



Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

Handbook outlining the role of SUDC UK Expert Advisors, Research Review Panels and the SUDC UK research grant application and review process.

Table of Contents

Contact Information	2
Introduction.....	2
The SUDC UK Expert Advisory Board	2
The Research Grant Application Process.....	3
Expert Peer Reviewers	5
The Research Review Panel.....	5
RRP Meetings	5
Assessment criteria	6
Appendix 1: SUDC UK Research Strategy.....	8
Appendix 2: RRP Terms of Reference	9
Appendix 3: RRP Conflict of Interest policy	12
Appendix 4 : Review assessment guidance.....	14
Appendix 5: Reviewer assessment form.....	16

Contact Information

If you have any queries, please contact info@sudc.org.uk

Introduction

SUDC UK is a registered, national charity dedicated to raising awareness, funding research and supporting families affected by Sudden Unexplained Death in Childhood (SUDC).

SUDC UK grant awards to research projects are made possible through the dedicated fundraising activities of bereaved families, individual charity supporters, communities, corporations and philanthropic trusts and funds. We are grateful to all our generous donors and to academics who are interested in better understanding SUDC and preventing future deaths.

Our vision is to STOP SUDC and we are dedicated to funding high quality research that makes a meaningful difference to the SUDC community, both now and in the future.

SUDC UK will only fund research which will:

- Contribute towards the prevention of SUDC
- Accelerate the change which will enable children to live with a reduced risk of SUDC

SUDC UK Expert Advisors

SUDC UK is grateful to be supported by a wide range of experts in the field of sudden death. You can find more information about SUDC UK's Expert Advisors on our website [here](#) (scroll down the webpage).

The role of SUDC UK's Expert Advisors is to:

- To provide considered and timely advice and guidance to SUDC UK on scientific matters, our medical education program, SUDC UK's advocacy work, our reactive approach to research publications, charity statements or any scientific, clinical or emotionally sensitive questions from family members.
- To support the SUDC UK research grant process when invited to do so by the independent Chair of our Research Review Panel and work in line with our process, conflict of interest policy and the principles of the Association of Medical Research Charities.
- Our Expert Advisors will have a commitment to SUDC UK and its mission, vision and values.
- Our Expert Advisors are from a diverse range of disciplines. For example, including paediatrics, pathology, child death review, police, social care, public health and experts in bereavement.
- Our expert advisory board is reviewed annually by the SUDC UK Board of Trustees and CEO and the board will evolve using a staggered approach for retire and invitation. A term is 3 years and members may serve a consecutive maximum of two terms (6 years).

