

DATED 1st March 2024

COLLABORATIVE SERVICES AGREEMENT

between

THE DEPARTMENT OF HEALTH AND SOCIAL CARE

And

ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH

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THIS AGREEMENT is dated March 2024

PARTIES

(1) **The Department of Health and Social Care** with headquarters at 39, Victoria Street, London SW1H 0EU ("**DHSC**"); and

(2) **Royal College of Paediatrics and Child Health**, a registered charity at 5-11 Theobald's Road, London WC1X 8SH ("**RCPCH**"),

(together, the "**Parties**").

BACKGROUND

(A) DHSC and RCPCH have been collaborating, together with University College London's Great Ormond Street Institute of Child Health to facilitate epidemiological research into rare paediatric conditions (the "**Project**") via the British Paediatric Surveillance Unit ("**BPSU**").

(B) RCPCH has previously agreed to host the BPSU. DHSC has agreed to provide funding and personnel resource to support the work of the BPSU.

(C) RCPCH will continue to host the BPSU and will provide managerial and professional support on the terms and conditions contained in this agreement (the "**Agreement**").

Agreed terms

1. INTERPRETATION

1.1 The definitions and rules of interpretation in this clause apply in this Agreement.

Applicable Law: all applicable laws, statutes, regulations, codes and government policies relating to the Project and the work carried out under this Agreement.

Arising Intellectual Property: any Intellectual Property arising as a result of the Project.

Background Intellectual Property: any Intellectual Property which is not Arising Intellectual Property.

Contribution: the contributions payable by DHSC for the Project as set out in Schedule 2 in which all amounts will be specified exclusive of any applicable VAT.

Effective Date: 01 March 2024.

Employment Liabilities: means all claims, actions, proceedings, orders, demands, complaints, investigations and any award, compensation, damages, tribunal awards, fine, loss, order, penalty, disbursement, payment made by way of settlement and costs, expenses and legal costs reasonably incurred in connection with a claim or investigation related to employment including in relation to the following:

(a) redundancy payments including contractual or enhanced redundancy costs, termination costs and notice payments;

(b) unfair, wrongful or constructive dismissal compensation;

(c) compensation for discrimination on grounds of sex, race, disability, age, religion or belief, gender reassignment, marriage or civil partnership, pregnancy and maternity or sexual orientation or claims for equal pay;

- (d) compensation for less favourable treatment of part-time workers or fixed term employees;
- (e) outstanding employment debts and unlawful deduction of wages including any PAYE and national insurance contributions;
- (f) employment claims whether in tort, contract or statute or otherwise;
- (g) any investigation relating to employment matters by the Equality and Human Rights Commission or other enforcement, regulatory or supervisory body and of implementing any requirements which may arise from such investigation.

Intellectual Property: any patents, rights to inventions, registered designs, copyright and related rights, database rights, design rights, topography rights, trade marks, service marks, trade names and domain names, trade secrets, rights in unpatented know-how, rights of confidence and any other intellectual or industrial property rights of any nature including all applications (or rights to apply) for, and renewals or extensions of such rights and all similar or equivalent rights or forms of protection which subsist or will subsist now or in the future in any part of the world.

Other Project Collaborators: University College London Great Ormond Street Institute of Child Health and any other parties agreed in writing by the Parties.

DHSC Representative: the representative to be appointed under clause 3.3.

Project: the project in relation to which the Parties and Other Project Collaborators will collaborate in accordance with this Agreement as further described in Schedule 1.

Project Services: the work to be performed by RCPCH under clause 2.1 and as more fully described in Schedule 1.

RCPCH Key Personnel: the employees of RCPCH from time to time to be appointed as a person required to perform a role in respect of the Project Services in accordance with clause 2.

RCPCH Representative: the representative to be appointed under clause 2.7.

1.2 Except where a contrary intention appears, a reference to a clause or schedule is a reference to a clause of, or schedule to this Agreement and a reference in a schedule to a paragraph is to a paragraph of that schedule.

1.3 Clause and schedule headings do not affect the interpretation of this Agreement.

1.4 A reference to a **company** or **organisation** shall include any company, organisation, corporation or other body corporate, wherever and however incorporated or established.

1.5 A reference to a **Party** is to a party to this Agreement.

1.6 A **person** includes a corporate or unincorporated body.

1.7 A reference to a statute or statutory provision:

- (a) is a reference to it as amended, extended or re-enacted from time to time; and
- (b) shall include all subordinate legislation made from time to time under that statute or statutory provision.

