ISRCTN16256452 https://doi.org/10.1186/ISRCTN16256452

Exploring the hidden burden of living with Glanzmann thrombasthenia

Submission date
27/01/2026

Recruitment status
Recruiting

Registration date
28/01/2026

Overall study status
Ongoing

Last Edited
31/03/2026

Condition category
Genetic Diseases

[X] Prospectively registered
[X] Protocol
[X] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] 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
Mrs Amy Owen-Wyard

ORCID ID
https://orcid.org/0009-0008-7468-4042

Contact details
EquiPath Analytics Limited
8 FALMOUTH
Worcester
United Kingdom
WR4 0TE
+44 7510310324
amy@epalimited.com

Type(s)
Public, Scientific

Contact name
Mrs Stacey McGeown

Contact details
8 Falmouth
Worcester
United Kingdom
WR4 0TE
+44 7850910227
stacey@epalimited.com

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)
Approved 30/03/2026, Liverpool Central REC (Health Research Authority, 2 Redman Place, London, E20 1JQ, United Kingdom; +44 (0)2071048000; liverpoolcentral.rec@hra.nhs.uk), ref: 368693

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 ≥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
30/03/2026

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?
Other files	Plain language summary		28/01/2026	No	No
Participant information sheet			28/01/2026	No	Yes
Participant information sheet	version 1.0	26/03/2026	31/03/2026	No	Yes
Protocol file			31/03/2026	No	No
Statistical Analysis Plan			31/03/2026	No	No