The Research Grant Application Process

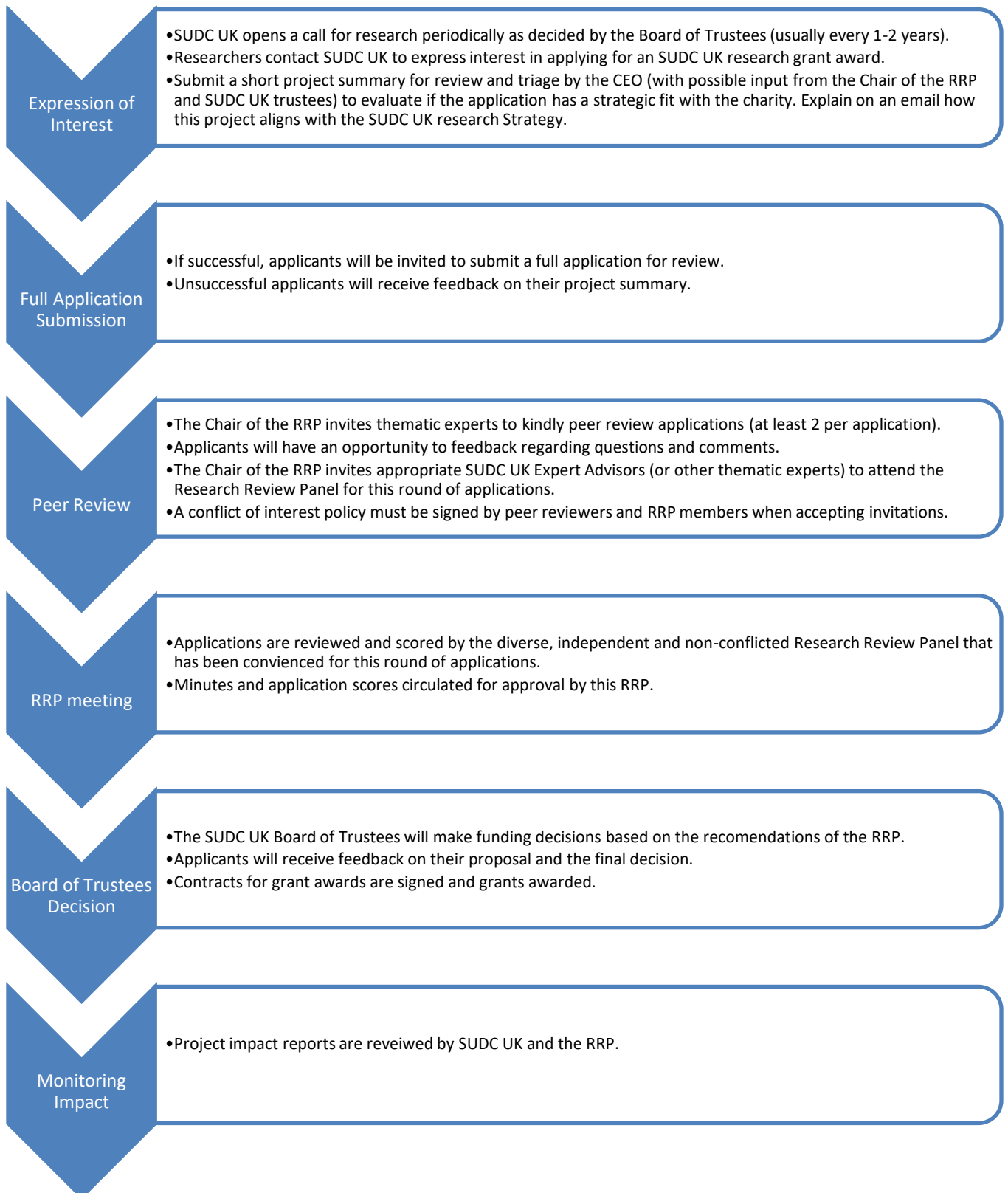
SUDC UK is an introductory member of the **Association of Medical Research Charities (AMRC)** and aims to adhere to their research management guidance and follow their principles of expert review: proportionality, independence, diversity, rotation, impartiality and transparency.

SUDC UK decides how to award grants with the help of an expert Research Review Panel (RRP).

SUDC is a rare category of death and hence, there are relatively few experts in SUDC research compared to fields of medical research. To ensure an effective, expert panel and manage conflict of interest within this small field of experts, a bespoke RRP is convened by the Chair of the RRP for each round of grant applications. The Chair will first look to the pool of appropriate, non-conflicted SUDC UK Expert Advisors and may also consider other thematic experts.

Please note that 100% of any grant would need to support direct project costs. **SUDC UK will only support direct costs that are explicitly identifiable as arising from the conduct of the research project. It will not cover any indirect costs.**

A summary of the SUDC UK research grant review process.



Expert Peer Review

The Chair of the RRP will invite thematic experts to kindly peer review applications (at least 2 per application).

SUDC UK uses national and international peer review to assist its Research Review Panel in assessing the quality of applications. Applicants that are invited to submit a full application will have the opportunity to **nominate up to 4 individuals** who would be **qualified to assess their application** critically and with whom they have had no working relationship in the last 3 years (E.g. joint publication, joint funding bid).

Applicants may also name up to 5 individuals or groups who should not be contacted to review this application. **Applicants may only request exclusions when there is a serious conflict of interest or commercial sensitivity.** SUDC UK may request justification for requests to exclude a potential reviewer. SUDC UK reserve the right to send applications to other reviewers of our choice.

The Research Review Panel

The purpose of the RRP is to meet, discuss and review submitted proposals for scientific research and to recommend appropriate applications to The Board of Trustees for approval for funding.

The panel consists of a Chair and a minimum of 4 other professional experts and 2 Family Voice representative members (7 members total).

Only two panel members may be absent due to unforeseen circumstances if recommendations are still to be taken forward to the Board of Trustees.

The full **Terms of Reference** and **Conflict of Interest Policy** for the RRP are outlined in the Appendix.

