

**Patient and Public Involvement and Engagement
(PPI E) Virtual Small Grants Scheme: 2021**

 **Guidance Notes and Application Form**



**Contents**

1. About the PPI E Small Grants Scheme
2. Strategic aims of the PPI E Virtual Small Grants Scheme: 2021
3. Breakdown of funding available
4. Timetable and application process
5. Information to note
6. Next Steps
7. Appendices:
	1. What do we mean by Patient and Public Involvement and Engagement (PPI E)?
	2. Planning and costing your Patient and Public Involvement and Engagement (PPI E)
	3. Examples of previous projects supported by the 2019 and 2020 Scheme
8. Application Form
9. **About the PPI E Small Grants Scheme**

The scheme was first introduced in 2018 as part of the five core objectives of the NIHR GOSH BRC Patient and Public Involvement and Engagement Strategy and its commitment to “*share information about our research activity and encourage conversations between patients, the public, researchers and staff”*



 **2. Strategic aims of the Virtual PPI E Small Grants Scheme: 2021**

It is specifically aimed at supporting researchers to actively involve and/or engage patients and the public in translational research aligning with the activity of existing [GOSH BRC Research Themes](https://www.gosh.nhs.uk/our-research/our-research-infrastructure/nihr-great-ormond-street-hospital-brc/about-brc/our-research-themes/https%3A/www.gosh.nhs.uk/research-and-innovation/nihr-great-ormond-street-brc/about-us/our-research-themes) to:

* develop Patient and Public Involvement and Engagement so it is practised more widely across the GOSH BRC and becomes embedded in the research process from the beginning;
* ensure Patient and Public Involvement and Engagement is well conducted and is a positive experience for all involved so that it has a demonstrable and meaningful impact on research;
* encourage the active involvement of patients and the public in setting research priorities and the strategic development of research;
* improve the quality and effectiveness of Patient and Public Involvement and Engagement activities already taking place;
* raise the profile of Patient and Public Involvement and Engagement among our research community and the public.

\*This year in line with future GOSH BRC Patient and Public Involvement and Engagement Strategy development we are allocating our funding for **virtual** (online) PPIE activities. This is also in response to the uncertainty around hosting in person activities due to COVID-19 restrictions/developments.

1. **Breakdown of funding available**

The NIHR GOSH BRC has **£5,000** in funding to be split across a number of projects. Below are some guidelines for consideration when planning and costing your application:

* £250- £500 - Part funding or funding a small activity
* £400 - £500 - Starter activities
* £500 - £1,000 - More detailed long term planned activity
* £1,000 - £2,000 - Innovation in Patient and Public Involvement & Engagement

Please note that applications will be assessed according to the estimated amounts above and it is not likely that awards will be made for more than one project in the £1,000-£2,000 bracket. We also encourage applications from teams who have not yet run a PPIE activity.

What will **not** be funded?

* Staff time including admin time (other than for therapeutic facilitator time for e.g. a clinical psychologist;
* Conference or training attendance unless it is being requested to present findings/poster exhibiting of findings;
* Continuation of a project previously funded by this call;
* The same project under different amount headings;
* Significant changes to a project which has not been agreed by the BRC funding panel;
* Service evaluation or any activity not related to PPIE in research - please see 7.1
* Activities which have not been planned in enough time to adhere to the spend deadline.

To note:

* The Lead applicant is responsible for the overall management and delivery of the PPI E activity and if delegating duties needs to ensure that these are carried out in accordance with the plan as outlined in the application form;
* Successful applicants will be required to track spend and share this with the PPI E Lead as the project develops;
* Any project funded through this call but must be fully invoiced by **28th February 2022**. There will be **no** mechanisms for GOSH BRC to be able to pay any invoices after this date. Therefore, please plan your projects with this in mind and the BRC will be in contact through the year to ensure you are on track with your plans.
1. **Timetable and application process**

