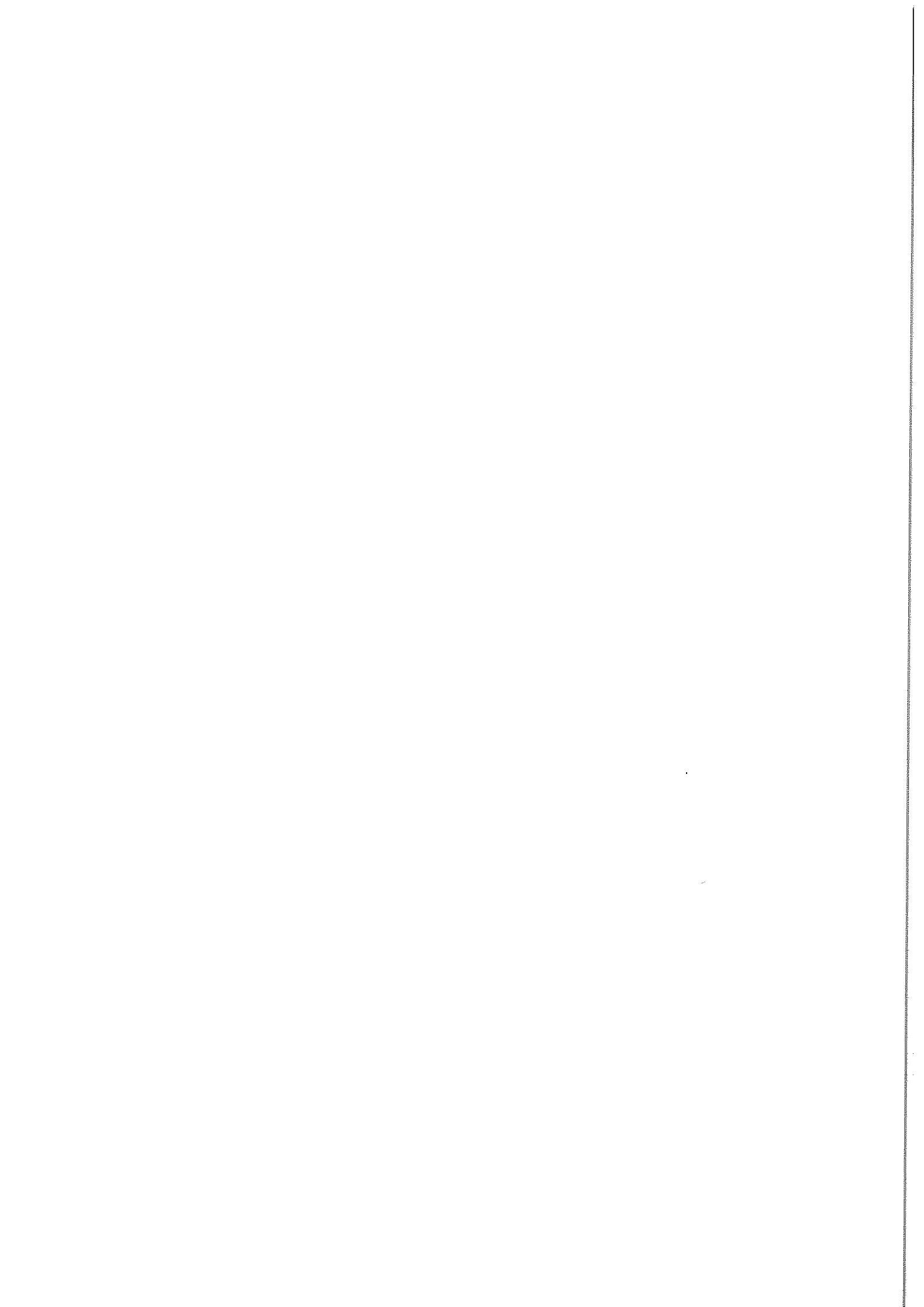
[REDACTED]
From: [REDACTED] Scottish Government
Sent: 22 December 2017 09:43
To: [REDACTED] Action for ME
Subject: RE: Approval request

Fine with me [REDACTED]

Hope you have a good break over the holidays and happy new year when it comes!

[REDACTED]
From: [REDACTED] Action for ME
Sent: 18 December 2017 12:34
To: [REDACTED] Scottish Government
Subject: Approval request

[REDACTED]
We're seeking your agreement on some changes to our initial proposal that relate to the production of 3 webinars and 4 professional briefings. We've had our first webinar (which was a great success) and have the 2 remaining scheduled for delivery in January, so no changes proposed here. However following our roundtable meetings and consultations with different HPs, patients and most recently the Scottish Collaborative, we would like to propose the following changes to our original plan of 4 briefings and propose we produce the following:



1. A professional briefing on M.E.\CFS and self-management targeting health professionals with lots of good signposting and links to further guidance and info.
2. A briefing specifically for OT's as there has been an identified need for this from OTs in Scotland.

And instead of the remaining 2 briefings:

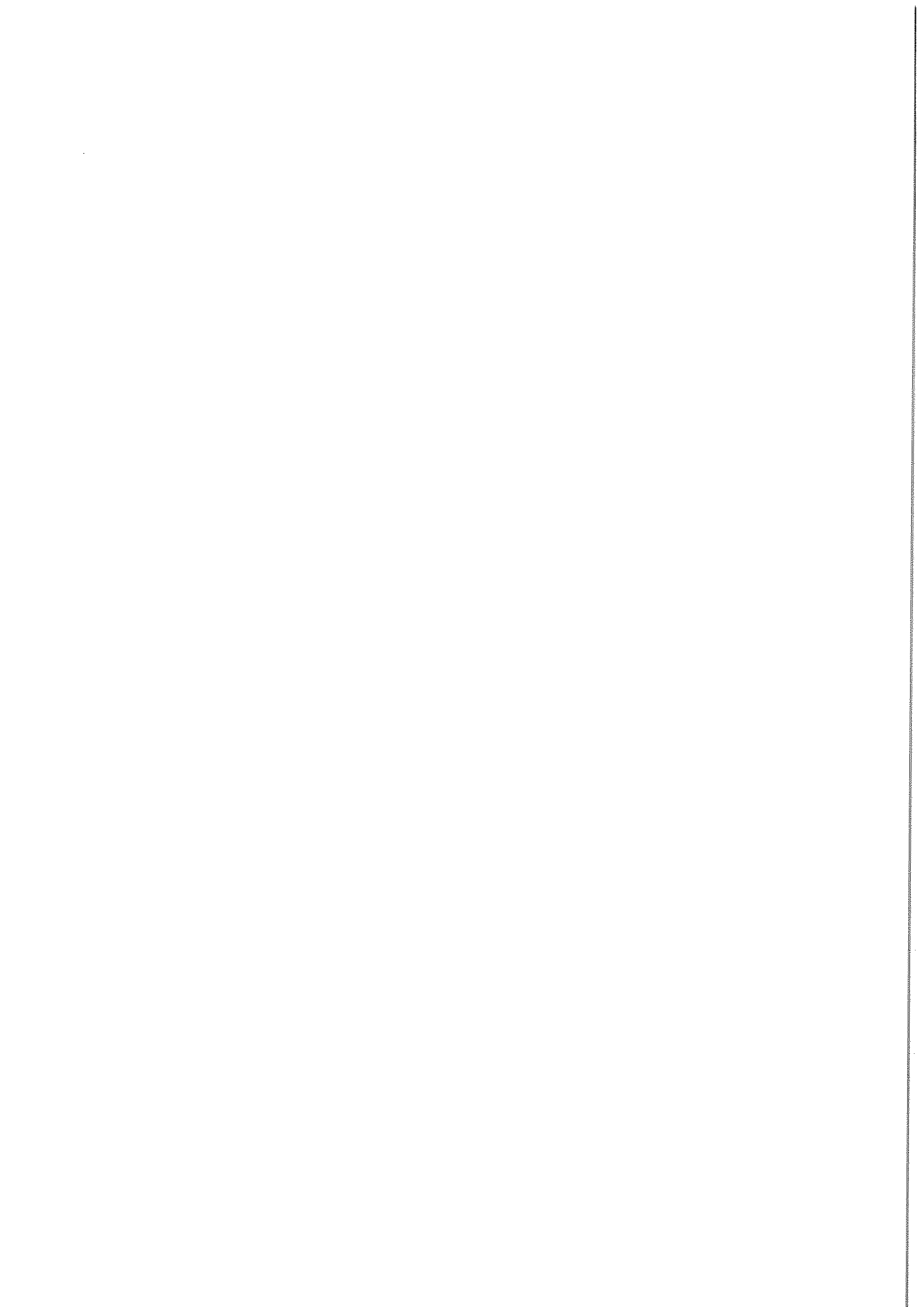
3. We produce the content and update the NHS Inform website. There is a memorandum of understanding in place to allow this to proceed with this.
4. We produce a patient facing booklet again with a focus on self-management and getting the most out of your health appointments.

