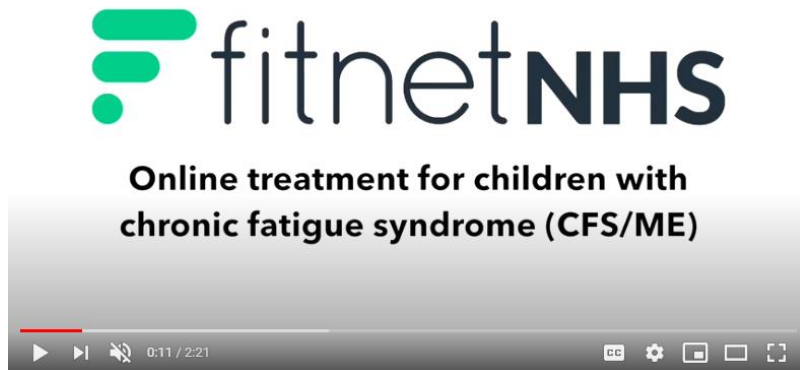


## Project Document D: Supporting (video/audio) media

### i) FITNET-NHS Clinician video

Home treatment for UK teenagers with CFS/ME - the FITNET-NHS Trial, available on YouTube:

<https://www.youtube.com/watch?v=Q4Bm-wh7B4>



Presented with the following information:

Information video for UK clinicians, including how to refer for treatment and diagnostic signs of CFS/ME in children. For further information visit: <http://www.bristol.ac.uk/fitnet-nhs>

Most children with CFS/ME in the UK currently have no access to local specialist treatment for the condition. The FITNET-NHS Trial is set up to deliver specialist treatment to families across the UK in their own homes. Children with CFS/ME from across the UK can be referred for treatment.

Video produced by: <http://giantrhinomedia.com/>

Disclaimer: None of the children appearing in this video are patients, nor are they CFS sufferers. All the unnamed people in the video are acting.

*Supporting documents for clinician video*

- **RUH governance form**

**FITNET-NHS information video**

**2018-03-25 Information for Bath RUH communications and governance**

Background: the FITNET-NHS Trial

The FITNET-NHS Trial tests online therapy for teenagers with chronic fatigue syndrome (CFS). It is hosted by the University of Bristol. Dr Emma Anderson is the Trial Manager. Professor Esther Crawley is the Principal Investigator at the University of Bristol, and also leads the clinical paediatric CFS team at Bath RUH that deliver the treatments within the trial. FITNET-NHS involves close collaboration between the

University of Bristol and Bath RUH. For more information, see the research trial website:

[www.bristol.ac.uk/fitnet-nhs/](http://www.bristol.ac.uk/fitnet-nhs/)

### CRN advice for video

We were advised by the Clinical Research Network (CRN) that a good way to communicate with clinicians (GPs and paediatricians) about this treatment trial is via short informational video. We produced a short video (just over 2 mins) aimed at clinicians to introduce the trial (covering the rationale for the trial, the treatments offered, how to refer, and how to spot signs of CFS in children).

### Approvals

The full video has been reviewed by the FITNET-NHS research Trial Management Group (University of Bristol), the Trial Steering Committee (independent advisory group), the HTA (trial funders), the paediatric CFS clinical team, and the Bath RUH communications and Information Governance teams, all of whom approve of the content.

### Hosting and dissemination plans

The video is hosted on YouTube, in line with standard practice for University of Bristol videos. Subtitles have been added in line with University of Bristol accessibility requirements. <https://youtu.be/Q4Bm-wh7B4>

A new YouTube channel has been made (FITNET-NHS Trial) specifically for hosting this video, and comments have been disabled. The video is currently 'unlisted' which will be changed to 'public' once approved for release.

