

# Exploring the hidden burden of living with Glanzmann thrombasthenia

<b>Submission date</b> 27/01/2026	<b>Recruitment status</b> Recruiting	<input checked="" type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
<b>Registration date</b> 28/01/2026	<b>Overall study status</b> Ongoing	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
<b>Last Edited</b> 28/01/2026	<b>Condition category</b> Genetic Diseases	<input type="checkbox"/> Individual participant data <input checked="" type="checkbox"/> Record updated in last year

## Plain English summary of protocol

### Background and study aims

Glanzmann thrombasthenia (GT) is a very rare inherited bleeding disorder. Doctors know how to treat bleeding episodes, but much less is known about how living with GT affects people's everyday lives. This includes emotional wellbeing, mental health, relationships, education, work, and the impact on families and caregivers.

The aim of this study is to better understand the real, lived experiences of adults with GT and of people who care for someone with GT. By listening directly to their stories, the study hopes to uncover the "hidden burden" of the condition that is often not captured in medical records. The findings will be used to improve understanding, support, communication, and future research for people affected by GT.

### Who can participate?

People can take part if they are aged 16 or over and have a self reported diagnosis of Glanzmann thrombasthenia. Self reported diagnosis is acceptable because GT is very rare and the study focuses on personal experiences rather than medical tests.

Caregivers can also take part. This includes parents, partners, siblings, or other family members who support someone with GT.

Young people under the age of 16 may take part if a parent or legal guardian provides consent and the young person agrees to take part where appropriate.

### What does the study involve? (for participants)

Participants will be invited to take part in a single interview lasting about 45 to 60 minutes. The interview will take place by video call or telephone, depending on what the participant prefers. During the interview, participants will be asked to talk about their experiences of living with GT or caring for someone with GT. Topics may include daily life, emotional wellbeing, school or work, relationships, experiences with healthcare, and challenges they face.

Taking part is voluntary. Participants can skip any questions they do not want to answer and can stop the interview at any time. With permission, the interview may be audio recorded to help the research team accurately capture what is said.

As a thank you for their time, participants will receive a £50 digital voucher.

What are the possible benefits and risks of participating?

There are no direct medical benefits from taking part. However, many people may find it helpful to share their experiences and know that their views could help improve understanding and support for others with GT in the future.

There are no physical risks. Some people may find it emotionally upsetting to talk about difficult experiences. The interviewers are trained to handle sensitive topics and can pause or stop the interview if needed. Participants will also be given information about support resources if they feel distressed.

Where is the study run from?

The study is sponsored and run by EquiPath Analytics Limited, based in the United Kingdom. Although the study is run from the UK, people from many countries around the world are able to take part because interviews are conducted remotely.

When is the study starting and how long is it expected to run for?

The study is expected to start recruiting participants in February 2026. Recruitment is planned to continue until December 2026. The overall study is expected to run until February 2027.

Who is funding the study?

The study is funded by Hemab ApS. The funder has no involvement in how the study is designed, how interviews are carried out, how data is analysed, or how results are reported.

Who is the main contact?

The main contacts for the study are the principal investigators, Amy Owen-Wyard and Stacey McGeown, at EquiPath Analytics Limited in the United Kingdom. They can be contacted by email at <amy@epalimited.com> or <stacey@epalimited.com>, or by telephone using the contact details provided in the study information.

## Contact information

### Type(s)

Public, Principal investigator, Scientific

### Contact name

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### Type(s)

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**Contact name**

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**Additional identifiers****Integrated Research Application System (IRAS)**

368693

**Study information****Scientific Title**

Exploring the hidden burden of living with Glanzmann thrombasthenia: a qualitative study

**Study objectives**

Primary Objective:

1. To explore the lived emotional, psychological, social, and practical experiences of adults with GT.

Secondary Objectives:

1. To describe the demographic and sociodemographic profile of PwGT, carriers, and caregivers, including age range, gender identity, geographic region, and care roles.
2. To understand caregiver experiences, including emotional labor, care management, stress, and coping strategies.
3. To identify unmet support needs, barriers to access, and structural or systemic obstacles affecting quality of life.
4. To generate evidence to inform clinical communication, resource development, and future patient-centered interventions.