On reviewing the draft briefings with the Scottish Collaborative last week it was felt that this would be much more effective. Please let me know what you think. More than happy to have a chat about this and to share a little bit more about why I believe this allows us to respond to more effectively to what is needed.



#GiveBigforME this Christmas and stop M.E. stealing lives

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9. 21 February 2018

From: Clare Ogden [mailto:clare@actionforme.org.uk]

Sent: 21 February 2018 15:34

To: [REDACTED] Scottish Government

Subject: Re: FMQ - ME - due 10:30 TODAY

[REDACTED]

Many thanks for your patience with this.

Please could you include a quote from us as follows:

Sonya Chowdhury, Chief Executive, Action for M.E. says: "This devastating neurological condition steals the lives of 20,000 men, women and children in Scotland, one in four of whom are so severely ill that they are remain hidden from view in darkened rooms, unable to bear even gentle hugs. Only by working collaboratively can we address the urgent needs of these vulnerable patients, including the need to advance biomedical research, so we are delighted to work with the Chief Scientist Office in Scotland in encouraging early-career scientists to move this field forward."

We also have some key facts and figures about M.E. to include in the Notes to editors, as follows:

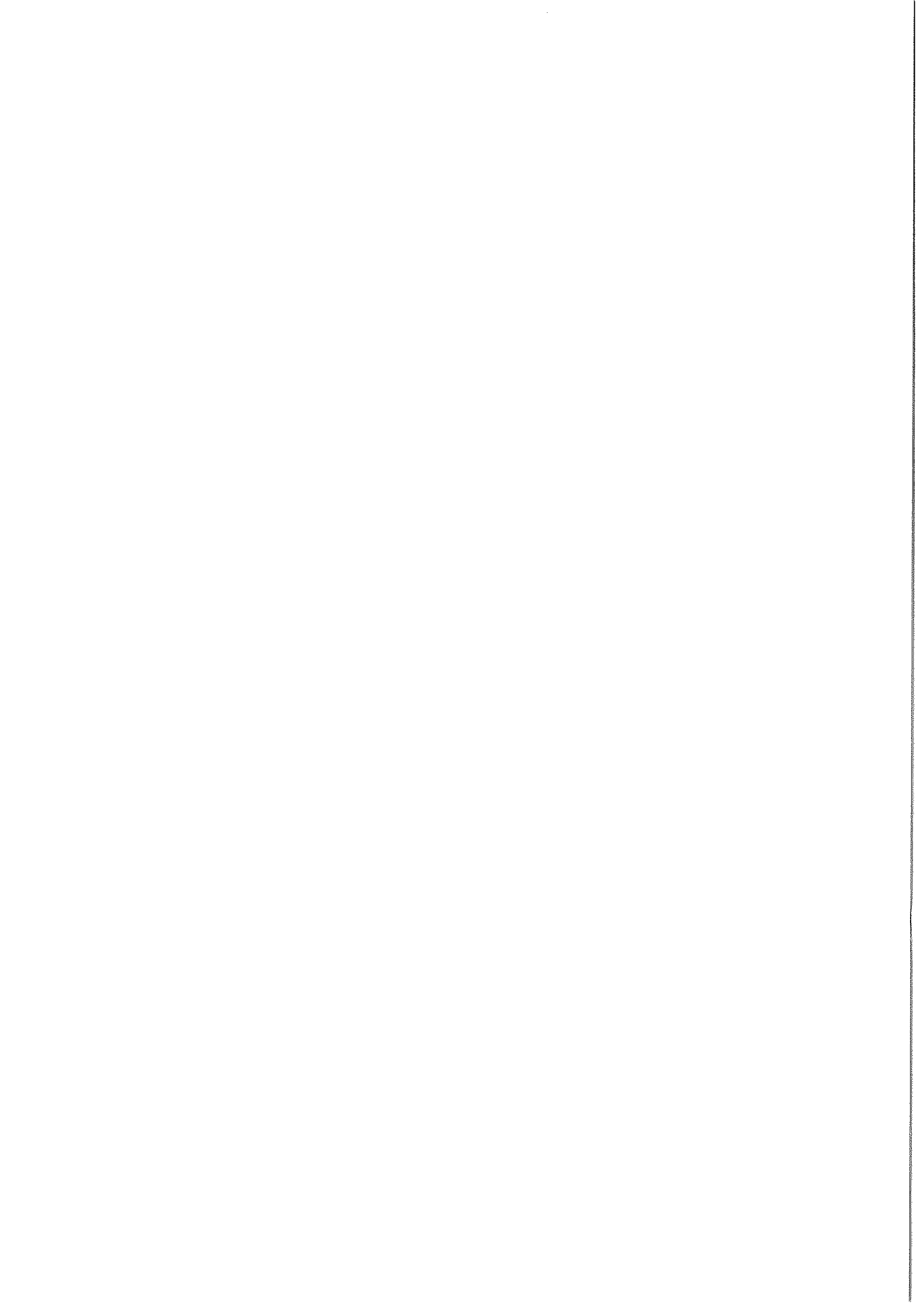
Myalgic Encephalomyelitis (M.E.) is a chronic, fluctuating, neurological condition, often diagnosed within the NHS as chronic fatigue syndrome (CFS) or M.E./CFS, affecting 20,000 men, women and children in Scotland, and 250,000 in the UK. People with M.E. score lower overall on health-related quality of life tests than most other chronic conditions – including prostate cancer, breast cancer, rheumatoid arthritis and schizophrenia. One in four people with M.E. is so severely ill that they are house- and/or bed-bound, unable to manage even basic self-care.

M.E. cost the UK economy at least £3.3 billion in 2014-15, including healthcare costs, disability-related welfare payments, productivity losses and unpaid informal care. Yet research into M.E. represents less than 1% of all active grants given by UK mainstream funding agencies, and more research is urgently needed to understand the biology of this debilitating condition.

ENDS

We would of course be very willing to offer case studies of people with M.E. in Scotland, willing to talk to the press - please share my contact details with journalists as necessary.

I also have a short list of contacts who have recently covered M.E.-related events in Scotland - would it be helpful for you to have this? I'm sure you have it covered, but am offering just in case!



Many thanks and best wishes

Clare

Clare Ogden
Head of Communications and Engagement
Action for M.E.
Office: [REDACTED]
Mobile: [REDACTED]

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From: [REDACTED] Scottish Government
Sent: 21 February 2018 11:56
To: Sonya Chowdhury; [REDACTED]; Action for ME; Clare Ogden
Subject: FW: FMQ - ME - due 10:30 TODAY