|  |  |  |
| --- | --- | --- |
| **Activity** | **Date**  | **Note** |
| Call opens  | Friday 28 May 2021 | Any queries please contact research.ppi@gosh.nhs.uk |
| Deadline for receipt of applications  | Thursday 24 June 2021 (midnight) | Submit Application form as a word document **NOT** in pdf format |
| Any clarifications/follow up queries sent to Lead applicants | by Friday 2 July 2021 | Via email |
| Deadline for responses to follow up queries  | Friday 9 July 2021 | If follow up queries are not answered your application may be withdrawn  |
| Applicants informed of outcome  | w/c 26 July 2021 | Panel meeting on 21 July 2021 |
| Deadline for all spend  | Monday 28th February 2022 | Applicants will be responsible for sourcing alternative funding if this deadline cannot be met. |
| Completion of all PPI E activities  | Thursday 31 May 2022 | Funding cannot be spent to support an activity after this date |
| **Possible impact of COVID-19 on planning virtual PPI E activities & funding note:**We recognise that this remains a challenging time so we ask you to consider the following :* Do you have capacity to prepare and plan for your PPI E activities in time to be able to deliver them within the deadlines stated in the timetable above;
* Funding will be released from the beginning of August 2021 and as per NHS financial regulations all funding must be spent in the financial year and completely invoiced by **28th February 2022**. Any invoices received in the next financial year will not be processed and the Lead applicant will be responsible for sourcing alternative funding to cover these costs. Please also note that unspent funds cannot be carried over into the next financial year or used for other projects.
 |

**5. Information to note**

* The Lead applicant must hold aGOSH or ICH UCL staff contract (either clinical or non-clinical) or be a student affiliated to GOSH or ICH UCL, if this situation changes then the project will need to be re-assessed ( this also applies to any staff costed to work as therapeutic facilitators of groups for e.g.: Psychology staff);
* The Lead applicant is responsible for ensuring PPI E activities are planned and carried out/collaborators must state their involvement – what role will they play, this includes any psychologist support for facilitating focus groups;
* Applications are encouraged that fit in with one or more of the strategic aims of the fund and may be in one particular project or selection of projects, or in setting research priorities at departmental or divisional level;
* Whilst it is not obligatory for the PPIE to support research in specific areas, priority will be given to projects that support translational research aligning with the activity of the existing GOSH BRC themes, [GOSH BRC Research Themes](https://www.gosh.nhs.uk/research-and-innovation/nihr-great-ormond-street-brc/about-us/our-research-themes);
* Applicants who have been successful in previous rounds are welcome to apply again with **new** project proposals;
* Successful applicants will be:
* Advised to contact the GOSH BRC Patient and Public Involvement Lead for research, Deirdre Leyden/seek their advice if necessary; research.ppi@gosh.nhs.uk;
* provided with further information on finance processes and procedures and asked to keep a record of spend and invited to attend either 121 or group training on delivering PPIE activities virtually;
* asked to submit a short written report on their project on completion;
* asked to share their learnings and the impact of their activity with others by attending a meeting at the end of the scheme.
* We understand that sometimes planned activities need to change due to patient/parent carer staff circumstances: successful applicants who for whatever reason request to make changes to planned PPIE activities and/or changes to breakdown of costings must contact the PPI E lead to discuss these and to have the revised project approved by the BRC.
* When costing your project please breakdown activities and provide a timeline which includes time taken to engage with patients and the public to be involved, activity planning.

*Do not under estimate the amount of time which can go into planning and delivering PPI E activities and how important it is to allow time to plan your project in advance.*

**6. Next Steps**

* Please complete in full the application form below If you have any queries or want to talk through your proposed PPI E activity/costings please contact: GOSH BRC PPI E Lead for research, Deirdre Leyden -  research.ppi@gosh.nhs.uk
* Submit your application to: BRC@gosh.nhs.uk with the email subject line: **NIHR GOSH BRC virtual PPI** **E Small Grants Scheme: 2021**. Please attach your application form as a word document **NOT** in pdf format. Please try and use a short Project title.

Applications will be reviewed and considered by a panel made up of senior staff from the NIHR GOSH BRC. The panel will consider:

* whether the project fits with the strategic aims and priorities of this fund;
* the potential immediate and long term impact of the project on translational research and how it will be evaluated;
* whether the project can realistically be delivered within cost and time constraints and if the

project has been thought through properly and is clear in its objectives;

* the likely quality of involvement in terms of it being a positive and meaningful experience for both public and researchers;
* whether applicants need to be contacted to provide further information about their proposal.

**7. Appendices**

**7.1 What do we mean by Patient and Public Involvement and Engagement (PPI E)?**

‘Patient and Public involvement’ in research is research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’ ‘about’ or ‘for’ them’. It is where patients and members of the public are actively involved in research projects and in research organisations.

