Trustees' Annual Report for the period

	Period start date				Period end date		
From	1	April	2021	**To**	31	March	2022

Section A Reference and administration details

Charity name	HaemSTAR: Haematology Specialist Training, Audit and Research
Other names charity is known by	HaemSTAR
Registered charity number (if any)	1199224
Charity's principal address	Office 129, Institute of Biomedical Research
	Edgbaston
	Birmingham
	Postcode **B15 2TT**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Phillip LR Nicolson	Chair		
2	Richard J Buka	Communications		
3	Andrew J Doyle	Vice-Chair		
4	Emily Millen	Secretary & Treasurer		
5	Tom Bull	Web Officer		
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	Unincorporated Association
Trustee selection methods (eg. appointed by, elected by)	Appointed by existing trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

This is the first year of the operation of the charity. The governing document was created on 31/3/21. The trustee declarations were signed and final application to the charities commission for charitable status was submitted on 30/11/21.

On 9/5/22 we were contacted by the charities commission asking us to change the objects of our charity from:

'*The Charity's objects are:*
Our overarching aim is to promote clinical research in non-malignant haematology in the UK (including England, Scotland, Wales and Northern Ireland. In doing so we will;

- *Benefit the health of patients with haematological conditions by opening more clinical studies and recruiting more patients to these studies*
- *Further the understanding of haematological conditions and their treatment by delivering research studies in greater numbers and with greater speed*
- *Educate and train junior doctors and haematologists to give them the skills to become the chief and principal investigators of the future*

According to the Charity Commission for England and Wales Guidance (2013) these purposes fall under descriptions of purposes 4, 6 and 8.
4. Advancement of Education
6. Advancement of health or the saving of lives. (includes prevention or relief of sickness, disease or human suffering)
8. The advancement of the arts, culture, heritage or science.

To carry out its purposes HaemSTAR will:

- *Conceive, develop, run, analyse and write up non-malignant haematology studies and audits. This may be supported by grants from other organisations.*
- *Support non-malignant haematology studies led by HaemSTAR or external investigators by;*
    - *Identifying hospital sites, principal investigators and sub-investigators at these sties.*
    - *Providing advice on and facilitating study set-up and conduct at these sites.*
    - *Providing grants or fellowships to institutions hosting those investigators and/or research nurses supporting those studies.*'

To:
'The object of the charity is:
(1) To protect and preserve the health of patients suffering from haematological conditions by:
(a) the promotion of clinical research into Non-Malignant Haematology in the United Kingdom, the causes, prevention and treatment of haematological conditions on terms that the results of such research will be published.
(b) the advancement of education and training of junior doctors and haematologists to give them the skills to become the chief and principal investigators of the future.'

This was agreed at an extra-ordinary committee meeting on the same day and the revised governing document was submitted to the charities commission on 1/6/22. We were subsequently granted charitable status on 9/6/22.

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

1. To protect and preserve the health of patients suffering from haematological conditions by:
    a. the promotion of clinical research into Non-Malignant Haematology in the United Kingdom, the causes, prevention and treatment of haematological conditions on terms that the results of such research will be published.
    b. the advancement of education and training of junior doctors and haematologists to give them the skills to become the chief and principal investigators of the future.'

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

During 1/4/21 to 31/3/22 we conceived, developed, ran, supported and/or wrote up thirteen projects. All of these projects further our charitable objects because 1) they all require project management (which is used to train junior doctors and haematologists in how to be researchers and principal investigators) and 2) they ultimately result in the publication of research findings that benefit patients. Projects take several years to complete from the time of inception. Activities completed 1/4/21 to 31/3/22 are highlighted in red text.

IVIg Flash-Mob:
- **Type of study:** Retrospective national audit.
- **Topic:** Compliance with American Society of Haematology (ASH) guidelines on intravenous immunoglobulin (IVIg) use in immune thrombocytopenia (ITP).
- **HaemSTAR role:** Conceived, developed and run by HaemSTAR in association with Dr Quentin Hill (Leeds) with assistance of

Birmingham Centre for Observational and Prospective Studies (BiCOPS) for data management. Supported & funded by the National Institute for Health Research (NIHR) West Midlands Local Clinical research Network (LCRN).

- **Size of study:** Data collection completed 2018 (involving 134 collaborators across 38 sites, 961 patients).
- **Main outcomes:** <50% compliance with dosing guidelines. 1 g/kg on single day no different in terms of platelet response to 1 g/kg on two consecutive days.
- **Outputs:** Oral abstract at British Society of Haematology (BSH) Annual Scientific Meeting (ASM) 2019. Published in British Journal of Haematology (BJHaem) 2022 (see 'Achievements' below).