This study is designed to generate rich, real world accounts of the lived experience of GT that cannot be captured through quantitative methods. Findings will be used to inform patient support resources, clinical communication, and future research priorities.

**Ethics approval required**

Ethics approval required

**Ethics approval(s)**

notYetSubmitted

**Primary study design**

Observational

**Secondary study design**

Cross sectional study

## Study type(s)

## Health condition(s) or problem(s) studied

Glanzmann thrombasthenia

## Interventions

This is a non interventional, observational, qualitative study. The study is funded by Hemab ApS, who have no involvement in study design, data access, analysis, or reporting. The Sponsor (EquiPath Analytics Limited) retains full independence and oversight.

This study will use a qualitative, exploratory design appropriate for capturing nuanced experiences. s allow flexibility while ensuring coverage of core areas of interest.

The study will follow an interpretivist paradigm, acknowledging that participants' experiences are shaped by social context. Interviews will be analyzed using Braun & Clarke's six-phase thematic analysis method, allowing identification of patterns both within and across participant groups.

No quantitative data will be collected. No experimental treatments or changes to standard clinical management will occur.

Given the rarity of GT and the global geographical distribution of individuals, self reported diagnosis is accepted. This is consistent with qualitative rare disease research, where clinical confirmation is often impractical and unnecessary for experiential exploration.

## Intervention Type

Other

## Primary outcome(s)

1. Explore the experience of living with GT measured using semi-structured interviews, analyzed using Braun & Clarke's six-phase thematic analysis method at a single time point

## Key secondary outcome(s))

## Completion date

24/02/2027

## Eligibility

### Key inclusion criteria

Participants will be eligible if they meet one or more of the following:

1. Individuals with a self-reported diagnosis of Glanzmann's Thrombasthenia (GT). (Given the rarity of GT and the exploratory qualitative nature of the study, self-reported diagnosis is considered appropriate and proportionate)
2. Primary or secondary caregivers of an individual with GT

AND:

3. Can read and understand the participant information sheet
4. Provide informed consent electronically prior to beginning the survey
5. Are aged  $\geq 16$  years, or have a caregiver completing the form on their behalf if under 16
6. For participants aged 16–17 years, informed consent will be obtained directly, as they are

considered competent to consent to low risk qualitative research. For participants under 16, a parent or legal guardian will provide consent, and the young person will provide assent where appropriate

**Healthy volunteers allowed**

Yes

**Age group**

Mixed

**Lower age limit**

16 years

**Upper age limit**

120 years

**Sex**

All

**Total final enrolment**

0

**Key exclusion criteria**

1. Decline or withdraw consent at any point during the study
2. Inability to comply with study procedures
3. Behavioural concerns that may compromise participant safety or data integrity, as assessed by the research team
4. Individuals unable to provide informed consent