2. OBLIGATIONS OF RCPCH

2.1 RCPCH agrees to perform the Project Services with all due skill and care.

2.2 RCPCH shall ensure that it uses employees in performing its obligations under this Agreement who are suitably qualified and experienced.

2.3 The Project Services shall be carried out, and the RCPCH Key Personnel shall be based during the period of this Agreement, at the RCPCH premises or such other place within the United Kingdom as RCPCH may reasonably direct from time to time.

2.4 RCPCH shall at all times:

(a) comply with good industry practice and any Applicable Law in the provision of the Project Services; and

(b) obtain and maintain consents, licences and permissions (statutory, regulatory, contractual or otherwise) that are necessary to enable it to perform the Project Services.

2.5 RCPCH Key Personnel remain employees of RCPCH at all times.

2.7 RCPCH shall appoint the RCPCH Representative, who shall be based at RCPCH premises and who shall be responsible for supervising the performance of RCPCH's obligations pursuant to this Agreement.

2.8 RCPCH shall inform DHSC immediately in writing in the event that any RCPCH Key Personnel ceases to be employed by RCPCH, and use its best endeavours to seek a replacement.

2.9 RCPCH shall inform DHSC of the identity of any replacement RCPCH Key Personnel as soon as a suitable replacement has been identified. DHSC shall be entitled to object to any proposed replacement within 7 calendar days of being informed of any such replacement if, in its reasonable opinion, it considers the proposed replacement to be unsuitable.

2.10 RCPCH shall ensure that the RCPCH Key Personnel is suitable and willing to carry out the obligations set out in Schedule 1, and shall ensure that RCPCH Key Personnel and the RCPCH Representative perform their obligations with all due care and diligence, in a professional and ethical manner and in accordance with guidelines agreed from time to time between the Parties.

3. OBLIGATIONS OF DHSC

3.1 In consideration of the Project Services provided by RCPCH under this Agreement, DHSC shall pay to RCPCH the Contribution in accordance with Schedule 2.

3.2 All payments made under clause 3.1 shall be to an account notified in writing by RCPCH to DHSC.

3.3 DHSC shall appoint the DHSC Representative, who shall be RCPCH's first point of contact in respect of the Project Services. DHSC shall notify RCPCH and the RCPCH Representative of the contact details of the DHSC Representative and shall keep RCPCH informed of any changes to the DHSC Representative.

3.4 DHSC shall at all times comply with any Applicable Law in respect of this Agreement and the provision of the Project Services by RCPCH.

4. INFORMATION FLOW

4.1 To enable the Parties to maximise the benefits of their collaboration, each Party shall:

(a) engage the other in planning discussions in relation to the Project from time to time;

(b) keep the other Party informed about its own progress in relation to the Project; and

(c) facilitate regular discussions between appropriate members of its personnel and those of the other Party in relation to the Project, including in relation to:

- (i) performance and issues of concern in relation to the Project;
- (ii) new developments and resource requirements;
- (iii) compliance with deadlines; and
- (iv) such other matters as may be agreed between the Parties from time to time.

4.2 Each Party shall:

(a) supply to the other Party information and assistance reasonably requested by it relating to the Project as is necessary to enable that other Party to perform its own obligations in relation to the Project; and

(b) review documentation, including draft specifications or service descriptions or other technical documentation, for use when performing its obligations in relation to a Project (if any), as soon as reasonably practicable at the request of the other Party, and notify it of any errors or incorrect assumptions made in any such documents so far as it is aware.

5. INTELLECTUAL PROPERTY

5.1 This Agreement does not affect the ownership of any Background Intellectual Property belonging to either Party. No licence to use any Intellectual Property is granted or implied by this Agreement except the rights expressly granted in this Agreement.

5.2 DHSC grants RCPCH a royalty-free, non-exclusive licence to use its Background Intellectual Property for the purpose of carrying out the Project, but for no other purpose. RCPCH may only grant a sub-licence to Other Project Collaborators to use the Background Intellectual Property of DHSC for the purpose of carrying out the Project.

5.3 RCPCH grants DHSC a royalty-free, non-exclusive licence to use its Background Intellectual Property for the purpose of carrying out the Project, but for no other purpose. DHSC may only grant a sub-licence to Other Project Collaborators to use the Background Intellectual Property of RCPCH or the purpose of carrying out the Project.

