

**DRAFT Terms of Reference – VIVALDI Social Care Stakeholder Oversight & Governance Group
(SOGG)**

1. Context	
Background to the study	<p>University College London (UCL), Care England and The Outstanding Society (OS) have established a new partnership with the aim to reduce the impact of infections and outbreaks in care homes. Together with care home staff, residents, family members and providers we have coproduced a plan for a 12 month pilot study which will start in October 2023. The study will use data that are routinely collected by the NHS and public health agencies to measure levels of common infections in care home residents, and will generate an anonymised database that can be used for research. Importantly we are not seeking individual-level consent from residents for participation, but they can opt out of sharing their data. This approach has been approved by the Health Research Authority Confidentiality Advisory Group (HRA CAG). Coproduction of the study highlighted that it is essential for the care sector to retain control over how the data can be used, and that we must prioritise outputs that address the priorities of people who live and work in care homes.</p>
2. Purpose of the Stakeholder Oversight and Governance Group (SOGG)	
Outline of scope of ToRs	The purpose of this document is to describe the membership, roles, responsibilities, authority, decision-making and relationships of the SOGG, including the timing, methods of providing information to and from the SOGG, frequency and format of meetings, and relationships with other committees.
Name of Group	Stakeholder Oversight and Governance Group (SOGG)
Oversight Group/ Committee	Sponsor, Funder
3. Roles and responsibilities	
Responsibilities of the SOGG	<p>To oversee use of data collected in the study, to ensure outputs are acceptable to care home residents, relatives, care home staff and care providers, and to maximise the value of the study for residents.</p> <p>The role of the SOGG is to provide oversee the use of data collected in the study and to provide advice to the Chief Investigator (CI), the Sponsor, Funder, and host institution on all aspects of data use. The key functions include:</p> <ul style="list-style-type: none"> • Agreeing c.10 infection measures that will be used for reporting, and their granularity (e.g. care home level data, provider level data, regional data etc.)

	<ul style="list-style-type: none"> • Agreeing which organisations will have access to these data, what can be made publicly available, and how often the measures will be produced • Monitoring feedback from care homes including whether any concerns have been raised about the use of data in the study and benefits of study participation.
Committee facilitators	Borscha Azmi, Project Manager
Other Committees or Groups	Data Access Committee (DAC) - reviews application for use of the research database Project Steering Committee (oversees project delivery on behalf of the Funder, UKHSA)
4. Before or early in the study	
SOG Agreement	SOGG members will not sign a contract but should formally register their agreement to join the group by confirming by email to the study project manager (1) that they agree to be a member of the SOGG and (2) that they agree with the contents of these Terms of Reference. Any potential competing interests should be declared at the same time.
4. Composition	
Tenure	The anticipated tenure for independent SOGG members will be the length of the study.
Membership	Members of the group are listed in Table 2 and will include care home residents and/or relatives, care home staff and/or managers, care providers, care sector representative organisations, and an academic / statistician who can provide advice on statistical disclosure controls
5. Group Interactions	
Frequency of SOGG meetings	The SOGG will meet virtually every 3-4 months. Additional meetings, in person or by teleconference, may be organised at the request of the SOGG or the study Chief Investigator. Some study issues may need to be dealt with between meetings, by email. SOGG members should be prepared for such instances.
Format of the meetings	The Project Manager will make every effort to identify a date that enables all members to attend. In order for the SOGG to meet, there must be at least 2 residents or relatives, 2 members of care home staff / managers, 2 care providers, and an academic and/or statistician who can provide advice on statistical disclosure controls, including the Chair. If the SOGG cannot agree, a further teleconference should be arranged with the full SOGG present.

SOGG organisation, attendance and decision making process	<p>Attendance will usually be limited to the members of the SOGG and the study team. Other observers will be at the discretion of the SOGG. The Chair's permission will be required for observers to attend all or part of the meetings.</p> <p>A short progress update on the study will be provided by the research team at the start of each meeting.</p>
6. Trial documentation and procedures to ensure effective communication	
Material to be considered during meetings	A short progress report will be prepared by the study team for the SOGG which will include details for proposed 'infection metrics'. The report will also include any feedback on data use or other elements of the study that has been received directly from care homes or via the VIVALDI social care engagement and communication group.
Reporting timelines	The SOGG should receive the report at least 1 week before any meetings.
7. Decision making	
Decisions or recommendations by the SOGG	Every effort should be made to achieve consensus. The role of the Chair is to summarise discussions and encourage consensus; therefore, it is usually best for the Chair to give their own opinion last. The Chair may however have the casting decision if the SOGG reach an impasse.
Constitution of a quorate for decision-making	At least two care home residents or relatives, 2 members of staff / care home managers and two providers should be present including the Chair, plus the study Chief Investigator and an academic / statistician
9. Reporting	
Reporting pathways	The SOGG will report their decisions to the study Chief Investigator and to the Project Oversight Committee. Minutes should be provided via the Project Manager, usually within 2 weeks of the meeting.
Minutes and actions	In the event of the SOGG having significant concerns regarding the project and data use this should be brought to the attention of the sponsor, project oversight committee and funder so that a meeting can be arranged between the relevant parties.

Table 2. Membership: Members will be asked to attend the meetings outlined below; future members may be invited where deemed appropriate. We aim to include representatives from the following groups:

Name	Role	Organisation
Laura Shallcross	Project Lead	UCL
Zoe Fry	Director	The OS
Mike Slator	Project Support Specialist	The OS
Russell Wynn	Senior Data Protection Officer	HC-1
Louis Holmes	Policy Manager	Care England
Charlotte Lezard	Policy and Public Affairs Officer	Care England
Diane Mayhew	Relative	Care Rights UK
Kate Meacock	Relative	Care Rights UK
Harriet (as above)	Healthwatch	Healthwatch
Katie Thorn	Digital Social Care	Digital Social Care
TBC		National Care Forum
Gareth Patefield	Project lead at UKHSA	UKHSA
Aileen Schissler	Information governance lead	NHSE
Daniel Hollingworth	Product Owner	Nourish
Andrew Coles	Chief Product Officer (CPO)	PCS
Tandeep Gill	Head of Business Development	PainChek
Drew Hunt	Senior Marketing Officer	PainChek
Saurabh Shah	Head of Care Services	Camascope
Nicola Turner	Relative	
Chris Carrigan	Data Advisor	Use MY Data
Liz Whyte	Provider	HC1
Samantha Crawley	Chief Executive Officer, Bracebridge Care Group Director	Bracebridge Care Group The Outstanding Society CIC
Eddy McDowall	Member Chief Executive	Care Provider Alliance Oxfordshire Association of Care Providers
Statistician / academic	Oliver Stirrup / Andrew Copas	UCL
Louise Keane	Nurse Education Lead & Social care Advisory council lead for NCL ICB	North Central London training Hub
Naomi Bhundia	Relative	Care Rights UK
Debbie Smith	Provider	Risedale
Francesco Santino Palma	Relative (Younger sister with a rare diagnosis of dementia living in residential care)	Use my Data
Ceri Steele	Relative (x2 parents in a care home)	Use my Data