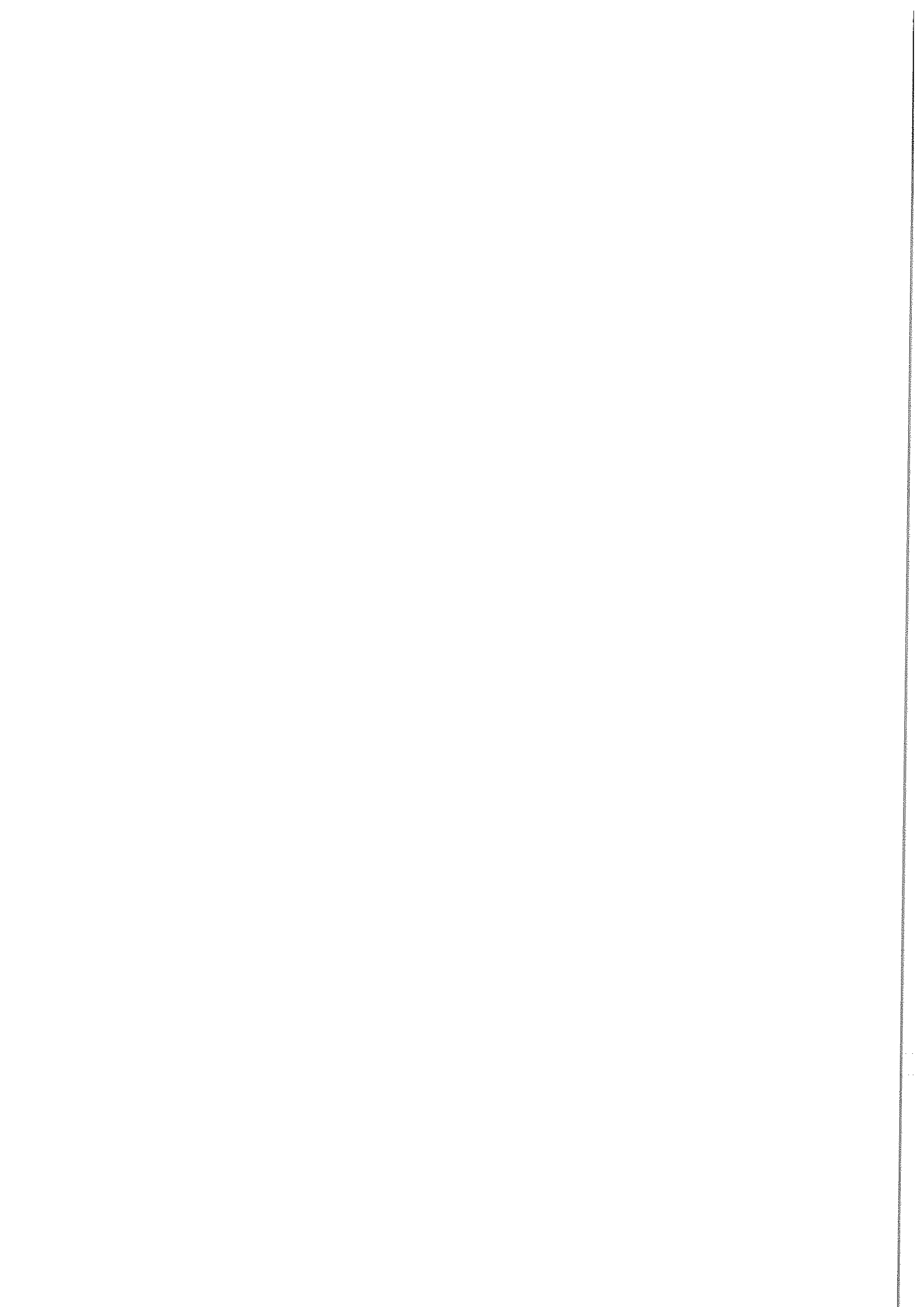
Hi

Very sorry for the short notice on this – health communications have decided that they would like a press release for this announcement and I am attaching their draft, they have asked if you would like to insert a quote. Also feel free to make any tracked changes on the text.

I am only in the office till 2pm today – grateful if you could let me know if you will be able to respond by then – if not I'll try and find a colleague to liaise.

Thanks

[REDACTED]



10. 13-19 February 2018

From: Clare Ogden [mailto:clare@actionforme.org.uk]
Sent: 19 February 2018 08:50
To: [REDACTED] Scottish Government
Subject: Action for M.E./CSO PhD call announcement

[REDACTED]
Lovely to meet you, albeit electronically!

I understand that the MoU has now been signed and we can launch news of this call when ready?

How would you like to manage co-ordinating the announcement... I can draft some copy this morning that includes a quote from us and a patient/carer with M.E., plus some details re the need around more M.E. research, and share it with you to edit/add to?

I hadn't planned to contact the press but Alan suggests there may be some interest - very happy to take your lead on this!

Once we have agreed a story content, we would post it on our own website and social media, and also include a piece in the forthcoming spring edition of our membership magazine, InterAction.

Many thanks and best wishes

Clare

Clare Ogden
Head of Communications and Engagement
Action for M.E.
Office: [REDACTED]
Press Office mobile: [REDACTED]

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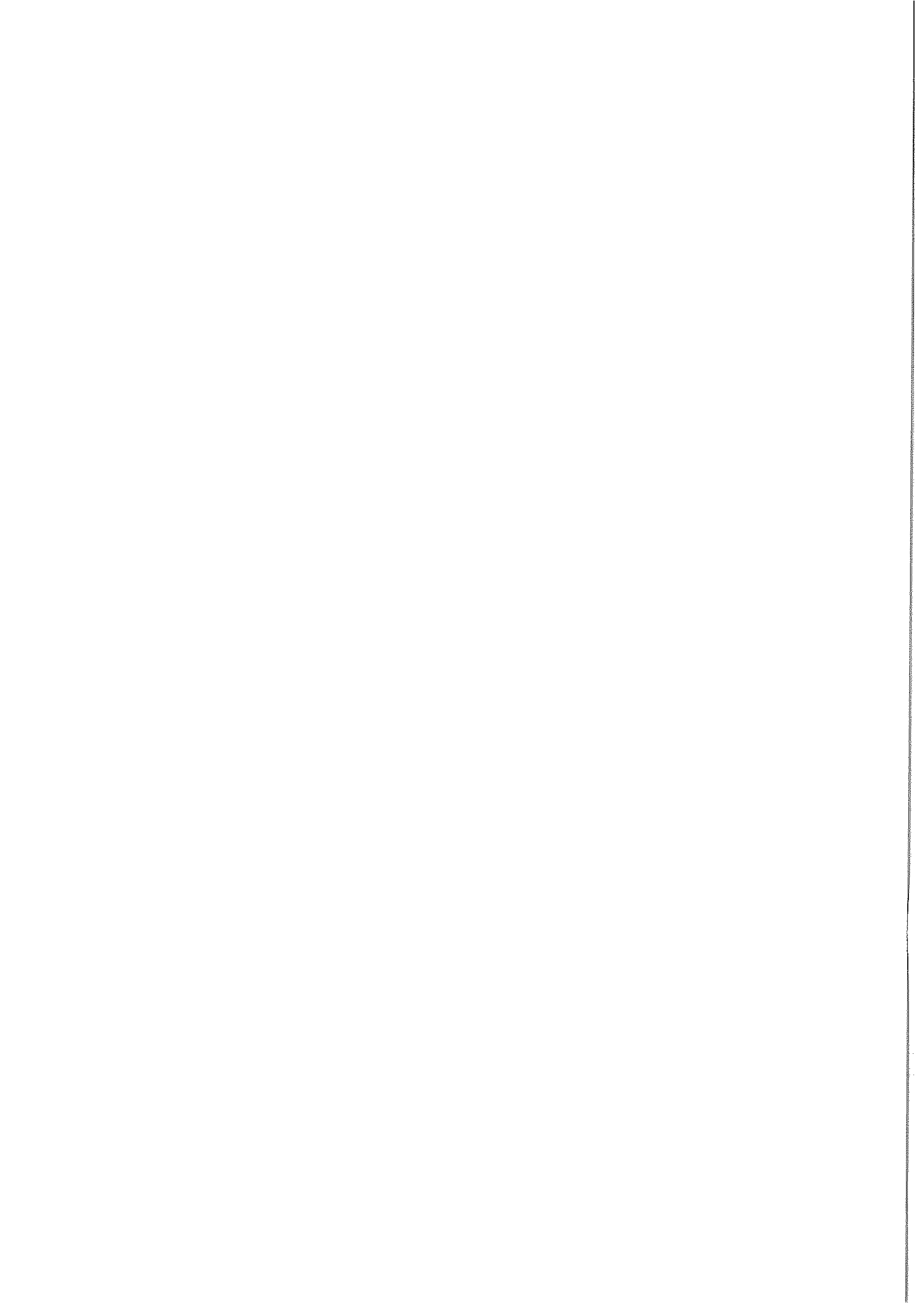
From: [REDACTED] Scottish Government
Sent: 13 February 2018 15:53
To: Clare Ogden
Cc: Sonya Chowdhury; [REDACTED] Scottish Government
Subject: RE: PhD call

Thanks Clare

Experience suggests that CSO/Charity collaborations can generate a fair amount of interest. I've copied my colleague [REDACTED] and will be involved in co-ordinating our announcements etc.

Best wishes

[REDACTED]



From: Clare Ogden [mailto:clare@actionforme.org.uk]

Sent: 13 February 2018 15:48

To: [REDACTED] Scottish Government

Cc: Sonya Chowdhury

Subject: RE: PhD call

[REDACTED]

Sonya has shared your email with me as I'm leading on the comms for this. Many thanks for the update – I have been told however that BBC Scotland will now be running this piece tomorrow at 12.30pm, having brought it forward a day, so unfortunately we will miss having the announcement included.

However, it's likely there will be quite a lot of interest in the topic – the discussion is about M.E. more generally, including the urgent need for more specialist services in Scotland – so there may well be an opportunity to follow-up, particularly when the award is announced in the early summer.