5.4 RCPCH will own all Arising Intellectual Property and may take such steps as it may decide from time to time, and at its own expense, to register and maintain any protection for such Intellectual Property, including filing and prosecuting patent applications. DHSC will promptly notify RCPCH after identifying any Arising Intellectual Property and provide RCPCH with all relevant information of such Arising Intellectual Property.

5.5 RCPCH grants DHSC a royalty-free, fully paid up, perpetual non-exclusive licence to use the Arising Intellectual Property and its Background Intellectual Property for the purpose of using or re-using the outputs of the Project.

6. CONFIDENTIALITY AND NON-DISCLOSURE

6.1 “**Confidential Information**” means all confidential information (however recorded or preserved) disclosed by a Party or its employees, officers, representatives, advisers or Other Project Collaborators (together its “**Representatives**”) to the other Party and that Party's Representatives in connection with the Project, including information which:

- (a) relates to the terms of this Agreement;
- (b) would be regarded as confidential by a reasonable business person, relating to:
 - (i) the business, assets, affairs, customers, clients, suppliers, or plans of the disclosing Party; and
 - (ii) the operations, processes, product information, know-how, designs, trade secrets or software of the disclosing Party; and
- (c) is developed by the Parties in the course of carrying out this Agreement and the Project.

6.2 The provisions of this clause shall not apply to any Confidential Information that:

- (a) is or becomes generally available to the public (other than as a result of its disclosure by the receiving Party or its Representatives in breach of this clause); or
- (b) was available to the receiving Party on a non-confidential basis before disclosure by the disclosing Party; or
- (c) was, is or becomes available to the receiving Party on a nonconfidential basis from a person who, to the receiving Party's knowledge, is not bound by a confidentiality agreement with the disclosing Party or otherwise prohibited from disclosing the information to the receiving Party; or
- (d) the Parties agree in writing is not confidential or may be disclosed.

6.3 Each Party shall keep the other Party's Confidential Information confidential and shall not: (a) use such Confidential Information except for the purpose of exercising or performing its rights and obligations under this Agreement in relation to the Project ("**Permitted Purpose**"); or (b) disclose such Confidential Information in whole or in part to any third party, except as expressly permitted by this clause.

6.4 A Party may disclose the other Party's Confidential Information to those of its Representatives who need to know such Confidential Information for the Permitted Purpose, provided that:

- (a) it informs such Representatives of the confidential nature of the Confidential Information before disclosure; and
 - (b) it procures that its Representatives shall, in relation to any Confidential Information disclosed to them, comply with the obligations set out in this clause as if they were a party to this Agreement,
- and at all times, it is liable for the failure of any Representatives to comply with the obligations set out in this clause.

6.5 A Party may disclose Confidential Information to the extent such Confidential Information is required to be disclosed by law, by any governmental or other regulatory authority and under the Freedom of Information Act 2000 ("**FOIA**") and both the respective Codes of Practice on the Discharge of Public Authorities Functions and on the Management of Records (which are issued under sections 45 and 46 of the FOIA respectively) or by a court or other authority of competent jurisdiction provided that, to the extent it is legally permitted to do so, it gives the other Party as much notice of such disclosure as possible and, where notice of disclosure is not prohibited and is given in accordance with this clause 6.5, it takes into account the reasonable requests of the other Party in relation to the content of such disclosure.

6.6 Each Party reserves all rights in its Confidential Information. No rights or obligations in respect of a Party's Confidential Information other than those expressly stated in this Agreement are granted to the other Party, or to be implied from this Agreement.

6.7 On termination of this Agreement, unless such things are needed by it to perform its obligations under the Project (and only until the end of such time), each Party shall:

- (a) return to the other Party all documents and materials (and any copies) containing, reflecting, incorporating or based on the other Party's Confidential Information;
- (b) erase all the other Party's Confidential Information from computer and communications systems and devices used by it, including such systems and data storage services provided by third parties (to the extent technically practicable); and
- (c) certify in writing to the other Party that it has complied with the requirements of this clause, provided that a recipient Party may retain documents and materials containing, reflecting, incorporating or based on the other Party's Confidential Information to the extent required by law or any applicable governmental or regulatory authority. The provisions of this clause shall continue to apply to any such documents and materials retained by a recipient Party.

6.8 Except as expressly stated in this Agreement, no Party makes any express or implied warranty or representation concerning its Confidential Information.

