

## RE-STAR YOUTH RESEARCHER PANEL (Y-RP)

### Duty of Care Protocol for Senior Members (18+)

Aim of document: to protect the rights, safety, dignity and well-being of Youth Researcher Panel members (the *Panel*) during their time on the project.

#### Duty of Care issues and actions

##### 1. Working with autistic young adults with a diagnosis of autism and ADHD

- All *Panel* members will have had a diagnosis of autism or ADHD at some time in their lives.
- The research team are experienced in working with individuals with autism and ADHD, and understand the issues involved.
- The research team will be mindful of the individual needs of *Panel* members. Before joining the *Panel*, the *Panel* hosts (SB and LL) will speak with each of them individually to find out which aspects they would like to be involved in, how capable they feel in fulfilling the various roles, and check that they are mentally/physically well enough to participate in *Panel* activities.

##### 2. Panel members should not feel coerced into becoming involved, and should feel they can stop being involved at any time

- The research team will ensure *Panel* members know that their involvement is voluntary and that they can stop being involved at any time. This will be made clear in *Panel* information sheets, and one-to-one conversations with individual *Panel* members.

##### 3. Ensuring *Panel* members understand what participating will involve

- Prior to joining the *Panel*, potential members will be sent an Information Sheet detailing the various roles and activities of the *Panel*.
- This will be followed by a one-to-one conversation with the Panel host (SB), during which they will have the opportunity to ask questions.
- *Panel* members will be provided with agendas and topics guides in advance of *Panel* meetings.
- To reduce anxiety around participation, the *Panel* host will be sure to set expectations and ground rules for the session (including confidentiality issues see item 9), providing clear explanations for these.
- The *Panel* host will provide opportunities for members to ask questions (both at the outset of joining, and prior to individual sessions).
- The first *Panel* meeting will include a discussion on how *Panel* member's views and ideas will feed into the research. This will be done in such a way that expectations are managed with realism and compassion.

##### 4. Ensuring Panel members can ask for help (or to take a break) during sessions

- The team will discuss how requests for help/breaks etc will be communicated with each individual member in advance of the sessions. For some this may be via a gesture, for

others a verbal statement, or for online sessions via a typed message or use of the 'raised hand' function.

#### **5. Reducing and recognising distress within sessions**

- The safety and wellbeing of *Panel* members will be paramount at all times.
- During the one-to-one conversations at the outset we will seek to identify individuals' triggers and signs of distress.
- *Panel* members will not be asked to get involved in any activities/topics they are not comfortable. At the start of sessions, the *Panel* host will warn members if any of the issues to be discussed are potentially distressing. Members will have an opportunity to opt out of/ask for help/take a break from sessions they find distressing. The Chair/research team will be responsive to this in the ways set out below.

#### **6. Considering emotional support that might need to be offered to *Panel* members**

- If a *Panel* member finds a situation distressing, the team will offer appropriate emotional support. This will be highly individualised.
- While we anticipate most issues of distress could be dealt with by a conversation afterwards, a full range of responses will be available. This will include (but are not limited to) offering an opportunity to discuss what has arisen after the meeting/session; signposting to appropriate sources of help (eg web support and phone lines); alerting their care professionals (with the *Panel* member's consent); alerting emergency services (in the event of an acute crisis).

#### **7. Checking in if a *Panel* member does not attend a session/meeting**

- If a *Panel* member fails to show up for a session/meeting, a researcher will follow-up with phone call/email/text (whichever is *Panel* member's preferred method of contact).
- If we still do not manage to make contact with the *Panel* member, we will try to contact them via the additional/emergency contact details given to us at the outset.

#### **8. Reimbursement of time**

- Panel members will be reimbursed for their time spent on RE-STAR activities, in line with [NIHR Involve guidelines](#).
- The following NIHR benchmarks for honorariums will be applied:

£12.50

For involvement in a task or activity such as reading and commenting on an abstract which equates to less than half an hour. For example, reviewing papers for the development of Alerts.

£25

For involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less. For example, participating in a focus group to provide feedback on a proposal.

£50

For involvement in a task or activity likely to require some preparation and which equates to approximately two hours of activity. For example, a teleconference with related papers to read or review a few short documents.

£75

For involvement in a task or activity where preparation is required and which equates to approximately half a day's activity. For example, participating in a meeting to interview a small number of candidates who have applied to join a committee or panel, participating in a focus group, or delivering training.

£150

For involvement in all-day meetings. For example, attending a committee or panel meeting as an observer prior to becoming an active public member of a committee/panel.

£300

For involvement in all-day meetings that require substantial preparation. For example, when chairing or co-chairing a meeting or when carrying out other discretionary work, which requires additional responsibilities.

#### 9. Dealing with power issues

- The *Panel* will be hosted by a co-investigator (SB) very experienced in this area. Ground rules for each meeting will be explained (see Panel protocol), ensuring that every voice is heard and treated with equal importance.
- The host will encourage individual members of the *Panel* to speak/convey their ideas, ensuring that everyone has an opportunity to speak.

#### 10. Confidentiality and privacy

- Issues of confidentiality and privacy amongst *Panel* members (including gender identity, personal pronoun use) will be made clear in the *Panel's* ground rules.
- *Panel* members will be asked to understand and respect each other's confidentiality, and agree not to discuss, inappropriately, the information shared among members.
- Similarly, researchers will not share this information outside of the research team. The only exclusion to this condition is in the instance of a safeguarding concern.

#### 11. Dealing with disclosures & safeguarding issues

- Researchers to have completed Good Clinical Practice training, safeguarding training and have a current and valid DBS.
- In the event of any safeguarding concern, the researcher will discuss these with ESB/DO at the next available opportunity, immediately in the event of urgent concerns. We will follow the usual clinical protocol, ideally with consent from the young adults. This will include informing various supports and encouraging the young adults to seek help/advice. Where appropriate, we will seek advice from the safeguarding lead in our collaborating partner NHS Trust (SLaM).

Supporting docs:

[SLaM safeguarding adults policy-v3-july-2020](#)

SLaM Lead for Safeguarding in Adults is David Lynch ([David.lynch@slam.nhs.uk](mailto:David.lynch@slam.nhs.uk))

#### 12. Dealing with grievances



- If a Panel member has a grievance with another Y-RP member or an academic team member, this should be raised with *another* member of the RE-STAR team (e.g., SB/LL/SC) and not the member concerned. The Panel member will then have the opportunity to discuss the grievance in confidence and the RE-STAR team member will seek to resolve.

SB = Sylvan Baker

LL = Lauren Low

ESB = Edmund Sonuga-Barke

SC = Susie Chandler

DO = Dennis Ougrin

Updated 31-05-23