

BSH Cohort Studies Grant Summary

Purpose:

This grant is to support the development of UK-based cohort studies of well-defined rare patient populations generating valuable datasets relating to patient phenotypes, outcome data and research data such as genetic data. The ideal cohort study would provide a framework for several rare disease entities in multiple sites, or other areas where funding is limited.

BSH will *not* provide long-term support and it is envisaged that BSH support will enable applications to other funders for large-scale continuing support.

Maximum value

Up to £50,000 a year to a total of £150,000 per project over the course of three years. This is the maximum value and timeframe but shorter timeframes with proportional funding would be encouraged.

Pilot details

Two cohort study grants to be offered in 2019.

Timeframe

Each project will run for three years, with a review annually to determine if the project should continue.

Partners

Should the pilot programme be successful, BSH may consider partnering with other organisations to share the costs, administration and evaluation of further projects.

Criteria

Mandatory:

- 1) Research collating and examining comprehensive data on a patient population with a defined haematological diagnosis with patient data collected from multiple centres nationally or internationally;
- 2) The proposal must demonstrate that the dataset is sustainable long-term with defined timelines and identifiable areas for further support;
- 3) The study needs to have defined outcomes and the proposal must clearly describe the research questions and methods to be used, data to be collected and sources of evidence;
- 4) The proposal must demonstrate that appropriate governance and ethics are in place;
- 5) The grant must be used to cover appropriate salary support, the development of a database, analysis of data or laboratory costs to explore biomarkers in the patient population such as genetic tests;
- 6) The dataset must be unique and not compete with established existing national datasets;

- 7) The proposal needs to acknowledge any limitations, bias and evidence gaps in the proposal.

Recommended

- 8) It should aim to generate publications relating to real world data, genetics or biomarker data and/or generate data supporting further research;
- 9) The proposal should suggest achievable annual milestones, which may be incorporated in the BSH annual reviews prior to disbursement of subsequent years' grant payments.

Application details

Applications must include the following relevant supporting information:

1. Personal letter;
2. Short curriculum vitae of the BSH member and supervisor;
3. A letter of support from the Head of Service/supervisor;
4. A project plan including:
 - a. Declaration of interests
 - b. Research project and likely impact
 - Will be assessed on*
 - i. strength of medical or scientific case, including detailed review of relevant previous literature;*
 - ii. level of innovation and whether the research is likely to lead to significant new understanding;*
 - iii. management strategy proposed, including equitable access to any shared resource;*
 - iv. feasibility of experimental plans, statistics, methodology and design including provision of sample size calculations, strategies to avoid bias and preliminary data where appropriate;*
 - v. how well risks have been identified and will be mitigated;*
 - vi. identification of realistic potential improvements to human or population health;*
 - vii. contribution to relieving disease, disability burden and/or improving Quality of Life (QoL);*
 - viii. identification of potential impacts of research and plans to deliver these.*
 - c. Research environment and people:
 - Will be assessed on*
 - i. track record of the individual(s) in their fields and whether they are best placed to deliver the proposed research;*
 - ii. levels of commitment of the host organisation to supporting the proposed research;*
 - iii. whether appropriate facilities will be available to the researchers.*
 - d. Ethics, including:
 - i. whether proposed research is ethically acceptable;*

- ii. any ethical issues that need separate consideration;*
 - iii. appropriateness of ethical review and research governance arrangements;*
 - iv. any adverse consequences for humans, animals or the environment.*
- e. A communications plan outlining the applicant's plans for engagement, communication and dissemination about the research and its outcomes with the research community and, where appropriate, with potentially interested wider audiences.
- f. Impact Summary.
- g. Data management plan: a sound, detailed plan for managing the research data including security of the data and who will be provided with or have access to the data and under what conditions.
- h. Detailed budget that must include a breakdown of salary, equipment, consumables, travel and subsistence etc. and, if the project is to be jointly funded, reference to any contribution from third party sources of funding. The budget will be judged on:
 - i. whether funds requested are essential and justified by the potential of the research and the contribution of alternative sources of funding if applicable;*
 - ii. investigator time and proposed involvement related to management of the research;*
 - iii. whether the proposal demonstrates value for money;*
 - iv. whether any animal use is fully justified.*

Eligibility – applicant

- Has been BSH member for 3+ years
- Has not received a cohort study grant from BSH before (nor has their project)
- Must be the Principal Investigator or a Co-Principal Investigator with direct responsibility over the preparation, conduct and administration of the project.

Process

- Reviewed externally in conjunction with the BSH Scientific and Publications Committee.
- Successful applicant and Scientific and Publications Committee to agree on annual funding milestones before commencing the project.
- Successful applicant to produce a short annual report about the progress of the project, detailing any new developments or obstacles, as well as any publications supported by the dataset generated by the study.
- BSH has the right to refuse further funding if there is a lack of progress and/or to obtain the return of BSH funds if BSH determines that the use of the funds is inappropriate.

Requirements after completion of project

Continued

- A report showing detailed expenditure over the course of the project.
- Any research publications resulting from the cohort study include acknowledgment of BSH.
- Presentation of the research by the successful applicant at the BSH Annual Scientific Meeting (ASM)