

Supplementary Information 2. Social media recruitment plan

Social media will play a key part in driving awareness and supplementing recruitment to the Exigency project.

Haemnet will post to a variety of social media platforms including:

- Twitter
- Instagram
- Facebook
- LinkedIn
- YouTube


Social media posts will provide a link to a dedicated Exigency website page hosted on the Haemnet site: www.haemnet.com/exigency/

This site is currently password protected until the study receives REC and HRA approvals.

This webpage will contain key information about the project, as well as details of how to get in touch with the research team if interested, along with a downloadable link to the Patient Information Sheet.

Examples of all of the advertisements and a screen-print of the Web page can be found below.

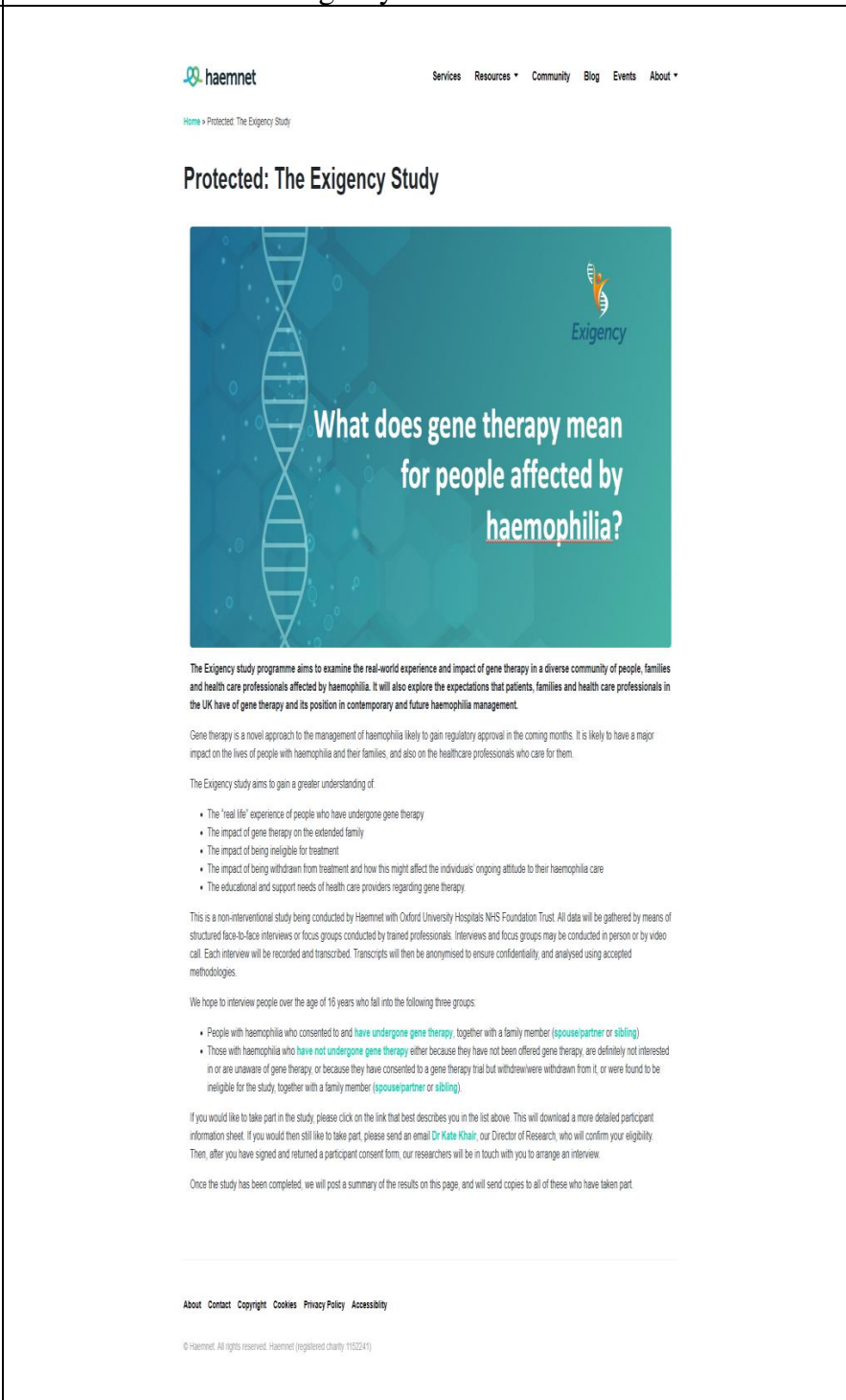
Platform(s)	Content For People with Haemophilia who definitely do not want to have gene therapy
Facebook, LinkedIn, Instagram and Twitter	 <p>The advertisement features a light blue background with a DNA double helix graphic on the right. At the top left is an orange outline of the United Kingdom. In the center, there is an icon of three people with speech bubbles. The text is as follows:</p> <p><i>Are you a man with haemophilia living in England?</i></p> <p><i>Have you decided that gene therapy is definitely not for you?</i></p> <p><i>We'd like to hear your views and invite you to take part in a focus group</i></p> <p>To find out more, head to: www.haemnet.com/exigency</p> <p>At the bottom left is the Haemnet logo (www.haemnet.com/exigency) and at the bottom right is the Exigency logo.</p>