6.9 The provisions of clauses 6.1 to 6.8 shall survive for a period of ten (10) years from termination of this Agreement.

7. EMPLOYEES AND NON-SOLICITATION

7.1 DHSC shall not (except with the prior written consent of RCPCH) directly or indirectly solicit or entice away (or attempt to solicit or entice away) from the employment of RCPCH any RCPCH Key Personnel or any other person involved in the Project during the period of this Agreement or for a further period of 12 months from the date of this Agreement's expiry.

8. INFORMATION GOVERNANCE

8.1 The Parties acknowledge their respective duties under the General Data Protection Regulation (Regulation (EU) 2016/679), the Data Protection Act 2018 and the Freedom of Information Act 2000 (the "**Data Protection and Disclosure Legislation**") and hereby confirm they will comply fully with the Data Protection and Disclosure Legislation and shall give all reasonable assistance to each other where appropriate or necessary to comply with any obligations arising under the Data Protection and Disclosure Legislation.

9. ANNOUNCEMENTS

9.1 Subject to clause 9.2, neither Party shall make, or permit any person to make, any public announcement, communication or circular ("**Announcement**") concerning this Agreement without the prior written consent of the other Party (such consent not to be unreasonably withheld or delayed).

9.2 Where an Announcement is required by law or any governmental or regulatory authority (including, without limitation, any relevant securities exchange), or by any court or other authority of competent jurisdiction, the Party required to make the Announcement shall promptly notify the other Party. The Party concerned shall make all reasonable attempts to agree the contents of the Announcement before making it.

10. ANTI-BRIBERY

10.1 Each Party shall in relation to this Agreement and the Project:

- (a) comply with all applicable laws, statutes, regulations, and codes relating to anti-bribery and anti-corruption including but not limited to the Bribery Act 2010 ("Relevant Requirements");
- (b) not engage in any activity, practice or conduct which would constitute an offence under sections 1, 2 or 6 of the Bribery Act 2010 if such activity, practice or conduct had been carried out in the UK;
- (c) comply with the other Party's Ethics, Anti-bribery and Anti-corruption policies in each case as that party or the relevant industry body may update them from time to time ("Relevant Policies");
- (d) have and shall maintain in place throughout the term of this Agreement its own policies and procedures, including adequate procedures under the Bribery Act 2010, to ensure compliance with the Relevant Requirements, the Relevant Policies and clause 10.1(b), and will enforce them where appropriate;
- (e) promptly report to the other Party any request or demand for any undue financial or other advantage of any kind received by it in connection with the performance of this Agreement;
- (f) within six (6) months of the Commencement Date, and annually thereafter, certify to the other Party in writing signed by one of its officers, compliance with this clause 10 by it and all persons associated with it under clause 10.2. Each Party shall provide such supporting evidence of compliance as the other Party may reasonably request.

10.2 Each Party shall ensure that any person associated with it who is performing obligations in connection with this Agreement does so only on the basis of a written contract which imposes on and secures from such person terms equivalent to those imposed on that party in this clause 10. Such Party shall be responsible for the observance and performance by such persons of the Relevant Terms, and shall be directly liable to the other Party for any breach by such persons of any of the Relevant Terms.

10.3 Breach of this clause 10 shall be deemed a material breach under clause 13.4.

10.4 For the purpose of this clause 10, the meaning of adequate procedures and foreign public official and whether a person is associated with another person shall be determined in accordance with section 7(2) of the Bribery Act 2010 (and any guidance issued under section 9 of that Act), sections 6(5) and 6(6) of that Act and section 8 of that Act respectively. For the purposes of this clause 10, a person associated with a party includes but is not limited to any subcontractor of that party.

11. WARRANTIES

11.1 Each Party warrants that it has full power and authority to carry out the actions contemplated under this Agreement.

11.2 Except as expressly provided in this Agreement, there are no conditions, warranties or other terms binding on the Parties with respect to the actions contemplated by this Agreement. Any condition, warranty or other term in this regard that might otherwise be implied or incorporated into this Agreement, whether by statute, common law or otherwise, is, to the extent that it is lawful to do so, excluded by this Agreement.

12. LIABILITY

12.1 Nothing in this Agreement limits or excludes a Party's liability for:

- (a) death or personal injury;
- (b) any fraud or for any sort of liability that, by law, cannot be limited or excluded; or
- (c) any loss or damage caused by a deliberate breach of this Agreement.