RRP Meetings

SUDC UK expects that a diverse and non-conflicted RRP will be convened at least once every two years.

The Board of Trustees will appoint an independent Chair who will not be a member of the Board of Trustees or have served as an Expert Advisor to SUDC UK. The Chair should not serve for more than two consecutive three-year terms (6 years).

RRP members for each grant round will be nominated by the Chair.

Panel meetings will be open to attendance by any member of the Board of Trustees as an observer. They may not participate in the discussions.

Each panel meeting shall consist of not less than 6 and not more than 12 people, including the Chair, representing diverse clinical research interests. For example, physiology, epidemiology, paediatrics,

pathology, child death review, and public health. The Panel will include at least two registered SUDC UK family members, personally affected by SUDC.

Bespoke creation of each RRP also ensures that members shall not be present during the consideration of any application for funding where they have a direct conflict of interest. They would not be involved in the RRP for this grant round or peer review any competing applications. Please see the Appendix for the **RRP conflict of Interest Policy**.

Designated Panel member

Professional experts on the panel are assigned to each application as 'designated panel members' by the Chair and present the application at a meeting. Designated panel members are selected for their relevant expertise in and independence from the application.

Designated panel members present a brief synopsis of the application, focusing on its strengths and weaknesses aligned with the assessment criteria.

Written comments received by the RRP do not replace the minimum quorum of committee members present at the meeting (5 members).

Following panel discussion the designated panel member will, in light of their own views, and the views of the panel members, make a record of key feedback that will be shared with the applicant.

Panel members

Following the introducers evaluation of an application, Family Voice representatives on the panel will be invited to share their evaluation, based on their lived experience.

Panel members will then participate in open discussion. After hearing the indicative aggregated scores for the application, each member will score the application anonymously using the established scoring rubric of zero to six.

SUDC UK staff attendees

SUDC UK organise the logistics of the meeting and the administration of the review process. The CEO will be in attendance to provide administrative support during the meeting, minute discussions, communicate decisions and feedback to the applicants, and are also responsible for any follow-up action after the panel meeting.

Assessment criteria

To make the review process as fair and transparent as possible, all reviewers are guided by grant specific assessment criteria. The five core assessment criteria are:

- SUDC UK Research Strategy
- Person
- Project
- Place
- Price

At all stages of the process reviewers use the grant specific assessment criteria to guide their written feedback and to make an overall assessment score.

You are asked to complete a reviewer assessment form which covers the 5 core assessment criteria for each application, see Appendix.

We have provided a list of questions for each of the 5 core criteria to help you evaluate the proposed research and identify the strengths and weaknesses. These questions are for guidance only. Panel members are invited to review the whole application but need only comment where they feel comfortable sharing their point of view, experience or expertise. Please note that some guiding questions may be relevant to full application submissions only.

We recommend using bullet points to summarise the key strengths and weakness of an application clearly and concisely. Please justify your comments and provide objective criticism and actionable suggestions/ recommendations for improvement, as appropriate.

Scoring

Reviewers will provide an assessment score for each application.

The **scoring rubric** is outlined below:

Impact	Score	Description	Guidance
High	6	Exceptional	Exceptional quality research of significant strategic importance. Potential to lead to significant gains in knowledge of SUDC. Essentially no weaknesses.
	5	Excellent	Excellent quality research of strategic importance. Potential to lead to large gains in knowledge of SUDC. Some minor weaknesses.
	4	Very High Quality	High quality research. Potential to lead to gains in knowledge of SUDC. Some minor weaknesses.
Med	3	High Quality	High quality research. Potential to lead to gains in knowledge of SUDC. Numerous minor weaknesses.
	2	Good	Good quality research. Potential to lead to gains in knowledge of SUDC. Some moderate weaknesses.
Lo	1	Poor	Significant concerns regarding methodology, feasibility, or leadership. Unlikely to contribute to improved understanding of SUDC. At least one major weakness.
	0	Not Eligible for Funding	Does not meet SUDC research priorities. Significantly flawed. Repeats findings already in literature.

RRP members will make an indicative assessment score using the scoring rubric of zero to six, prior to a review panel meeting. Scores will be recorded on the reviewer assessment form.

Where the aggregated indicative score from reviewers meets the minimum threshold (**score >4**), the application will be discussed at a panel meeting. Where there is significant discord in individual scores for a given application, the application may be introduced to the RRP at the discretion of the Research team.