TTP Flash-Mob.

- **Type of study:** retrospective national audit.
- **Topic:** Compliance with BSH Guidelines on treatment of Thrombotic Thrombocytopenic Purpura (TTP).
- **HaemSTAR role:** Conceived, developed and run by HaemSTAR in association with Prof Marie Scully (University College London) with assistance of BiCOPS for data management. Funded by unrestricted grants from Sanofi and Octapharma.
  Size of study: Data collection completed 2019 (148 collaborators, 80 sites, 251 patients, 148 with full data).
  Main outcomes: 28% of patients received plasma exchange within 8 hours. Main variable associated with delayed plasma exchange was diagnostic uncertainty.
  Outputs: Poster abstract at ASH Annual Congress 2020. Oral abstract at BSH ASM 2021. Published in Journal of Thrombosis and Haemostasis (JTH) 2022 (see 'Achievements' below).

CA-COVID19 (Coagulation Abnormalities in COVID19)

- **Type of study:** Retrospective Observational Study.
- **Topic:** Laboratory coagulation results and thrombotic and bleeding complications of patients admitted with COVID-19
- **HaemSTAR role:** Conceived and developed by Dr Deepa Arachchillage from Imperial College in association with HaemSTAR. Promoted by HaemSTAR. Run utilising the HaemSTAR network. Data management performed by Imperial College. Funded by Bayer.
- **Size of study:** Data collection completed 2021 (370 collaborators, 26 sites, 5883 patients).
- **Main outcomes:** Patients taking oral anticoagulation at time of diagnosis were more likely to be admitted to the intensive care unit (ICU). Patients developing thrombosis, major haemorrhage or multi-organ failure had a higher mortality. There was no difference in thrombosis rates or mortality between pregnant and non-pregnant women.
- **Outputs:** Two publications in BJHaem (see 'Achievements' below). Further publication submitted for publication in Rheumatology.

ITP in the COVID19 era

- **Type of study:** Retrospective Observational Study.
- **Topic:** Timing of onset, clinical characteristics, response to treatment and outcomes of patients with ITP and treated as per physician choice with non-immunosuppressive therapies.
- **HaemSTAR role:** Conceived and developed by Dr Sue Pavord (Oxford). Run and promoted by the ITP Forum and HaemSTAR. Data management provided by Public Health England (PHE). Funded by The Oxford Centre for Haematology Research.

- **Size of study:** Data collection completed 2021 (335 patients across 24 sites
- **Main outcomes:** Thrombopoetin Receptor Agonists (TPO-RAs) were effective for ITP in the upfront treatment setting with 82% of patients not requiring second line treatment.
- **Outputs:** Publication in BJHaem (see 'Achievements' below)

CAVEaT (Cancer Associated Venous Thrombosis and Thrombocytopenia)

- **Type of study:** Retrospective National Audit
- **Topic:** Compliance with International Society for Thrombosis and Haemostasis (ISTH) and BSH guidelines on management of venous thrombosis in the setting of thrombocytopenia due to haematological malignancy or its treatment.
- **HaemSTAR role:** Conceived and developed by Dr Stephen Booth (Oxford). Run and promoted by NHS Blood and Transplant (NHSBT) and HaemSTAR. Data management provided by NHSBT. Funded by NHSBT.
- **Size of study:** Data collection completed 2021 (35 collaborators, 106 patients, 20 sites).
- **Main Outcomes:** Management was according to guidelines in 47% of high risk thrombosis and 5% of low risk thrombosis. Approach to management was heterogenous. Thrombosis progression rates similar to other cancer associated thromboses but patients experienced high rates of bleeding.
- **Outputs**: Published in JTH 2022.

ITP Post COVID19 Vaccine

- **Type of study:** Retrospective Observational Study.
- **Topic:** Timing of onset, clinical characteristics, response to treatment and outcomes of patients with ITP developing following COVID19 vaccination.
- **HaemSTAR role:** Conceived and developed by Dr Quentin Hill (Leeds). Run and promoted by the ITP Forum and HaemSTAR. Data management provided by PHE. Funded by PHE.
- **Size of study:** Data collection completed in 2022.
- **Size of Study:** No results available as study yet to publish.
- **Main outcomes:** yet to publish.
- **Outputs:** yet to publish.