12.2 Subject to the foregoing provision and except for clause 13.6, the aggregate liability of either Party to the other for all and any breaches of this Agreement, any negligence or arising in any other way out of the subject matter of this Agreement will not exceed an amount equivalent to the Contributions paid or payable under this Agreement.

13. TERM AND TERMINATION

13.1 This Agreement shall commence on the Effective Date and, subject to clause 13.4, shall continue until 31 March 2025 (the **"Initial Term"**).

13.2 RCPCH and DHSC may agree in writing not less than 3 months prior to expiry of the Initial Term to extend this Agreement for a further 12 month period commencing from 1 April 2025 (the **"First Extended Term"**) and any revision to the Contributions.

13.3 RCPCH and DHSC may agree in writing not less than 3 months prior to expiry of the First Extended Term to extend this Agreement for a further 12 month period commencing from 1 April 2026 (the **"Second Extended Term"**) and any revision to the Contributions.

13.4 Either RCPCH or DHSC may terminate this Agreement immediately by written notice to the other if the other Party commits a material breach of this Agreement which (in the case of a breach capable of a remedy) it does not remedy or procure remedy within 30 days of receiving written notice of the breach.

13.5 On termination or expiry of this Agreement, unless such things are needed by it to perform its obligations under the Project, each Party shall immediately:

- (a) return or destroy (as directed in writing by the other Party) any documents, handbooks, or other information or data provided to it by the other Party for the purposes of this Agreement. If reasonably required by the other Party, it shall provide written evidence (in the form of a letter signed by it no later than thirty (30) days after termination of this Agreement) that these have been destroyed and that it has not retained any copies of them; and
- (b) return all of the other Party's equipment and materials, failing which, the other Party may enter the relevant premises and take possession of them. Until these are returned or repossessed, that Party shall be solely responsible for their safe-keeping.

13.6 RCPCH shall be liable for and indemnify and keep indemnified DHSC against any Employment Liabilities in connection with the RCPCH Key Personnel arising from or as a consequence of:

- (a) the expiry or termination of this Agreement other than for termination for material breach of this Agreement by DHSC under clause 13.4, or
- (b) any act or omission of RCPCH, their agents or employees.

13.7 On termination of this Agreement for material breach by RCPCH under clause 13.4:

(a) DHSC shall not be liable for any Contributions in relation to the period following the termination date; and

(b) RCPCH shall reimburse on a pro rata basis DHSC any such Contributions paid in relation to the period following the termination date.

13.8 Termination shall be without prejudice to the accrued rights of the Parties at the termination date. For the avoidance of doubt, the obligations set out in clauses 2 and 3 shall survive termination of this Agreement, however arising.

14. FORCE MAJEURE

14.1 A Party shall not be liable for any delay in performing or for failure to perform its obligations under this Agreement if the delay or failure results from any cause or circumstance beyond its reasonable control, including any breach or non-performance of this Agreement by the other Party ("**Force Majeure Event**"), provided that the same arises without the fault or negligence of such Party.

14.2 If a Force Majeure Event occurs, the date(s) for performance of the obligation affected shall be postponed for as long as is made necessary by the Force Majeure Event, but if such Force Majeure Event continues for a period of or exceeding three months, the Party not affected in its performance may terminate this Agreement immediately by written notice to the other Party.

14.3 The Parties shall use their reasonable endeavours to minimise the effects of any Force Majeure Event.

15. ASSIGNMENT AND SUB-CONTRACTING

15.1 DHSC may not, without the prior written consent of RCPCH, assign, sub-license, sub-contract, transfer or charge this Agreement or any part of it.

15.2 RCPCH may not, without the prior written consent of DHSC, assign, sub-license, sub-contract, transfer or charge this Agreement or any part of it.

16. RELATIONSHIP OF THE PARTIES

16.1 The relationship between the Parties is that of independent contractors dealing at arm's length and nothing in this Agreement shall be construed so as to constitute RCPCH as an agent or employee of DHSC, and RCPCH is not authorised to represent DHSC as such.

17. NOTICES

17.1 Any notice required to be given under this Agreement may be delivered personally or sent by prepaid post or courier or as an email attachment to the other Party at the address given at the beginning of this Agreement, or such other address as may be notified in accordance with this clause 17 from time to time.