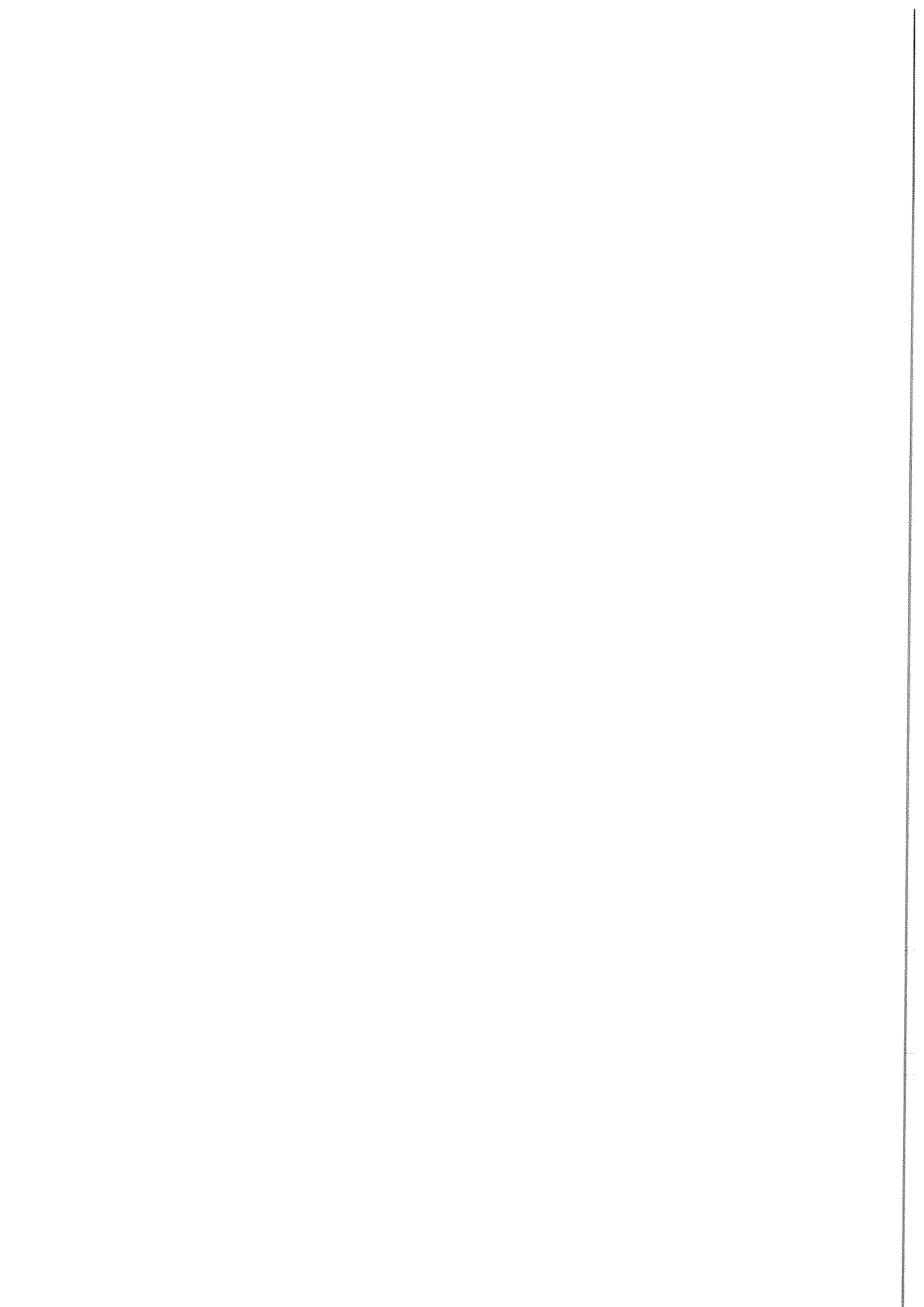
With best wishes

Clare

Clare Ogden
Head of Communications and Engagement
Action for M.E.
Office: [REDACTED]
Press Office mobile: [REDACTED]

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11. 21 February 2018

From: [REDACTED] Scottish Government
Sent: 21 February 2018 15:35
To: Clare Ogden; [REDACTED] Scottish Government
Subject: RE: FMQ - ME - due 10:30 TODAY

Thanks Clare

Will action as below.

All the best

[REDACTED]

From: Clare Ogden [mailto:clare@actionforme.org.uk]
Sent: 21 February 2018 15:34
To: [REDACTED] Scottish Government
Subject: Re: FMQ - ME - due 10:30 TODAY

[REDACTED]

Many thanks for your patience with this.

Please could you include a quote from us as follows:

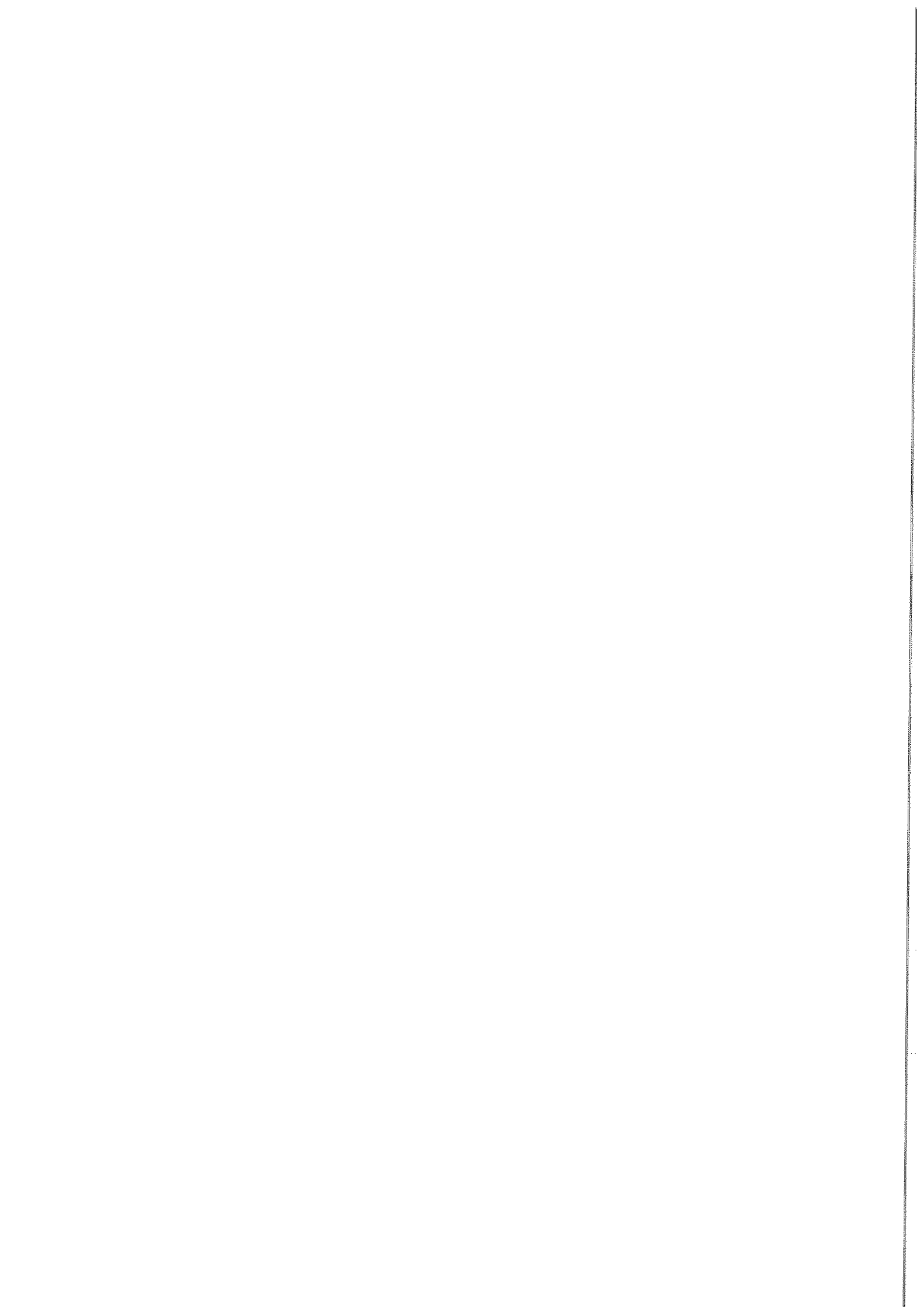
Sonya Chowdhury, Chief Executive, Action for M.E. says: "This devastating neurological condition steals the lives of 20,000 men, women and children in Scotland, one in four of whom are so severely ill that they are remain hidden from view in darkened rooms, unable to bear even gentle hugs. Only by working collaboratively can we address the urgent needs of these vulnerable patients, including the need to advance biomedical research, so we are delighted to work with the Chief Scientist Office in Scotland in encouraging early-career scientists to move this field forward."

We also have some key facts and figures about M.E. to include in the Notes to editors, as follows:

Myalgic Encephalomyelitis (M.E.) is a chronic, fluctuating, neurological condition, often diagnosed within the NHS as chronic fatigue syndrome (CFS) or M.E./CFS, affecting 20,000 men, women and children in Scotland, and 250,000 in the UK. People with M.E. score lower overall on health-related quality of life tests than most other chronic conditions – including prostate cancer, breast cancer, rheumatoid arthritis and schizophrenia. One in four people with M.E. is so severely ill that they are house- and/or bed-bound, unable to manage even basic self-care.

M.E. cost the UK economy at least £3.3 billion in 2014-15, including healthcare costs, disability-related welfare payments, productivity losses and unpaid informal care. Yet research into M.E. represents less than 1% of all active grants given by UK mainstream funding agencies, and more research is urgently needed to understand the biology of this debilitating condition.

ENDS



We would of course be very willing to offer case studies of people with M.E. in Scotland, willing to talk to the press - please share my contact details with journalists as necessary.