**Public**: A general term we use to describe patients, potential patients, parents, carers, staff and members of the public involved in our work.

**Involvement**: Working in partnership with patients and the public throughout the research process.

*Examples of involvement are:*

* helping identify research questions and priorities;
* looking at research processes and advising researchers on how practical and acceptable they are;
* advising researchers on outcome measures and how meaningful and reliable they are to patients;
* improving the language and accessibility of patient information and invitation letters;
* becoming advocates and disseminators of research findings.

**Participation is not Involvement** – participation is where a patient is actively taking part/recruited into a research trial or study as part of or in additional to their routine clinical care.

*Examples of participation include:*

* completing a questionnaire or participating in a focus group which is part of a research study
* taking part – participating in a research trial or other research study as part of or in additional to their routine clinical care.

There are different levels of patient/public involvement. For instance, patients/members of the public may be:

* joint grant holders/co-applicants on a project;
* members of a project steering group or patient panel;
* participants in a one-off workshop/ focus group or at PPI meetings in person or by telephone or Zoom; online questionnaire.

 *There isn’t any one way of involving patients and the public in research. The level of involvement and the stages of the research process at which patients and the public are involved may be determined by the nature of the research project.*

**7.1 What do we mean by Patient and Public Involvement and Engagement (PPI E)?**

**‘Public engagement’** or **‘Engagement’**: *Where information and knowledge about research is provided and disseminated.*

*Examples of engagement (on line or in person) are:*

* *science festivals / lectures open to the public with debates and discussions on research;*
* *outreach at schools or colleges;*
* *open days at a research centre where members of the public are invited to find out more about research (for example the NIHR GOSH BRC Family Fun Day for research)*
* *awareness raising of research through media such as t.v. programmes, newspapers and social media;*
* *dissemination to research participants, colleagues or members of the public on the findings of a study.*

\* Please note : Patient and Public Involvement in research is **NOT** service evaluation – i.e. looking at how to make improvements to a service offered to patients – this is more in line with the patient experience, although of course the patient experience and their views is at the heart of their involvement in research. (There is a whole team dedicated to patient experience at GOSH)

**7.2 Planning and costing your virtual Patient and Public Involvement and Engagement (PPI E) - Guidelines**

|  |  |  |
| --- | --- | --- |
| **PPI E Activity** | **Amount PP /activity** | **Other information/ Useful links**  |
| **Zoom licence** Please check what Zoom licence your department is signed up for  | <https://www.finder.com/uk/zoom>Either log into free Zoom account every 40 mins or sign up for monthly over 40 mins. | GOSH Zoom accounts are for 40 mins only. If planning to run a two hour focus group meeting or daylong event a Zoom pro account is necessary. [GOSH Intranet info on Zoom](http://goshweb.pangosh.nhs.uk/search/Pages/results.aspx?k=Zoom&cs=This%20Site&u=http%3A%2F%2Fgoshweb.pangosh.nhs.uk) [GOSH GOLD Zoom training](https://lms.goshgold.org/local/gosh_course_view/view.php?id=1023) |
| **Advisory /Focus Group** (6-8 people is the advised number for a focus group) | £20 - £25 (per meeting) | Proxy payment usually by e-Amazon vouchers – these are ordered centrally and allocated by PPI E Lead or payment via BACS.  |
| **Teleconference / Online (Zoom) meetings**  | £20 - £30 (per meeting) | Proxy payment and/or as above. |
| **Research activity**  | £20 per hour  | Proxy payment as above. Examples include: reviewing information prior to attending meetings or giving virtual feedback. |
| **Steering/Management/ Committee Group** (during the life cycle of a research project: from idea to dissemination. | £160 (per day)£75 - £80 (per half day) | This includes preparing for meetings by reading information, includes more ongoing involvement agreed with patient/public.  |
| **Child care costs**  | Between £50 - £100 (estimate)  | Invoice will be required as proof. |
| **Facilitator time** | For e.g. Clinical Psychologist | Time allocated/rate of pay/ band for e.g. 4 hours @ £55.20/hour/ Band 8c – please provide correct costing if planning for this support, check with HR.  |
| **Transcription costs** | Costs vary £100 - £200  |  Invoices required. GOSH has a contract with One-Note. Check with PPIE Lead.  |
| **Services outside of GOSH/ICH** | Costs will vary  | Check with PPI E Lead first. If for e.g. using a media company / other services get a quote and add 20% VAT. |