Where external peer review is requested, these scores will be used to guide the decision of the panel.

After hearing the indicative aggregated scores for the application and following open discussion, each member will be able to adjust their indicative score anonymously. The scores will be collated electronically.

Ranking and recommendations

The median score of individual member scores, rounded to the nearest whole number, is used to rank all proposals under consideration. The RRP panel will then review the rank order of applications and make recommendations for progression to the next stage of the review process.

For an application to be recommended for potential funding, a score of 3 or above must be achieved.

Communication of decisions

The SUDC UK team will communicate funding decisions to all applicants following each stage of the review process.

Funding outcomes will be published and reported in line with AMRC guidelines.

Feedback

All applicants will receive an anonymous summary of reviewer comments, across the assessment criteria from the SUDC UK Team.

Appendix 1: SUDC UK Research Strategy



Please see our website- <https://sudc.org.uk/professionals/>

Appendix 2: RRP Terms of Reference

1. Role and Scope of the RRP

- 1.1. SUDC UK is a registered, national charity dedicated to raising awareness, funding research and supporting families affected by Sudden Unexplained Death in Childhood (SUDC).
- 1.2. The role of the RRP is to support the implementation of the charity's Research Strategy by providing expert independent advice to the Board of Trustees on funding applications, based on external expert reviews and the charity's research funding process and review criteria and scoring guidance.

SUDC UK is an introductory member of the Association of Medical Research Charities (AMRC) and aims to adhere to their research management guidance and follow their principles of expert review: proportionality, independence, diversity, rotation, impartiality and transparency.

2. Panel Membership

- 2.1. The present and attending panel consists of a Chair and a minimum of 5 others. In the absence of the Chair, another member will be nominated by the panel or Chair to temporarily fulfil the role.
- 2.2. Only two panel members may be absent due to unforeseen circumstances if recommendations are still to be taken forward to the Board of Trustees.

3. Diversity

- 3.1. Bespoke panel creation for each round and rotation of panel membership ensures that we are able to bring new ideas and thinking to the peer review process and incorporate views from a diverse range of experts over time.

4. Transparency

- 4.1. For transparency, all RRP Members will have their name and current role or relationship to SUDC UK published on the SUDC UK website.

5. Accountability

- 5.1. RRP members are accountable to the RRP Chair, in the first instance, and the Board of Trustees.

6. Panel Review

- 6.1. In line with the Research Strategy, RRP processes and procedures will be formally reviewed every 3 years. The policy will also be amended to respond flexibly to the needs of the panel and in response to any significant changes.

7. Induction

- 7.1. All SUDC UK Expert Advisors members will be provided with a robust induction. This will include an opportunity to meet with the CEO, RRP Chair and our Communications Manager, and a welcome/training meeting with other members of the Expert Advisory Board. The training will cover: the charity's aims, mission and values, Research Strategy, Terms of Reference, Conflict of Interest Policy, Research funding process, review criteria and scoring guidance.

- 7.2. SUDC UK Expert Advisors will document any existing conflicts of interest which may affect their role on the RRP and send these to SUDC UK who will collate them for the RRP Chair.
- 7.3. SUDC UK will ensure that members have any necessary training to enable them to fulfil their role. For example, training lay panel members in the review process.

8. Attendance and organisation

- 8.1. An RRP will be convened to review research funding applications. These may range from small grants to fellowships. Travel awards will be reviewed outside of this process by Expert Advisors only, on a rotational basis.
- 8.2. The SUDC UK Team are responsible for all administration involved in the grant application and review process. Paperwork for each RRP will be distributed electronically at least 2 weeks prior to the meeting.
- 8.3. Expert Advisors are expected to accept invitations to attend RRP meetings whenever possible.
- 8.4. If a panel member is unable to attend a meeting, they should submit written comments two days before the meeting so their views can be included for consideration. The Board of Trustees will review the support of Expert Advisors and RRP's annually.
- 8.5. The review of applications will follow the Application Review Criteria and Scoring Guidance.
- 8.6. A member of the SUDC UK team will attend the meeting for administrative purposes and provide guidance upon request in relation to strategic or organisational queries.
- 8.7. In rare instances, non-members may be invited to join the panel to provide specialist expert advice which is outside the skills set of the current Expert Advisory Board.