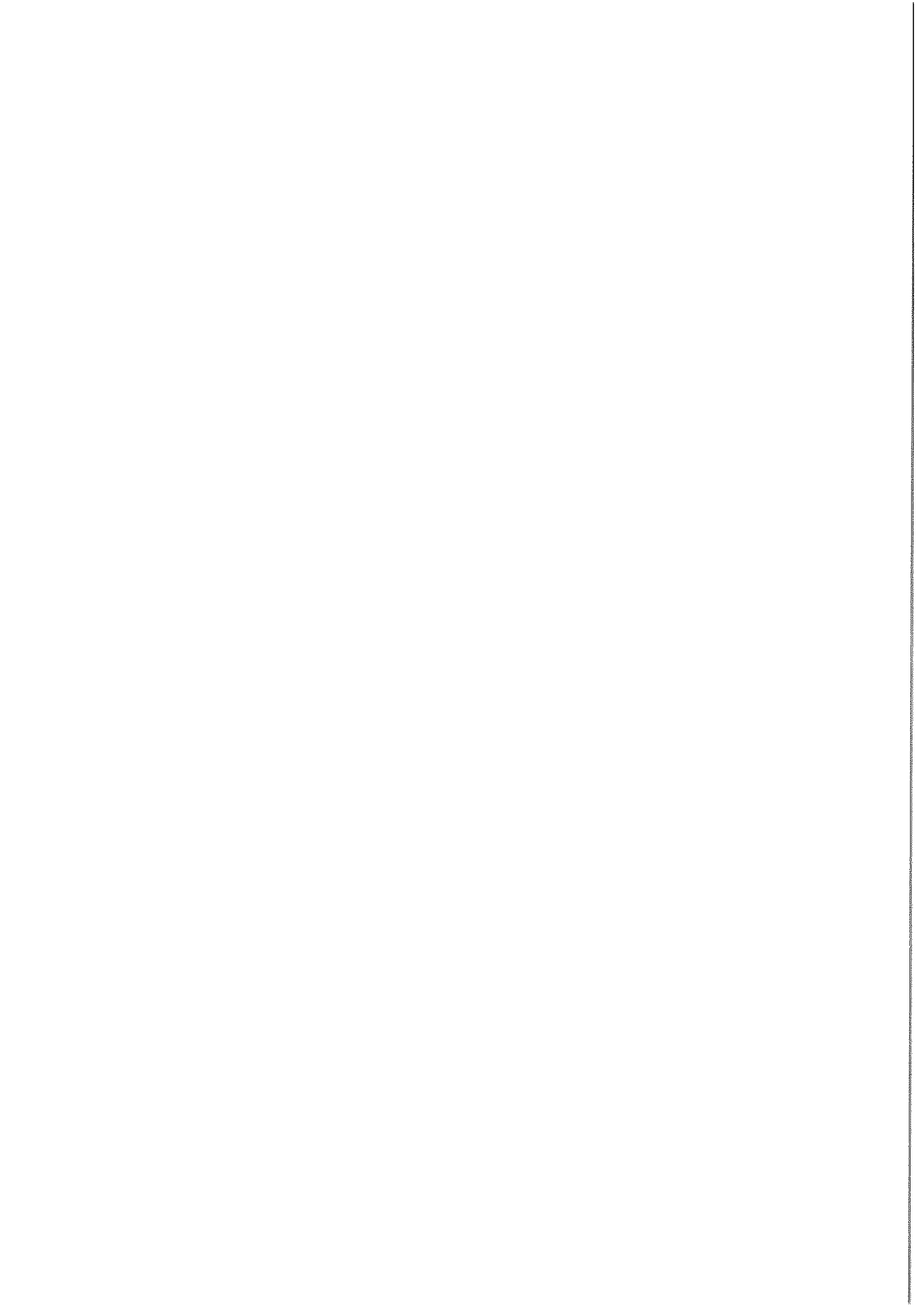
I also have a short list of contacts who have recently covered M.E.-related events in Scotland - would it be helpful for you to have this? I'm sure you have it covered, but am offering just in case!

Many thanks and best wishes

Clare

Clare Ogden
Head of Communications and Engagement
Action for M.E.
Office: [REDACTED]
Mobile: [REDACTED]

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12. 22 February 2018

From: Clare Ogden [mailto:clare@actionforme.org.uk]
Sent: 22 February 2018 09:54
To: [REDACTED] Scottish Government
Subject: Re: Call published

[REDACTED]

Many thanks for letting me know - our story is now live at <https://www.actionforme.org.uk/news/new-phd-funding-for-biomedical-me-research/>

I'm just about to share it on social media, too.

Best wishes

Clare

Clare Ogden
Head of Communications and Engagement
Action for M.E.
Office: [REDACTED]
Mobile: [REDACTED]

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From: [REDACTED] Scottish Government
Sent: 22 February 2018 09:16
To: Clare Ogden
Cc: [REDACTED] Scottish Government
Subject: Call published

Clare

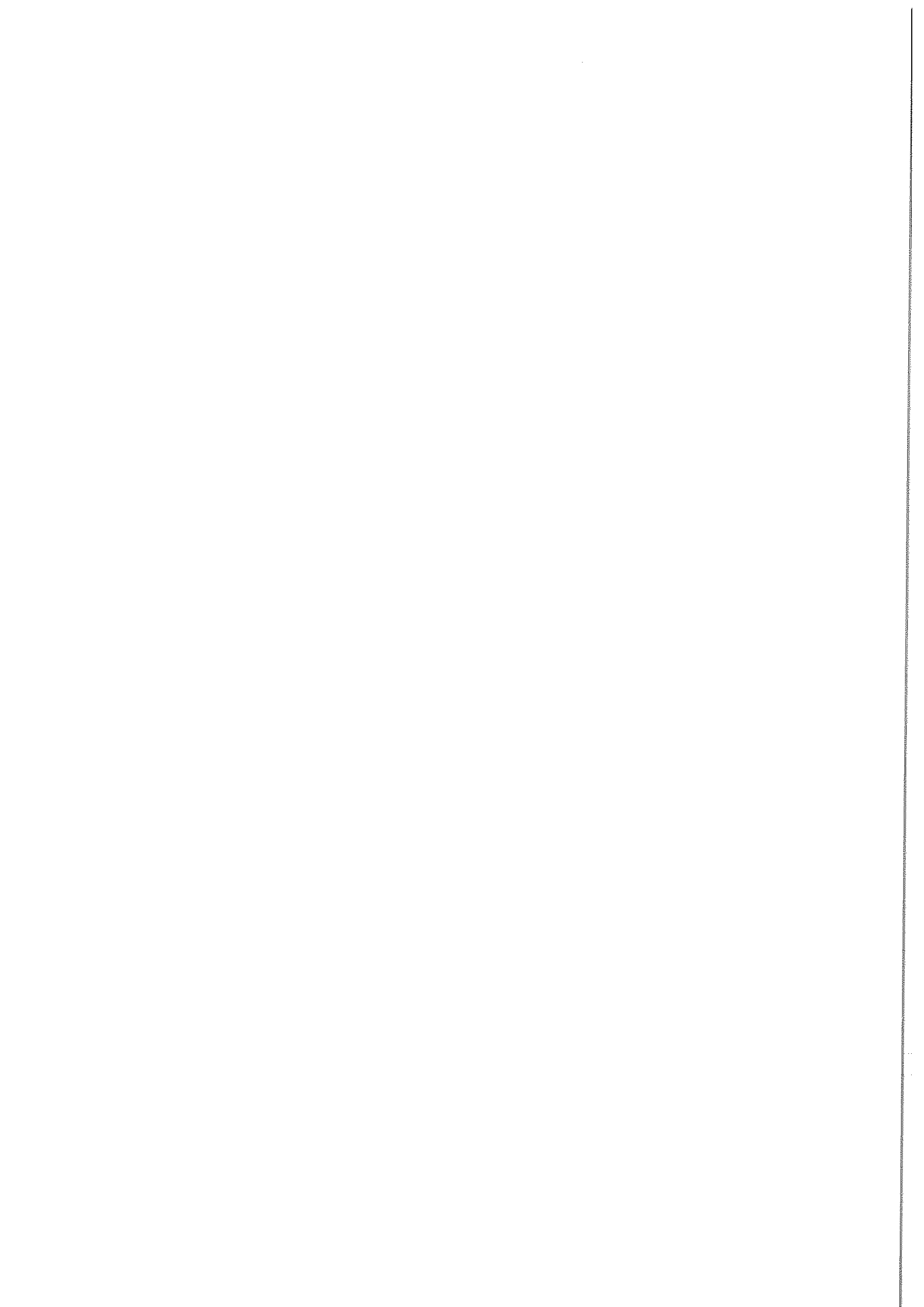
I have just published the call - <http://www.cso.scot.nhs.uk/me/>

Which links to this page - <http://www.cso.scot.nhs.uk/mephd/>

Thanks for getting back to [REDACTED] yesterday.