17.2 Any notice so sent shall be deemed to have been duly given:

(a) if sent by personal delivery or courier, upon delivery at the address of the relevant Party;

(b) if sent by prepaid post, four days after the date of posting;

(c) if sent as an email attachment upon receipt of read receipt or delivery receipt provided that a copy of such notice is then sent to the recipient by personal delivery, courier or prepaid post.

18. VARIATION

Any variation of or amendment to this Agreement shall only be effective if it is in writing and signed by both Parties.

19. WAIVER

Failure of RCPCH or DHSC to enforce or exercise, at any time or for any period, any term of this Agreement, does not constitute, and shall not be construed as, a waiver of such term and shall not affect any future right to enforce such term or any other term in this Agreement.

20. DISPUTE RESOLUTION

20.1 Where there is a dispute or claim arising out of or in connection with this Agreement (including any non-contractual disputes or claims) (a “**Dispute**”) the Parties shall first attempt to settle it by negotiation between the DHSC Representative and the RCPCH Representative.

20.2 Where the representatives fail to resolve the Dispute within five days of the Dispute arising, the representatives shall escalate the Dispute to a senior person within their respective organisations.

20.3 Within five days of receipt the senior person of each organisation shall meet to seek to resolve the Dispute.

20.4 Where the senior person in each organisation is unable to resolve the Dispute directors or other senior representatives of the Parties with authority to settle the Dispute will, within fourteen days of a written request from either the RCPCH Representative to the DHSC Representative or from the DHSC Representative to the RCPCH Representative, meet in a good faith effort to resolve the Dispute.

20.5 If the Dispute is not resolved at that meeting, the Parties will attempt to settle it by mediation in accordance with the Centre for Effective Dispute Resolution (“**CEDR**”) Model Mediation Procedure. Unless otherwise agreed between the RCPCH Representative and the DHSC Representative, the mediator will be nominated by CEDR. To initiate the mediation a Party must give notice in writing (the “**ADR notice**”) to the other Party requesting mediation. The mediation will start not later than 28 days after the date of the ADR notice.

20.6 A Party may not commence any court proceedings in relation to a Dispute until it has attempted to settle the Dispute by mediation in accordance with clause 14 20.5 and either the mediation has terminated or the other Party has failed to participate in the mediation, provided that the right to issue proceedings is not prejudiced by a delay.

21. SEVERANCE

The invalidity or unenforceability of any term of or any right arising pursuant to this Agreement shall not adversely affect the validity or enforceability of the remaining terms and rights.

22. ENTIRE AGREEMENT

This Agreement constitutes the entire agreement and understanding between the Parties with respect to the subject matter of this Agreement and supersedes any prior agreement, understanding or arrangement between the Parties, whether oral or in writing. No representation, undertaking or promise shall be taken to have been given or be implied from anything said or written in negotiations between the Parties prior to this Agreement except as expressly stated in this Agreement. No Party shall have any remedy in respect of any untrue statement made to it on which

it has relied in entering into this Agreement (unless such untrue statement was made fraudulently) and that Party's only remedy shall be for breach of contract as provided in this Agreement.

23. SURVIVAL

Provisions of this Agreement which are either expressed to survive its termination or, from their nature or context, are apparently intended to survive such termination shall remain in full force and effect notwithstanding termination.

24. RIGHTS OF THIRD PARTIES

24.1 No term of this Agreement shall be enforceable under the Contracts (Rights of Third Parties) Act 1999 by a third party, but this does not affect any right or remedy of a third party which exists or is available apart from under that Act.

24.2 Notwithstanding that any term of this Agreement may be or become enforceable by a person who is not a Party to it, the terms of this Agreement or any of them may be varied, amended or modified or this Agreement may be suspended, cancelled or terminated by agreement in writing in accordance the terms of this Agreement or this Agreement may be rescinded (in each case) without the consent of any such third party.

25. GOVERNING LAW AND JURISDICTION

25.1 This Agreement and any Dispute shall be governed by, and construed in accordance with, the law of England and Wales.

25.2 The Parties irrevocably agree that the courts of England and Wales shall have exclusive jurisdiction to settle any Dispute.

This Agreement has been entered into on the date stated at the beginning of it.