**7.3 Examples of previous** [**projects**](https://www.gosh.nhs.uk/our-research/our-research-infrastructure/nihr-great-ormond-street-hospital-brc/brc-opportunities/nihr-gosh-brc-patient-and-public-involvement-and-engagement-call/) **supported by the 2019 and 2020 BRC PPIE Small Grants Scheme**

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| --- |
| **PPI E Project Title - 2019** |
| **Child and parental views of options available for hearing loss in unilateral microtia** |
| **Parents views on AHP care delivery in an intensive care setting** |
| **Designing child, young person and family friendly research materials for studying psychosocial barriers to kidney transplantation in children** |
| **PPI activities to explore child, parent and physiotherapist perceptions of physiotherapy rehabilitation after Selective Dorsal Rhizotomy in children with cerebral palsy** |
| **PPI E focus group to identify research priorities for children and families affected by arrhythmogenic cardiomyopathy** |
| **Rare Disease Cohorts: Patients with Dystrophic and Junctional Epidermolysis Bullosa and Chronic Granulomatous Disease will be part of the target population** |
| **Exploring family and children’s views of acute rehabilitation provision at a tertiary hospital** |
| **Telling it, like it iS****Adolescents with Tourette’s’ Syndrome informing peers about research in the National Specialist Tourette’s Syndrome Clinic (NSTSC), GOSH** |
| **The GOSICH Future Researchers Christmas Lecture** |
| **Epilepsy – Carers Uniting with REsearchers (E-CURE)** |
| **Assessing patient/carer experience within the GOSH Ketogenic Diet Neurology service** |
| **Show, don’t tell! Using animation to engage children and young people in research** |
| **Pyruvate Dehydrogenase Complex (PDC) Deficiency Natural History Study** |
| **Integrating data-driven approaches into display and interpretation of clinical data for children and young people with Cystic Fibrosis at GOSH: perspectives on the ‘what, when and how’** |

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| **PPI E Project Title - 2020** |
| **Charting Hurdles in Anorectal Malformations: a PPIE focus group event to identify what matters** |
| **Perspectives of parents and Children and Young People on the research priorities for children with cochlear implants** |
| **'Cloaca family' open day and research forum** |
| **Evaluation and development of the new neuromuscular clinical and physiotherapy provision for non-ambulant boys and your men with Duchenne Muscular Dystrophy** |
| **The feasibility of using swallowing exercises in adolescents with swallowing impairments: A co-design project** |
| **Identifying the research views and priorities of parents whose children have very early developmental skills and attend Neurodisability clinics at GOSH for assessment** |
| **Exploring family and children’s views of acute rehabilitation provision at a tertiary hospital** |
| **Participated design of a virtual reality app to benefit patients with cardiovascular disease** |

**Section 8**

**Patient and Public Involvement and Engagement (PPI E) virtual**

**Small Grants Scheme: 2021**

**Application Form**

(All information supplied on this form will be treated as confidential)

Before submitting your application please read the *Guidance Notes for Applicants* above.

Please **do not** submit this form as a PDF.

**SECTION A: APPLICANT(S) DETAILS**

|  |  |
| --- | --- |
| **Lead Applicant(s): Main point of contact throughout the project** |   |
| **Title** |  |
| **Full name**  |  |
| **Post held** |  |
| **Contact details** (email/contact number) |  |
| **Full or Honorary GOSH Contract****Full or Honorary ICH UCL Contract** Please specify in the box  |  |
| **ICH Programme and Section/GOSH Directorate** |  |
| **What will your role be in delivering the project?** |  |
| **Collaborator(s):** |  |
| **Title(s)**  |  |
| **Full name(s)** |  |
| **Post(s) held** |  |
| **Contact details** (email/contact number) |  |
| **What will their role be in delivering the project?** |  |
| **Student(s):** |  |
| **Will students help deliver the project – if so in what capacity?** | [ ]  Yes [ ]  No |
|  |
| **If yes please outline by whom/how often they will be supervised** |  |
| **If yes can you confirm that that a student’s supervisor will be present if you are involving patients in your proposal?** |  |

