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 | Are you a man with haemophilia living in England? Have you decided that gene therapy is definitely not for you? We’d like to hear your views and invite you to take part in a focus group To find out more, head to: www.haemnet.com/exigency |
| Platform(s) | Content for people with haemophilia who have not been offered gene therapy |
|------------|--------------------------------------------------------------------------------|
| Facebook,  | Are you a man with haemophilia living in England? Are you interested in gene therapy but have not been offered participation in a clinical trial by your haemophilia team? We'd like to hear your views and invite you to take part in a focus group. To find out more, head to: www.haemnet.com/exigency |
| LinkedIn,  | Exigency Are you a man with haemophilia living in England who was screened for gene therapy only to be told you were not eligible? We'd like to hear your story. To get involved and find out more go to www.haemnet.com/exigency |
| Instagram and Twitter | Content for people with haemophilia who consented to have gene therapy but were withdrawn by the study |

| Platforms          | Content for people with haemophilia who have undergone gene therapy |
|-------------------|---------------------------------------------------------------------|
| Facebook, LinkedIn, Instagram and Twitter | Are you a man with haemophilia living in England who has had gene therapy?  
**We’d like to hear your story**  
To get involved and find out more go to www.haemnet.com/exigency |

| Platforms          | Content for people with haemophilia who consented to have gene therapy but chose not to take part |
|-------------------|--------------------------------------------------------------------------------------------------|
| Facebook, LinkedIn, Instagram and Twitter | Are you a man with haemophilia living in England who successfully screened for gene therapy but decided not to take part?  
**We’d like to hear your story**  
To get involved and find out more go to www.haemnet.com/exigency |
Platform

www.haemnet.com/Exigency/

Protected: The Exigency Study

What does gene therapy mean for people affected by haemophilia?

The Exigency study programme aims to examine the real-world experience and impact of gene therapy in a diverse community of people, families and healthcare professionals affected by haemophilia. It will also explore the expectations that patients, families and healthcare professionals in the UK have of gene therapy and its position in contemporary and future haemophilia management.

Gene therapy is a novel approach to the management of haemophilia B and is now being regulated and approved in the coming months. It is likely to have a major impact on the lives of people with haemophilia and their families, and also in the healthcare professionals who care for them.

The Exigency study aims to gain a deeper understanding of:

- The "real" experience of people who have undergone gene therapy.
- The impact of gene therapy on the extended family.
- The impact of being diagnosed with haemophilia.
- The impact on the psychological and emotional well-being of the patient.
- The societal and economic impact of haemophilia patients undergoing gene therapy.

This is an international 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 with affected families, friends and medical professionals.

The views and experiences expressed in this report are those of the participants and do not necessarily reflect the views of the researchers or their organizations. Participation in this study has been voluntary, and participants have been given the option to withdraw at any time without explanation.

The Exigency study is part of a larger programme of research into gene therapy and haemophilia, and is being conducted in collaboration with the University of Oxford and Oxford University Hospitals.

If you would like to take part in the study, please contact us directly. The information in this report will not be used for any purpose other than to provide a summary of the findings.

Once the study has been completed, we will post-summary of the results on this page, and will send copies to all of those who have taken part.

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Fletcher S, et al. BMJ Open 2022; 12:e060351. doi: 10.1136/bmjopen-2021-060351