Schedule 1 Project Description

1. The British Paediatric Surveillance Unit ("BPSU") facilitates epidemiological research into rare paediatric conditions and diseases. Research teams behind BPSU studies often consist of Paediatricians, paediatric trainees or research teams based at the UKHSA. It uses active disease surveillance methodology via the electronic mailing of a monthly report card to clinicians signed up to the BPSU reporting scheme. Reporting clinicians are asked that they then complete a questionnaire to gather more information. The BPSU has demonstrated that it can react speedily to public health emergencies with the most recent instance with the study of Acute Hepatitis. The methodology is unique, it allows many studies (up to 12) to be run at any one time. The BPSU alongside with its existing reporting system is collecting data through a new data collection platform complete with a data safe haven for analysis for research teams.

2. The funding from the DHSC will contribute to the overall BPSU funding which contributes to:

- the salary costs (2WTE staff) and running costs of the BPSU, as well as agreed remuneration for any Public and patient representatives on the BPSU Scientific committee(SC) and reimbursement of SC members of BPSU related work;
- the production of an annual report and other agreed reports to disseminate findings; and
- public patient engagement.

3. The Parties and University College London's Great Ormond Street Institute of Child Health "UCLGORICH") have a shared interest in the outputs of the BPSU.

4. The key objectives of the Project are to:

- Survey rare paediatric conditions across the UK and ROI;
- Offer a methodology to allow the rapid response to public health emergencies;
- Increase awareness amongst clinicians and public of rare diseases;
- Through information dissemination, allow for paediatricians to have a better understanding of how best to diagnose and treat such conditions.

Government bodies and other agencies such as the Joint Committee on Vaccination and Immunisation ("JCVI") use evidence gathered by the BPSU to inform on responses to public health issues. BPSU can monitor public health interventions e.g. effectiveness of immunisation programmes; advise and measure the impact of changes in national screening policies e.g. HIV; congenital syphilis and allow for a rapid response following the emergence of new disease e.g. congenital Zika syndrome and variant CJD. Impact can be measured by how the evidence gathered is used e.g. 17 changing of vaccination regimen i.e. Hib; identification of sources of outbreaks i.e. E. coli 0157.

5. The BPSU is recognised as a tripartite activity supported by DHSC, UCLGOSICH and RCPCH. A governance board for the BPSU meets twice a year and proposed work for the forthcoming year is provided to both The Office for the Health Improvement and Disparities in DHSC and the National Infection Service in the UK Health Security Agency (UKHSA) for input. The board consists of representatives of each of the partners and the chair of the BPSU SC. The board assesses the BPSU's impact and gives strategic guidance to SC. The SC meets 6 times a year and has a membership of clinicians, lay; medical advisers (trainees from UCLGOSICH and DHSC). The SC priority is to review applications; help guide and develop successful applicants; make sure the workplan is being delivered and targets are being met. DHSC (and UKHSA) have a full level of engagement at both board and SC level.

6. Applications that arise from DHSC or any other of the partners are reviewed in the same way as any other application: via the independent BPSU SC. Any activity that exceeds the core remit of the BPSU and requires additional procurement activity will need to be openly put to market to ensure no perceived bias. The aims of the BPSU as described above are shared by all the collaborators. Not only does the BPSU contribute evidence to inform on public health policy but its data also informs on patient management and service delivery. All the partners benefit from the aim of increase research capacity within the NHS; through the training of medical advisors for DHSC (and UKHSA) and through the bursaries to junior doctors.

7. RCPCH will seek to deliver the following outputs:

- 3 new studies approved to start each year
- Regular e-bulletins – up to 3 a year
- 1 annual report per year
- 1 Public patient engagement event a year
- 1 Scientific meeting/workshop over period of current grant

- Development of a web-based case notification and data collection portal

Schedule 2 Contributions

The total Contributions payable to RCPCH for the Initial Term are [REDACTED]. RCPCH shall invoice DHSC the Contributions for the Initial Term as follows:

- [REDACTED]
- [REDACTED]

Signed for and on behalf of THE DEPARTMENT OF HEALTH AND SOCIAL CARE (public health)

Signature:

[REDACTED]

Name: [REDACTED]

Position: [REDACTED]

Date: 30/01/2024

Signed by for and on behalf of ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH

Signature:

[REDACTED]

Name: [REDACTED]

Position: [REDACTED]

Date: 01/03/2024

Signed for and on behalf of THE DEPARTMENT OF HEALTH AND SOCIAL CARE (commercial)

Signature: [REDACTED]

Name: [REDACTED]

Position: [REDACTED]

Date: 01/03/2024