**SECTION B: VIRTUAL PPI E RESEARCH PROJECT SUMMARY**

|  |  |
| --- | --- |
|  **Project Title – please use a short title**  |  |
|  **Total amount requested**  | **£**  |
| **Please state which GOSH BRC research theme the translational research that your PPI E activity underpins best aligns with**1. [GOSH BRC Research Themes](https://www.gosh.nhs.uk/research-and-innovation/nihr-great-ormond-street-brc/about-us/our-research-themes)
 |  |
| **R&D Number** (if applicable) |  |
| **Project Start Date**  |  |
| **Project End Date** |  |

|  |
| --- |
| **About the project** (in no more than 1,000 words excluding references and one figure/table) |
| Please describe briefly and in lay terms the **research study** or **research area** you want to involve patients and the public in. **Please note**: Service evaluation in itself is not considered as research.  Please answer all of the following :1. Project background and rationale.
2. What specifically would this funding allow to happen?
3. Key objectives and deliverables
4. Research plan/methodology
5. The resources required for delivery, with justification
6. Timeline of when planning and activities would happen
7. How you expect the PPI E to **impact** on your translational research/research area and how you will record, measure and evaluate this?
8. Is your PPI E proposal supporting new translational research?
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|  |
| **About your research** (in no more than 300 words) |
| Please describe your research in lay English – easy to understand terms in a way that could be published to a general audience. If awarded, this may be made publicly available and applicants are responsible for ensuring that the content is suitable for publication. *Lay English is a style of writing that the intended audience can understand on first reading. Well-written, lay English should engage and inform an audience. It is about clarity of language which avoids using jargon, technical terms, acronyms (abbreviations) and any other text that is not easy to understand. If technical terms are needed, they should be properly explained. When writing in lay English, the writer should not change the meaning of what they want to say, but they may need to change the way they say it.* |
|  |
| **Who you will be involving - patients, parent carers, staff, public** (in no more than 500 words excluding references and one figure/table) - please answer **ALL** of the below. |
| 1. Which groups you will be involving
2. Why you want to work with these particular people/groups
3. How you will identify and enlist these people/groups
4. Any support you will provide to help them get involved
5. How will their input improve/inform your translational research
6. The mechanism for involving patients/the public in your research, such as focus groups, panel etc. If you are planning to hold a meeting, focus group or event please give details of how it will be facilitated
7. Details for how you plan to fully invoice the BRC for all activities by 28th February 2022.
 |
|  |
|  **About your funding request**  |
| 1. What will you do and how will you do it?-Please provide an outline breakdown of likely costs. An example table below for reference *(please read the application guidance above)*

|  |  |  |
| --- | --- | --- |
| **Activity** | **Information** | **Cost** |
| Psychologist facilitator time (hours /rate) |  |  |
| Zoom licence if needed  |  |  |
| Vouchers  |  |  |
| Payment to parents/patients  |  |  |

1. Please also provide details of any funding or resources coming from elsewhere (e.g. a charity you work with)
2. If this request is for an expansion of your work, or you anticipate it will be ongoing, how will it be funded in going forward?
3. Will any form of this project take place if this application is not funded or is partly funded? If so what will it look like?
4. If your project is funded and goes over budget are you able to make up the shortfall?
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**SECTION C: DECLARATIONS AND SIGNATURES**

In order for your proposal to be accepted you and anyone you will collaborate with to deliver your PPI E project are required to sign below. These signatures are required to ensure that the applicants agree to deliver the proposed project, and that the PPI E research activity can be accommodated by the department where the work will be undertaken. These signatures can be supplied as an e-signature. Any changes to circumstances involving staff who have taken responsibility for delivering PPIE must be communicated. If successful you will be required to submit a report of your PPI E activity and attend a meeting to update on how the activity went.

|  |
| --- |
| I can confirm that the information given on this form is complete and correct, that any other collaborators have seen a copy of this application and will be actively engaged in this project. Signed: ……………………………………………………………………………………………………………………. Date: ………………………………….. **(Lead Applicant(s)**Signed: ………………………………………………………………………………………………………………….... Date: …………………………………..**(Senior manager approval for staff time to run the project)**Signed: ………………………………………………………………………………………………………………….... Date: …………………………………..**(Collaborator)**Signed: ………………………………………………………………………………………………………………..….. Date: …………………………………..**(Collaborator)** |