**Date of first enrolment**

24/02/2026

**Date of final enrolment**

21/12/2026

**Locations****Countries of recruitment**

United Kingdom

Afghanistan

Åland Islands

Albania

Algeria

American Samoa

Andorra

Angola

Anguilla

Antarctica

Antigua and Barbuda

Argentina

Armenia

Aruba

Australia

Austria

Azerbaijan

Bahamas

Bahrain

Bangladesh

Barbados

Belarus

Belgium

Belize

Benin

Bermuda

Bhutan

Bolivia

Bonaire Saint Eustatius and Saba

Bosnia and Herzegovina

Botswana

Bouvet Island

Brazil

British Indian Ocean Territory

Brunei Darussalam

Bulgaria

Burkina Faso

Burundi

Cabo Verde

Cambodia

Cameroon

Canada

Cayman Islands

Central African Republic

Chad

Chile

China

Christmas Island

Cocos (Keeling) Islands

Colombia

Comoros

Congo

Congo, Democratic Republic

Cook Islands

Costa Rica

Croatia

Cuba

Curaçao

Cyprus

Czech Republic

Côte d'Ivoire

Denmark

Djibouti

Dominica

Dominican Republic

Ecuador

Egypt

El Salvador

Equatorial Guinea

Eritrea

Estonia

Eswatini

Ethiopia

Falkland Islands

Faroe Islands

Fiji

Finland

France

French Guiana

French Polynesia

French Southern Territories

Gabon

Gambia

Georgia

Germany  
Ghana  
Gibraltar  
Greece  
Greenland  
Grenada  
Guadeloupe  
Guam  
Guatemala  
Guernsey  
Guinea  
Guinea-Bissau  
Guyana  
Haiti  
Heard Island and McDonald Islands  
Holy See (Vatican City State)  
Honduras  
Hong Kong  
Hungary  
Iceland  
India  
Indonesia  
Iran  
Iraq  
Ireland  
Isle of Man

Israel  
Italy  
Jamaica  
Japan  
Jersey  
Jordan  
Kazakhstan  
Kenya  
Kiribati  
Korea, North  
Korea, South  
Kosovo  
Kuwait  
Kyrgyzstan  
Lao People's Democratic Republic  
Latvia  
Lebanon  
Lesotho  
Liberia  
Libya  
Liechtenstein  
Lithuania  
Luxembourg  
Macao  
Madagascar  
Malawi

Malaysia

Maldives

Mali

Malta

Marshall Islands

Martinique

Mauritania

Mauritius

Mayotte

Mexico

Micronesia, Federated States of

Moldova

Monaco

Mongolia

Montenegro

Montserrat

Morocco

Mozambique

Myanmar

Namibia

Nauru

Nepal

Netherlands

New Caledonia

New Zealand

Nicaragua

Niger

Nigeria

Niue

Norfolk Island

North Macedonia

Northern Mariana Islands

Norway

Oman

Pakistan

Palau

Palestine, State of

Panama

Papua New Guinea

Paraguay

Peru

Philippines

Pitcairn

Poland

Portugal

Puerto Rico

Qatar

Romania

Russian Federation

Rwanda

Réunion

Saint Barthélemy

Saint Helena, Ascension and Tristan da Cunha

Saint Kitts and Nevis

Saint Lucia

Saint Martin (French part)

Saint Pierre and Miquelon

Saint Vincent and the Grenadines

Samoa

San Marino

Sao Tome and Principe

Saudi Arabia

Senegal

Serbia

Seychelles

Sierra Leone

Singapore

Sint Maarten (Dutch part)

Slovakia

Slovenia

Solomon Islands

Somalia

South Africa

South Georgia and the South Sandwich Islands

South Sudan

Spain

Sri Lanka

Sudan

Suriname  
Svalbard and Jan Mayen  
Sweden  
Switzerland  
Syria  
Taiwan  
Tajikistan  
Tanzania  
Thailand  
Timor-Leste  
Togo  
Tokelau  
Tonga  
Trinidad and Tobago  
Tunisia  
Turkmenistan  
Turks and Caicos Islands  
Tuvalu  
Türkiye  
Uganda  
Ukraine  
United Arab Emirates  
United States Minor Outlying Islands  
United States of America  
Uruguay  
Uzbekistan

Vanuatu

Venezuela

Viet Nam

Virgin Islands, British

Virgin Islands, U.S.

Wallis and Futuna

Western Sahara

Yemen

Zambia

Zimbabwe

### **Study participating centre**

**Online study**

-

-

England

-

## **Sponsor information**

### **Organisation**

Equipath Analytics Limited

## **Funder(s)**

### **Funder type**

### **Funder Name**

Hemab ApS

## **Results and Publications**

## Individual participant data (IPD) sharing plan

### IPD sharing plan summary

Not expected to be made available

### Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">Other files</a>	Plain language summary		28/01/2026	No	No
<a href="#">Participant information sheet</a>			28/01/2026	No	Yes