The CRN will promote the video to clinicians (GPs and paediatricians) across the UK by sharing a link to the video. The video is also intended to be featured on the University of Bristol FITNET-NHS Trial research website: [www.bristol.ac.uk/fitnet-nhs/](http://www.bristol.ac.uk/fitnet-nhs/) and on the Bath RUH paediatric CFS website: [www.ruh.nhs.uk/cfs](http://www.ruh.nhs.uk/cfs), and may also be shared and linked to by other people and other websites (e.g. blogs). We also intend for our professional contacts, including Royal College of General Practice (RCGP), Royal College of Paediatrics and Child Health (RCPCH) and the University of Bristol's Centre for Child and Adolescent Health, (CCAH) to share it via newsletters to their members and via social media (e.g. Twitter) once it is released. We may also show the video at relevant conferences as part of academic/clinical presentations made by the research or clinical teams involved in the research.

### Considerations in the production of the video:

Daniel Edney (Giant Rhino Media), a contractor known to the research team, was commissioned to produce the video. The video footage and style were chosen with careful consideration of the sensitivity of the topic and anonymity of children involved, and was the result of a collaborative process between Mr Edney, Professor Crawley and Dr Anderson.

The visual images in the video include:

1. Generic footage of children walking in a school. This is stock footage, bought specifically to use in the video. The children were deliberately blurred out so that they could not be identified. These images represent healthy children at school, with an awareness that stock footage is not to be used to suggest any individual child is suffering from an illness
2. Footage of one teenage child to illustrate struggling with work, attending a GP surgery and accessing online treatment. Footage of another teenage child to illustrate accessing online treatment.

- The footage was carefully shot and selected so that the images would be illustrative **without showing any identifiable features of either child.**

- The two children involved were aware of the nature of the video. They both reviewed and approved the footage for use in the video, and reviewed and approved of the finished video and provided written consent.

3. Footage of online therapy, including the welcome page for the FITNET-NHS treatment program we are testing and a mocked-up Skype therapy session, featuring an actor playing the role of therapist. The actor reviewed and approved of the finished video and provided written consent.

4. Footage of a mocked-up GP visit showing Emma Anderson (Trial Manager) playing the role of GP.

5. Professor Esther Crawley (talking throughout the video).

It is to be noted that no filming took place at Bath RUH and no real patients were featured in the film. Daniel Edney has signed a non-disclosure document agreeing not to reveal the identity of the children involved in the video. The children and actor have signed their consent to the use of their footage in the video, including the right to withdraw that consent and how to do it.

Emma Anderson has completed a privacy impact assessment which did not require any further information according to the needs of the form, though we are providing the information in this document for clarity. The following documents are all provided for the Bath RUH records as requested:

- PIA (completed by Emma Anderson)
- Non-disclosure agreement (Daniel Edney, producer)
- Signed consent forms for use of footage (children and actor)

We hope that this information and the documents provided meet the Bath RUH communications and governance requirements. The video is currently 'unlisted' on YouTube and is not publicly available, and has been shared solely for gaining appropriate approvals. We will not make it publicly available or share it further until we receive confirmation from Bath RUH to go ahead.

If any further information or clarification is required, please contact Emma Anderson (Trial Manager) on (contact details)

- **RUH Privacy Impact Assessment**

**Privacy Impact Assessment screening questions:**

Does the project involve you using new technology which might be perceived as being privacy intrusive? For example, the use of biometrics or facial recognition.		X
Will the project result in you making decisions or taking action against individuals in ways which can have a significant impact on them?		X
Is the information about individuals of a kind particularly likely to raise privacy concerns or expectations? For example, health records, criminal records or other information that people would consider to be particularly private.		X
Will the project require you to contact individuals in ways which they may find intrusive?		X

\* **The 'new information' is simply the actors' images used in the video.** The actors volunteered their time specifically to appear in this video, and with full awareness of the purpose of the video (to impart information about the FITNET-NHS Trial to clinicians across the UK). Apart from Professor Crawley - who commissioned this video and is the point of contact for both data controller organisations (RUH and University of Bristol), **no RUH patients or staff feature in the video, and no actual information is collected.**

Because the nature of this PIA form is about the release of information about RUH staff and/or patients, the questions are not relevant to the video. Instead, I have supplied a separate sheet with further information about the video, its purpose and the actors who appear in it. I have discussed this with our RUH IG contact, Dominique Emmanuel.