ConNeCT:

- **Type of study:** Prospective Observational Study.
- **Topic:** Neurological, cognitive and neuropsychiatric complications of TTP.
- **HaemSTAR role:** Conceived and developed by Dr Tina Dutt and Dr Rebecca Shaw (Liverpool). Run and promoted by the University of Liverpool and HaemSTAR. Data management provided by University of Liverpool. Funded by the Bayer Haemophilia Awards Programm.
- **Size of study:** Target of 200 patients and 50 healthy volunteers. Data collection ongoing (planned completion August 2023). 96 patients recruited as of 2022.
- **Main outcomes:** Yet to finish data collection.
- **Outputs:** Yet to finish data collection.

A^{2}PLS (Anticoagulation in Antiphospholipid Syndrome):

- **Type of study:** Retrospective National Audit.
- **Topic:** Compliance with BSH guidelines on management of antiphospholipid syndrome (APS).

- **HaemSTAR role:** Conceived by Dr Christina Crossette-Thambiah (Imperial College). Developed and run by HaemSTAR. Data management provided by Imperial College. Funded by Bayer AG.
- **Size of study:** Target recruitment: 500 patients. Recruitment ongoing until end of 2022. 300 patients recruited as of 31/3/2022.
- **Main outcomes:** Yet to finish data collection.
- **Outputs:** Yet to finish data collection.

Vaccine Induced Thrombosis with Thrombocytopenia (VITT) Identification:

- **Type of study:** Retrospective Observational Study.
- **Topic:** Whether cases of VITT could be identified from routinely collected hospital admission and outcome data.
- **HaemSTAR role:** Conceived, developed and run by Dr Emily Millen (Nottingham) and Dr Andy Doyle (Kings College London), PHE and HaemSTAR. Data management and statistical analysis performed by PHE. No significant costs or funding.
- **Size of study:** Completed data collection 2022. (257 patients across 43 hospitals).
- **Main outcomes:** Yet to publish.
- **Outputs:** Yet to publish.

BAT-X (Bleeding Assessment Tool in patients with X-linked agammaglobulinaemia [XLA]):

- **Type of study:** Prospective Observational Study.
- **Topic:** To establish whether patients with XLA have increased bleeding.
- **HaemSTAR role:** Conceived, developed and run by Dr Pip Nicolson and Dr Chris Smith (Birmingham) and HaemSTAR. Data management provided by University of Birmingham. Funded by the British Heart Foundation (BHF).
- **Size of study:** Target recruitment: 50 patients. Recruitment ongoing until end of 2023. 19 patients recruited as of 31/3/22.
- **Main outcomes:** Yet to finish data collection.
- **Outputs:** Yet to finish data collection.

2SR (Two-Sample Rule Survey)

- **Type of study:** Healthcare Practitioner Questionnaire
- **Topic:** to establish attitudes towards and compliance with two-(historic) sample rule in blood transfusion.
- **HaemSTAR role:** Conceived by Dr Lorna Cain (Birmingham) and Dr Suzy Morton (Birmingham, NHSBT). Developed with the help of HaemSTAR. Data management to be provided by NHSBT. Funded by NHSBT. Not yet started recruiting.
- **Size of study:** Target 200 responses. Data collection completion planned for Summery 2022.
- **Main outcomes:** Yet to publish
- **Outputs:** Yet to publish

HaemSTAR RAPIDO (A 'Flash-Mob' UK national audit of the use of Reversal Agents in Patients antIcoagulated with Direct Oral anticoagulants)

- **Type of study:** Retrospective National Audit.
- **Topic:** Compliance with BSH guidelines for the use of reversal agents in patients with major haemorrhage who are taking direct oral anticoagulants (DOACs).
- **HaemSTAR role:** Conceived and developed by Dr Richard Buka (Stoke) and HaemSTAR. To be run by HaemSTAR. Data management to be provided by BiCOPS. Funded by AstraZeneca and the Dudley Leukaemia Unit Appear Fund. Not yet started recruiting.