Best wishes

[REDACTED]



13. 21 February 2018

From: [REDACTED] Scottish Government
Sent: 21 February 2018 11:56
To: Sonya Chowdhury; [REDACTED]; Action for ME Clare Ogden
Subject: FW: FMQ - ME - due 10:30 TODAY

Hi

Very sorry for the short notice on this – health communications have decided that they would like a press release for this announcement and I am attaching their draft, they have asked if you would like to insert a quote. Also feel free to make any tracked changes on the text.

I am only in the office till 2pm today – grateful if you could let me know if you will be able to respond by then – if not I'll try and find a colleague to liaise.

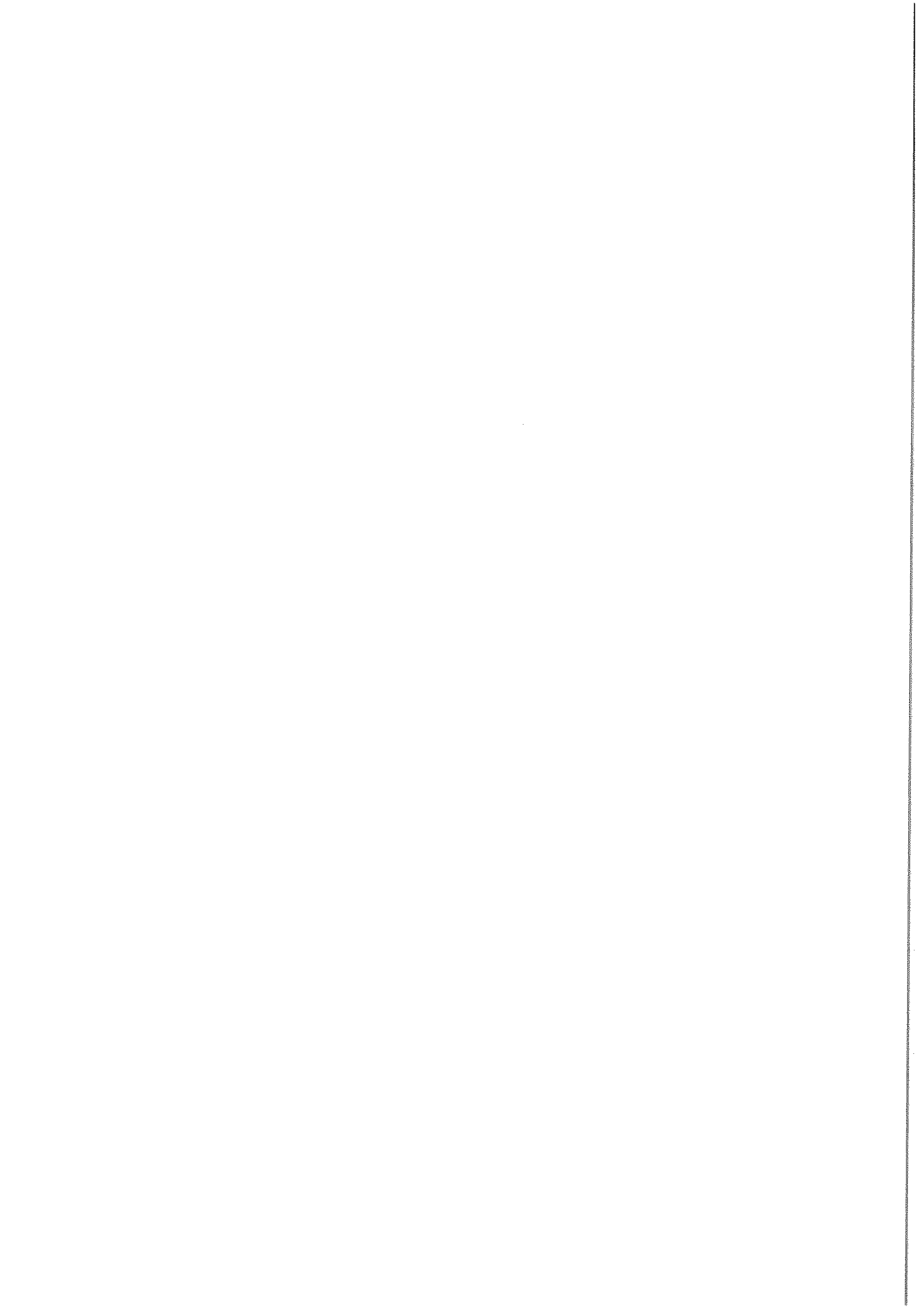
Thanks

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]



Attachment to email 21 Feb 2018 11:56

News



Scottish Government
Riaghaltas na h-Alba
gov.scot

DRAFT

New funding for M.E research £90,000 for Ph.D studentship.

New funding will support research into the causes, diagnosis and treatment of Myalgic Encephalomyelitis (ME).

Jointly funded by Scottish Government and Action for ME, £90,000 will be provided for a Scottish university to host a new Ph.D studentship in biomedical research, specifically focussed on improve understanding of ME.

Health Secretary Shona Robison said:

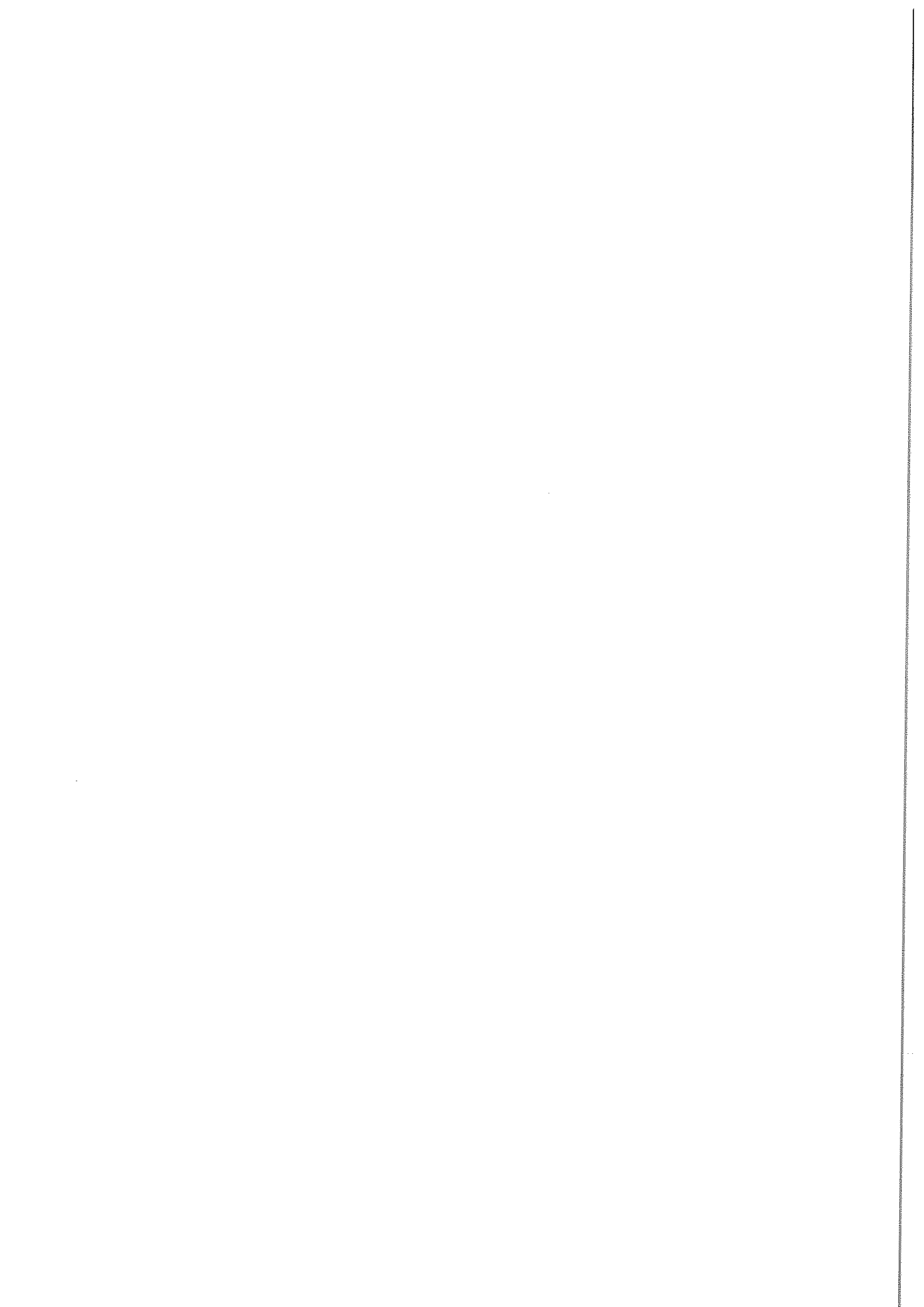
“We are committed to ensuring that people in Scotland living with ME are able to access the best possible care and support. We have listened to the views of those living with ME,

that is why we are funding this new post – to support the development of new and effective approaches to diagnosis and treatment of the condition.