9. Conflict of interest and confidentiality

- 9.1. All panel members must agree to abide by the RRP Conflict of Interest Policy when they join a panel.
- 9.2. Panel members must ensure that the details of all research applications remain confidential.
- 9.3. All RRP members must, on an individual application basis, consider and declare any conflict of interest. Panel members should declare the conflict as soon as is reasonably possible. All conflicts of interest must be raised with the SUDC UK Research Team and/or Chair prior to the panel meeting.
- 9.4. If a conflict of interest is identified, the panel member will absent themselves from the entire meeting. In this case, the member will not receive any paperwork associated with application, as per the RRP **Conflict of Interest Policy**.
- 9.5. If there is uncertainty about a possible conflict of interest, it will be discussed with the SUDC UK Team and RRP Chair.

10. Skills and experience

- 10.1. All RRP members will have a commitment to SUDC UK and its mission, vision and values.
- 10.2. Members will be able to devote the necessary time and effort to support SUDC UK and the research review process.
- 10.3. Invited panel members will have experience of the peer review process and have been awarded grants through a similar expert review competitive process. (Note. This clause does not apply to lay members).
- 10.4. Members will value and be constructive about other members' opinions in

discussions. It is crucial that members work together to make collective decisions.

- 10.5. Members will maintain confidentiality on sensitive and confidential information.
- 10.6. Members will understand the importance and purpose of the panel meetings and will prepare for them adequately and attend regularly.
- 10.7. Members will use their personal and professional experience to critically analyse information and, when necessary, challenge constructively.
- 10.8. Panel members will have excellent, independent judgement skills.
- 10.9. Panel members will be able to speak their mind and have the ability to provide effective support and challenge in panel meetings.
- 10.10. Members will recognise the limitations of their knowledge and seek additional insight when necessary.

11. Roles and responsibilities

- 11.1. All RRP members will support the implementation of the Research Strategy and contribute to the development and refinement of the Research Review Panel processes and procedures.
- 11.2. RRP members will provide expert independent advice to the Board of Trustees and make recommendations on which grant applications should be funded.
- 11.3. Panel members will assess research applications received by SUDC UK using the Review Criteria and Scoring Guidance, focusing on the quality of science and strategic fit.

12. Role of the Chair

- 12.1. The Chair is responsible for ensuring the panel is effective and that the panel provides robust, objective advice to the Board of Trustees. The Chair will ensure that:
 - a) The panel implements the Application Review Criteria and Scoring Guidance.
 - b) Panel member workload does not compromise opportunity for discussion. Any concerns should be raised directly with the SUDC UK CEO.
 - c) External reviewer comments are taken into consideration in discussions and support decision making.
 - d) The full range of scientific opinion is taken into consideration.
 - e) Any significant differing opinions are explored thoroughly and documented where agreement cannot be met.
 - f) All members have the opportunity to be heard and considered.
 - g) Any minutes documented by the SUDC UK Team accurately represent the panel discussion.
 - h) Any specific concerns regarding ethics and other governance requirements are addressed.
 - i) A delegate chair is appointed if they are required to leave the meeting because of a conflict of interest.
 - j) The process for assigning reviewers is fair and reflects the expertise required to evaluate the applications appropriately.
- 12.2. The Chair and/or a member of the SUDC UK team will attend trustee meetings to discuss the approved minutes and report the recommendations of the

panel.

I, the undersigned, have read and agree to the Research Review Panel Terms of Reference laid out in this document.

Name:

Institution:

Date:

Appendix 3: RRP Conflict of Interest policy

1. Role and Scope of the Policy

SUDC UK is guided by the Association of Medical Research Charities' (AMRC) principles of expert review: proportionality, independence, diversity, rotation, impartiality and transparency.

As an expert providing written review or a member of the Research Review Panel (RRP), you are being asked to provide independent and impartial advice without undue influence from other factors.

Therefore, we ask that you agree to abide by the terms of this conflict of interest policy, prior to reviewing any funding applications.

This conflict of interest policy clearly articulates the type of conflicts that may arise in research funding, and specifies the actions you must take if you identify a conflict of interest, or think you may have a conflict of interest. The presumption is not that your actions will be influenced by any conflict of interest, but rather whether public perception could reasonably consider this a possibility.