Platform(s)	Content For People with Haemophilia who have not been offered gene therapy
Facebook, LinkedIn, Instagram and Twitter	 <p>The advertisement features a white background with a blue DNA helix at the bottom. It includes an orange outline of England, an icon of three people with speech bubbles, and a DNA helix icon. The text asks if men with haemophilia in England interested in gene therapy but not offered a clinical trial would like to participate in a focus group. It provides the website www.haemnet.com/exigency for more information. Logos for haemnet and Exigency are present.</p>

Platforms	Content for people with haemophilia who consented to have gene therapy but were withdrawn by the study
Facebook, LinkedIn, Instagram and Twitter	 <p>The advertisement has a blue background with a DNA helix. It features the Exigency logo at the top. The text asks if men with haemophilia in England who were screened for gene therapy but found ineligible would like to share their story. It provides the website www.haemnet.com/exigency for more information. The haemnet logo is in the bottom right corner.</p>

Platforms	Content for people with haemophilia who have undergone gene therapy
Facebook, LinkedIn, Instagram and Twitter	 <p>The poster features a blue background with a faint DNA double helix. At the top center is the Exigency logo, which consists of a stylized orange and green figure. Below the logo, the word "Exigency" is written in a blue, sans-serif font. The main text, in white on a dark blue background, asks: "Are you a man with haemophilia living in England who has had gene therapy?" followed by "We'd like to hear your story". At the bottom, an orange button contains the text: "To get involved and find out more go to www.haemnet.com/exigency". The Haemnet logo is in the bottom right corner.</p>

Platforms	Content for people with haemophilia who consented to have gene therapy but chose not to take part
Facebook, LinkedIn, Instagram and Twitter	 <p>The poster features a blue background with a faint DNA double helix. At the top center is the Exigency logo, which consists of a stylized orange and green figure. Below the logo, the word "Exigency" is written in a blue, sans-serif font. The main text, in white on a dark blue background, asks: "Are you a man with haemophilia living in England who successfully screened for gene therapy but decided not to take part?" followed by "We'd like to hear your story". At the bottom, an orange button contains the text: "To get involved and find out more go to www.haemnet.com/exigency". The Haemnet logo is in the bottom right corner.</p>

Platform	www.haemnet.com/Exigency/
Haemnet Website	 <p>haemnet Services Resources Community Blog Events About</p> <p>Home > Protected: The Exigency Study</p> <h2>Protected: The Exigency Study</h2> <h3>What does gene therapy mean for people affected by haemophilia?</h3> <p>The Exigency study programme aims to examine the real-world experience and impact of gene therapy in a diverse community of people, families and health care professionals affected by haemophilia. It will also explore the expectations that patients, families and health care professionals in the UK have of gene therapy and its position in contemporary and future haemophilia management.</p> <p>Gene therapy is a novel approach to the management of haemophilia likely to gain regulatory approval in the coming months. It is likely to have a major impact on the lives of people with haemophilia and their families, and also on the healthcare professionals who care for them.</p> <p>The Exigency study aims to gain a greater understanding of:</p> <ul style="list-style-type: none"> • The 'real life' experience of people who have undergone gene therapy • The impact of gene therapy on the extended family • The impact of being ineligible for treatment • The impact of being withdrawn from treatment and how this might affect the individuals' ongoing attitude to their haemophilia care • The educational and support needs of health care providers regarding gene therapy. <p>This is a non-interventional study being conducted by Haemnet with Oxford University Hospitals NHS Foundation Trust. All data will be gathered by means of structured face-to-face interviews or focus groups conducted by trained professionals. Interviews and focus groups may be conducted in person or by video call. Each interview will be recorded and transcribed. Transcripts will then be anonymised to ensure confidentiality, and analysed using accepted methodologies.</p> <p>We hope to interview people over the age of 16 years who fall into the following three groups:</p> <ul style="list-style-type: none"> • People with haemophilia who consented to and have undergone gene therapy, together with a family member (spouse/partner or sibling) • Those with haemophilia who have not undergone gene therapy either because they have not been offered gene therapy, are definitely not interested in or are unaware of gene therapy, or because they have consented to a gene therapy trial but withdrew/were withdrawn from it, or were found to be ineligible for the study, together with a family member (spouse/partner or sibling). <p>If you would like to take part in the study, please click on the link that best describes you in the list above. This will download a more detailed participant information sheet. If you would then still like to take part, please send an email Dr.Kate.Khair, our Director of Research, who will confirm your eligibility. Then, after you have signed and returned a participant consent form, our researchers will be in touch with you to arrange an interview.</p> <p>Once the study has been completed, we will post a summary of the results on this page, and will send copies to all of those who have taken part.</p> <p>About Contact Copyright Cookies Privacy Policy Accessibility</p> <p>© Haemnet. All rights reserved. Haemnet (registered charity 1152241)</p>