“Taken together, we are committed to working with partners such as Action for ME to both increase our understanding of ME, and improve the support available for those living with it.”

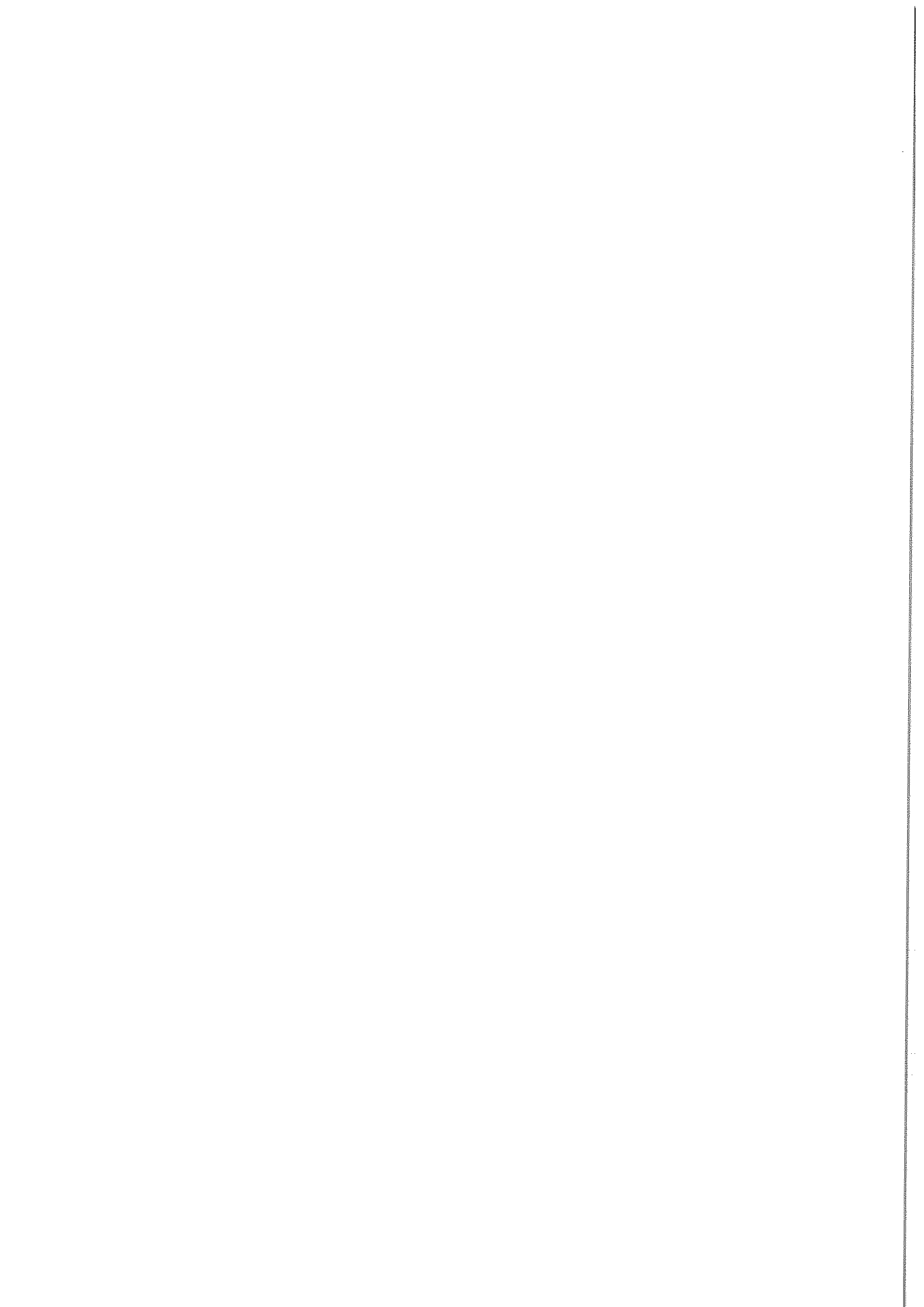
Action for ME quote:

Background



Action for ME has previously received £300,000 from the Scottish Government's Transforming Self-Management Fund, for the Inform ME Scotland project. This project will develop a peer-mentoring, self-management support network - to build confidence and reduce isolation in people affected by M.E.

Since 2015/16 the Scottish Government has invested £2.5 million funding for the Specialist Nursing and Care Fund, to improve access to specialist nursing support.



14. 26 January 2018

From: [REDACTED] Scottish Government

Sent: 26 January 2018 10:24

To: Audrey Birt; Action for ME [REDACTED];

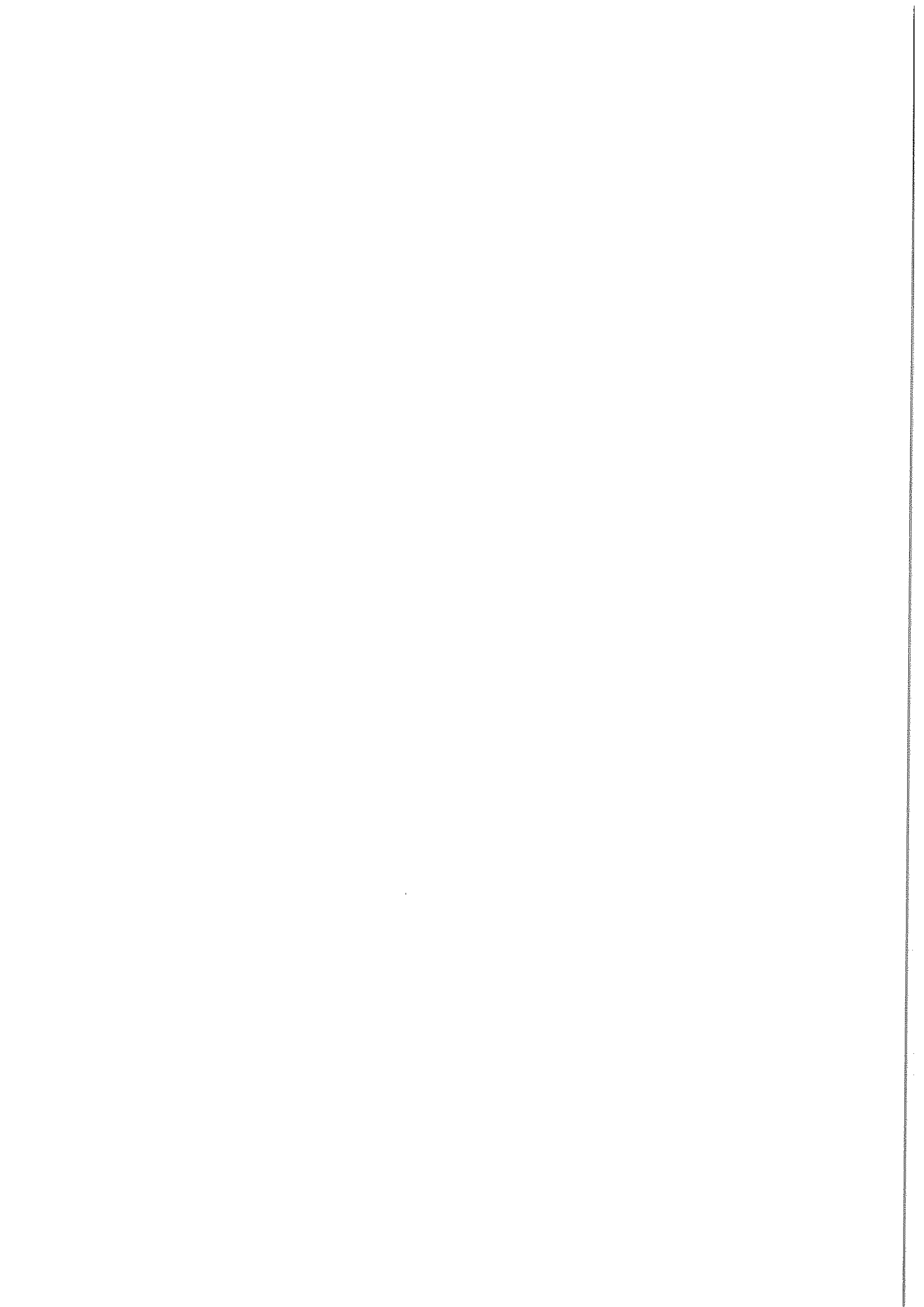
Theresa Burns; Action for ME [REDACTED]

Cc: [REDACTED] Action for ME

Subject: RE: SLWG Neurological Programme Jan 29 10-12

[REDACTED]
Thanks for the agenda.
Please could I join in on-line?