2. Confidentiality

The contents of the application must remain confidential and may not be reproduced, stored or disseminated for any purposes beyond the review process. You may not discuss the content of applications with peers or the applicants themselves. Applicants should not approach you during the review process regarding their application – all correspondence will occur through the SUDC UK administrative process.

3. Disclosure of Conflict of Interest

You must disclose a conflict of interest if **any** of the following statements apply:

- a. You work within the same department as the applicant.
- b. You interact regularly with the applicant in a professional or personal capacity.
- c. You have been a co-applicant with the applicant, within the last three years.
- d. You have been a student or supervisor of the applicant within the last three years.
- e. You are a close friend or relative of the applicant.
- f. You have a long-standing scientific or personal difference with the applicant.
- g. You are in a position to gain or lose financially from the outcome of the application (eg holding stock in an industry partner company or a competitor).
- h. You are preparing a grant application which is similar to the submitted application.
- i. You have previously reviewed the application.
- j. You have collaborated or co-authored with the applicant within the last three years.
- k. You work at the same institution as the applicant.
- l. You feel there are other circumstances which may give rise to a conflict of interest.

4. Managing Conflicts of Interest

1. All written reviewers and final research review panel (RRP) members must, on an individual application basis, consider and declare any conflict of interest. Panel members should declare the conflict as soon as is reasonably

possible. All conflicts of interest must be raised with the SUDC UK CEO and/or Chair prior to the panel meeting.

2. If any written reviewer or RRP member is applying for funding from SUDC UK, they must absent themselves from the meeting and will not be able to assign external reviewers. They will not be sent any paperwork relating to that funding round.

3. If a written reviewer or RRP member identifies a conflict of interest from statements 3.a) – i), they must not review the application and they must absent themselves from the meeting when that application is discussed. They will not be sent any paperwork relating to the application or have access to the discussions surrounding it.

4. If a written reviewer or panel member identifies a conflict of interest from statements 3.j) – l), they must inform the SUDC UK Research Team and/or the Chair. Your individual circumstance will need to be discussed with the SUDC UK Research Team and/or the Chair in the first instance. If it is agreed that the specific circumstances do not warrant exclusion from the reviewing process, a note of the potential conflict will be recorded for transparency.

5. The Chair of the panel is responsible for resolving areas of uncertainty. This may involve a whole panel discussion.

6. As funding decision makers, the Board of Trustees (in accordance with guidance from the Charity Commission) are subject to the same conflict of interest statements set out in point 3, a)-l).

5. Raising concerns about a conflict of interest

If a written reviewer or panel member wishes to raise a concern about another member not identifying a potential conflict of interest, they should report to the Chair. If the concern is regarding the Chair, the member should raise their concern with the Chair of Trustees -

helen@sudc.org.uk.

I, the undersigned, have read and agree to the terms laid out in the Research Review Panel Conflict of Interest policy.

Name:

Institution:

Date:

Appendix 4: Review assessment guidance

SUDC UK Priorities

Please consider how the application aligns with SUDC UK's Research Strategy

Is the research relevant to SUDC UK research priorities? These are summarised as:

SUDC UK will only fund research which will

- Contribute towards the prevention of SUDC
- Accelerate the change which will enable children to live with a reduced risk of SUDC

Person

Please consider if the applicant has the skills and experience necessary to deliver the project.

Where applicable, what value, expertise and/or support do the co-applicants or collaborators bring to the project?

- Does the applicant have the research experience necessary to fulfill the project?
- Have they demonstrated capacity to effectively communicate research findings through peer-reviewed publications, talks/presentations, engagement with patients and the public, or through other professional activities?
- Is there evidence of their potential for effective project management capabilities to successfully deliver the project?

Project

Please consider the quality of the proposed research project and the potential for meaningful impact. Project proposals should be well-framed, relevant, focused, appropriately designed and feasible within the given timeframe.

- How important is the research question?
- Is the research clearly and convincingly explained?
- Are the methods and proposed analyses appropriate, including sample size, power calculations and justification of effect size?
- What are the potential risks and is there a plan to manage these?
- Is the work ethically sound? If needed, are considerations for participant recruitment and patient burden appropriately identified?
- Are there robust plans for continued patient and public involvement?
- Are there appropriate measures in place for research governance? This includes data management, required ethical and regulatory approvals and/or licenses?
- Has a plan for sharing research findings and generating impact been demonstrated?
- What is the potential for scalability or translation of findings?