- **Size of study:** Target 600 patients in each of two phases of data collection, one set for completion summer 2022, another autumn 2023.
- **Main outcomes:** Yet to complete data collection
- **Outputs:** Yet to complete data collection

AIHA Epi (The epidemiology of autoimmune haemolytic anaemia post COVID19 and COVID19 vaccination)

- **Type of study:** Retrospective Observational Study
- **Topic:** Epidemiology of autoimmune haemolytic anaemia (AIHA) in the post-COVID19 era.
- **HaemSTAR role:** Conceived by Dr Quentin Hill (Leeds). Developed by Dr Mohammed Altohami (Leicester) and HaemSTAR. To be run by HaemSTAR. Data management to be supported by PHE. Funded by PHE.
- **Size of study:** Still in set up phase. Details not known.
- **Main outcomes:** Yet to start data collection.
- **Outputs:** Yet to start data collection.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Section D Achievements and performance

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Summary of the main achievements of the charity during the year

Conference abstracts:

Bull TP, McCulloch R, Nicolson PLR, Shaw RJ, Sayar S, Langridge A, Pettit M, Perry R, Tucker D, Scully S & HaemSTAR Investigators. Factors Influencing Time from Initial Presentation to Start of Plasma Exchange (PEX) in Patients with Acute Thrombotic Thrombocytopenic Purpura (TTP) (BSH2021-241)

Publications:

Nicolson PLR, Perry R, Buka R, Fisher A, Scott, G, Magill L *et al*. A single 1 g/kg dose of intravenous immunoglobulin is a safe and effective treatment for immune thrombocytopenia; results of the first HaemSTAR "Flash-Mob" retrospective study incorporating 961 patients. Brit J Haem. 2022;196:433-452 https://doi.org10.1111/bjh.17692

Bull TP, McCulloch R, Nicolson PLR, Doyle AJ, Scully M et al. Diagnostic uncertainty presents barriers to timely management of acute thrombotic thrombocytopic purpura in the United Kingdom; Results of the HaemSTAR 2019 'Flash-Mob' Study. British Journal of Haematology. J Thromb Haemost. 2022. https://doi:10.1111/jth.15681

Arachchillage DJ, Rajakaruna I, Odho Z, Crossette-Thambiah C, Nicolson PLR, Roberts LN, Allan C, Lewis S, Riat, R, Mounter P, Lynch C, Langridge A, Oakes R, Aung, N, Drebes A, Dutt T, Raheja P, Delaney A, Essex S, Lowe G, Sutton D, Lentaigne C, Sayar Z, Kilner M, Everington T, Shapiro S, Alikhan R, Szudlo R, Makris M, and Laffan M. Clinical outcomes and the impact of prior oral anticoagulant use in patients with COVID-19 admitted to hospitals in the UK – a multicentre observational study. Brit J Haem. 2022;196:79-94.

Crossette-Thambiah C, Nicolson PLR, Rajakaruna I, Langridge A, Sayar Z, Perelta MR, Essex S, Oakes R, Mounter P, Lewis S, Dutt T, Scott I, Nini Aung N, Shapiro S, Laffan M, Arachchillage DRJ. The clinical course of COVID-19 in pregnant versus non-pregnant women requirinfag hospitalisation: results from the multicentre UK CA-COVID-19 study. BJHaem. 2021;195:85-89.

Rampotas A, Watson E, Burton K, et al. A real-world study of immune thrombocytopenia management during the COVID-19 pandemic in the UK. *Br J Haematol*. 2022;196:351–355.

Section E Financial review

Brief statement of the charity's policy on reserves

We do not have a reserve policy.
Cash in bank at 31/3/22 was £32,914.92 in unrestricted funds. Our committed spending for 2022-23 merely comprises website hosting fees of approximately £240. It is unlikely that this represents any significant financial risk. For 2022-23 we hope to be able to use our funds to support registrars attending conferences and other academic meetings, to make research publications open access, to run our own conference / meeting and to support research studies. Of the studies set out in our summary of activity, most would benefit from, but do not directly require financial

	support as they originate from investigators outside of HaemSTAR. We will need, however, to financially support the RAPIDO study, this will cost more than our current cash in the bank. Therefore this is dependent upon receipt of a grant from Astra Zeneca (contract currently being drawn up as of 31/3/22). If we do not receive the grant then the study will not go ahead and we are not financially liable.
Details of any funds materially in deficit	None.

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about: • the charity's principal sources of funds (including any fundraising); • how expenditure has supported the key objectives of the charity; • investment policy and objectives including any ethical investment policy adopted.	Our income prior to 1/4/21 was from a donation from the organising committee of the ISTH 2012 Annual SSC Meeting (Liverpool). This was for £23,479.36. During 1/4/21 – 31/3/22 we also received a £10,000 donation from the Dudley Leukaemia Unit Appeal Fund.

Section F Other optional information

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Dr Phillip LR Nicolson	
Position (eg Secretary, Chair, etc)	Chair	
Date	11/1/23	