[REDACTED]



15. 19 December 2017

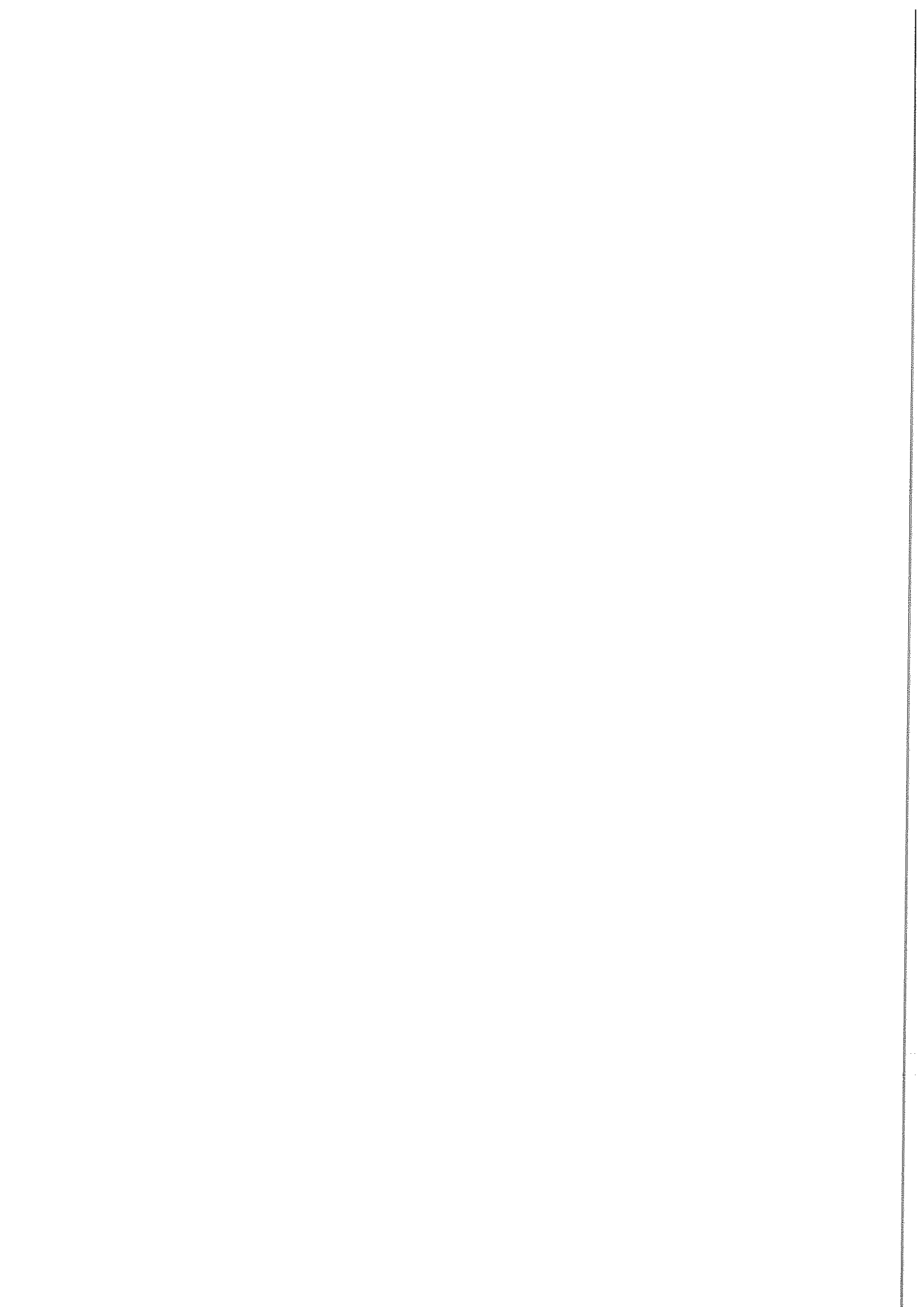
From: [REDACTED] [mailto:actionforme.org.uk] Action for ME
Sent: 19 December 2017 13:51
To: [REDACTED] Scottish Government
Subject: Re: Agenda for SLWG Neurological programme and online link

Hope your feeling better soon. Happy Christmas and the best for 2018.
[REDACTED]

Sent from my iPhone

On 19 Dec 2017, at 10:29, "[REDACTED]" > wrote:

Hi Everyone,
Sorry not to be able to join you all today.
I have a chest infection and no puff.
Hope to catch up with you all in the New Year.
Best Wishes,
[REDACTED]



16. 31 January 2018

From: [REDACTED]@actionforme.org.uk]

Sent: 31 January 2018 13:37

To: [REDACTED] Action for ME

[REDACTED] Scottish Government

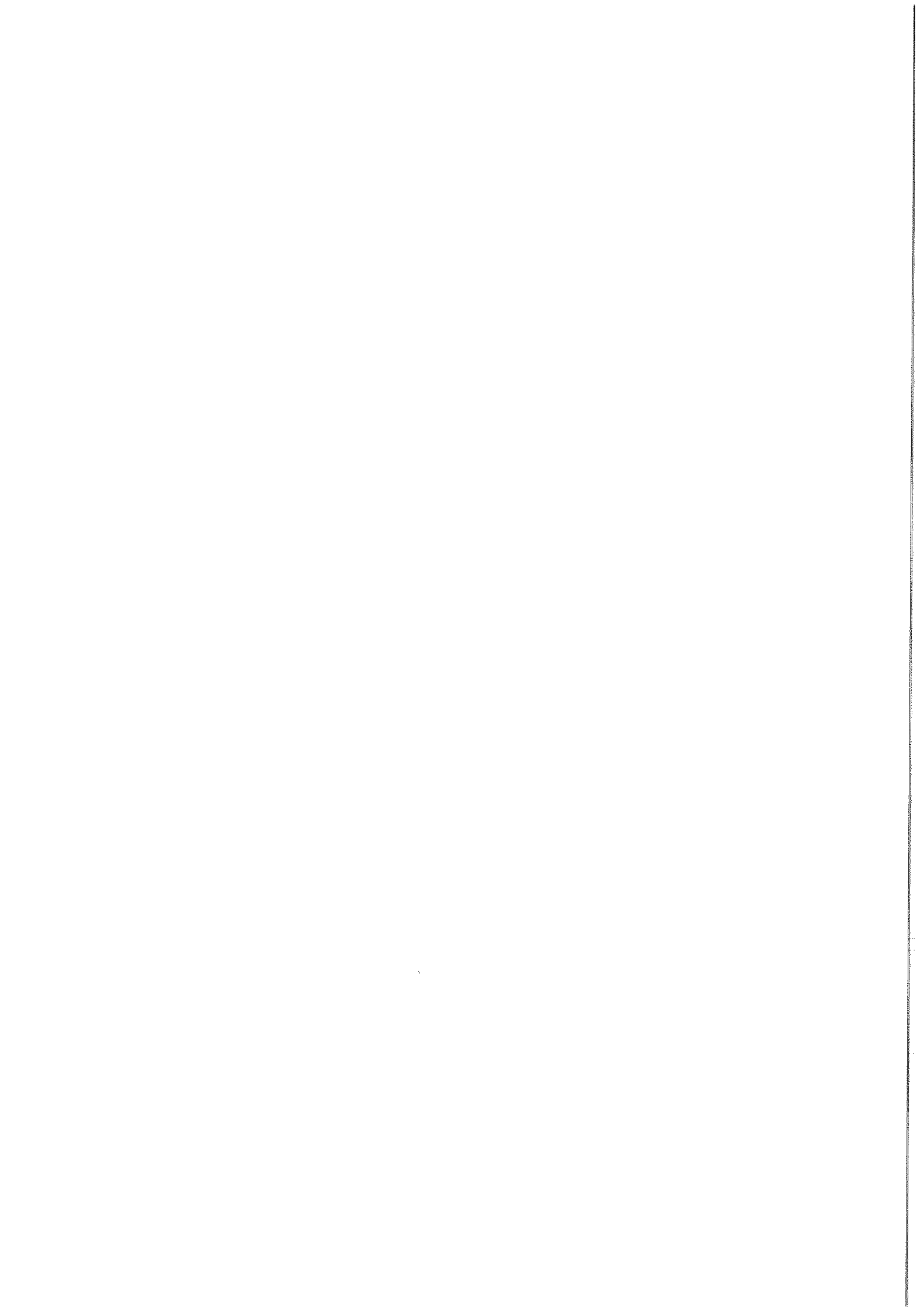
Cc: [REDACTED] Action for ME

Subject: RE: SLWG Neurological Programme Jan 29 10-12

Hi All,

Happy with the minutes and the proposal re. improving communication with NAoS.

[REDACTED]



17. 26 January 2018

From: [REDACTED]@actionforme.org.uk] Action for ME

Sent: 26 January 2018 10:04

To: [REDACTED], Action for ME

[REDACTED] Scottish Government

Cc: [REDACTED]

Subject: RE: SLWG Neurological Programme Jan 29 10-12

[REDACTED]
Thanks, I will attend the meeting in person on Monday.
[REDACTED]