SUDC UK

Sudden Unexplained Death in Childhood

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Place

Please consider if the research environment/ infrastructure is suitable to support project delivery and to provide appropriate opportunities for training and career development.

- Is the proposed environment suitable and does it have the variety of expertise and disciplines to support the project?
- Will the project utilise already established infrastructure/ methods/ equipment?
- Will the research environment provide appropriate opportunities for development of the applicant?
- Has the host institution demonstrated a clear commitment to the proposed project for the duration of the grant?
- Are there any dependencies on other organisations or funding of which SUDC UK should be made aware?

Price

Please consider if the requested funds are reasonable, justifiable and offer good value for money. SUDC UK research grants are made possible by our dedicated community of fundraisers and donors.

- Are the funds requested essential for the work and justified by the importance and potential of the research?
- Does the project demonstrate good value for money?

Note: For highly novel but potentially impactful research: Reviewers may consider reducing funds if high risk but worthy research.

Appendix 5: Reviewer assessment form

Reviewer Name Forename(s), Surname

Date of review Date

Application Title:

Scoring Rubric

Impact	Score	Description	Guidance
High	6	Exceptional	Exceptional quality research of significant strategic importance. Potential to lead to significant gains in knowledge of SUDC. Essentially no weaknesses.
	5	Excellent	Excellent quality research of strategic importance. Potential to lead to large gains in knowledge of SUDC. Some minor weaknesses.
	4	Very High Quality	High quality research. Potential to lead to gains in knowledge of SUDC. Some minor weaknesses.
Med	3	High Quality	High quality research. Potential to lead to gains in knowledge of SUDC. Numerous minor weaknesses.
	2	Good	Good quality research. Potential to lead to gains in knowledge of SUDC. Some moderate weaknesses.
Lo	1	Poor	Significant concerns regarding methodology, feasibility, or leadership. Unlikely to contribute to improved understanding of SUDC. At least one major weakness.
	0	Not Eligible for Funding	Does not meet SUDC research priorities. Significantly flawed. Repeats findings already in literature.

Please indicate your overall assessment score here:

Recommendation for funding: Please tick on of the below

- Full funding
- Partial funding
- Not recommended for funding

Reviewer's comments

Please consider each of the review criteria below to determine the impact and scientific merit of the project proposal. Please refer to the grant specific assessment criteria for further guidance.

We would like to thank you for taking the time to complete this review. We are incredibly grateful for your expert opinion which will help us to fund research which has the potential to improve understanding of SUDC in the hope of preventing future deaths.

Below, please summarise the factors that informed your overall assessment score:

- Please ensure that you use language which can be easily understood by a non- scientist and non-specialist in the field of study
- We ask that you provide clear and concise comments and objective criticism
- Please provide justification for your comments and the overall score, and whether you are supportive of the proposal or not.
- Please clearly identify strengths and weaknesses of the proposal
- Include any appropriate references

SUDC UK Research Strategy	Please consider how the application aligns with SUDC UK's Research Strategy and our commitment to fund research which will <ul style="list-style-type: none"> · Contribute towards the prevention of SUDC · Accelerate the change which will enable children to live with a reduced risk of SUDC
Strengths	
Weaknesses	

Person	Please consider if the applicant has the skills and experience necessary to deliver the project. Where applicable, what value, expertise and/or support do the co-applicants/ collaborators bring to the project?
Strengths	
Weaknesses	

Project	Please consider the quality of the proposed research project and the potential for meaningful impact. Project proposals should be well-framed, relevant, focused, appropriately designed and feasible within the given timeframe.*
Strengths	
Weaknesses	

Place	Please consider if the research environment/ infrastructure is suitable to support project delivery and to provide appropriate opportunities for training and career development.
Strengths	
Weaknesses	

Price	Please consider if the requested funds are reasonable, justifiable and offer good value for money. SUDC UK research grants are made possible by our dedicated community of fundraisers and donors.
Strengths	
Weaknesses	

Additional comments to applicant

Reviewers may provide guidance to the applicant and/or raise specific queries.

Additional comments to applicant (optional)
Click or tap here to enter text.

An anonymous summary of reviewer feedback will be provided to applicants.