- **Non-disclosure agreement**

## **Non-Disclosure Agreement:**

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### **Background Information:**

When third party organisations/individuals are contracted to carry out or support a NHS function, an agreement must be in place that specifies the appropriate confidentiality, data protection and security requirements.

The terms and conditions specified in the agreement should be consistent with the best practice expected of NHS organisations as defined within the Caldicott Report, NHS Codes of Practice and information governance standards. The Data Protection Act 1998 reiterates this point and makes it a legal requirement that effective contractual arrangements exist where a third party processes personal data or images.

The Royal United Hospital NHS foundation Trust has adopted the following terms and conditions when the processing of 'personal data' (as defined by the Data Protection Act (1998)) is undertaken by a contractor/ third party organisation/individual. Copies should be signed and held by all relevant parties.

Each individual involved in any processing of personal data has a responsibility to ensure they work in accordance with required legislation. This agreement covers the processing and holding of personal data as defined in the Data Protection Act 1998.

All staff, volunteers, contractors and others who support the work of the Trust, but are not directly employed by the Trust, must be fully aware of the confidentiality/data protection requirements of the personal identifiable information they may come in contact with. This can include name, address, postcode, date of birth, sex, NHS/NI number, ethnic group or occupation.

Access to person identifiable information held by the Trust is not permitted except where there has been formal authorisation from an appropriate senior manager within the Trust.

There are three steps that should be followed before transferring any data.

1. Do you have the authority, including the legal power, to release the data to someone else? Bulk transfers of data require the Trusts Data Protection Officers written approval
2. Does it need to be sent or can some other arrangements be made?
3. If you have the authority to send the data and you are sure you need to send it, have you made appropriately secure practical arrangements for any transfer.

It is a condition of this agreement that in no circumstances will information be passed on or discussed with any unauthorised person. Any patient information, particularly their health or treatment details, is highly sensitive. A breach of confidentiality during

- **Consent form**

All individuals appearing in the video (not those in the stock footage) signed the following consent form:

<b>CONSENT FORM FOR USE OF VIDEO FOOTAGE IN FITNET-NHS INFORMATION VIDEO</b>	
Please put your initials next to each statement to confirm your agreement, and then sign and date below.	
	INITIA
1. I confirm that I have seen the finished informational video about the FITNET-NHS Trial at the following link: <a href="https://www.youtube.com/watch?v=Q4Bm-wh7B4">https://www.youtube.com/watch?v=Q4Bm-wh7B4</a>	
2. I understand that this video is intended to be shared with clinicians (doctors and paediatricians) across the UK using the above link.	
3. I understand that a link to the video is intended to be featured on the Bath RUH CFS team website: <a href="http://www.ruh.nhs.uk/cfs">www.ruh.nhs.uk/cfs</a> and the University of Bristol FITNET-NHS research website: <a href="http://www.bristol.ac.uk/fitnet-nhs/">www.bristol.ac.uk/fitnet-nhs/</a>	
4. I understand that the video may also be shared with and accessed by other people (e.g. patients/public), which may include links to the video from other websites.	
5. I understand that every effort has been and will be made to protect my anonymity for appearing in the video. I know I will not be named in conjunction with the video.	
6. I am aware that the video producer, Daniel Edney of Giant Rhino Media, is a freelance professional, commissioned by the University of Bristol for the work, and he has signed a non-disclosure agreement so as not to reveal my identity for my part in the video.	
7. I understand that I can withdraw my consent at any time and without giving reason and if I do, the footage with me in it will be deleted from the video.*	
<p>I give my consent for the full video (including the footage of me) to be used in line with the above considerations.</p> <p>Please sign here: _____</p> <p>Please write your full name here: _____</p> <p>Today's date: _____</p>	
<p>Name of person taking consent: Dr Emma C. Anderson, FITNET-NHS Trial Manager</p> <p>Signature:</p> <p>Date:</p>	
<p>*If you wish to withdraw your consent for the use of your footage in the video, get in touch with Emma Anderson on:</p>	

ii) **FITNET-NHS podcast for families**

Recorded video-call interview with Dr Emma Anderson, Trial Manager, available on the following web page: <https://www.bristol.ac.uk/academic-child-health/research/research/cfsme/fitnet-nhs/>

