

Service Users and Carers as Co-Applicants, project team members and co-researchers

NHS RD Forum Service User and
Carer Working Group

Service users and carers as: co-applicants, project team members and co-researchers

- Management and governance implications.
- Understanding the contractual and legal governance issues from both an organisational *and* individual service user perspective?
- Ensuring awareness of responsibilities in these roles and what the implications might be - sponsors, grant holding organisations, members of the research team

Co-applicants

- *“Co-applicants are individuals with responsibility for the day-to-day management and delivery of the project. Collaborators normally provide specific expertise on particular aspects of the project. **Co-applicants are considered part of the project team and are expected to share responsibility for its successful delivery”.***

Project team members:

- Study collaborators are part of the core project management team in the same way as the co-applicant described above.

Co-researchers

- Service user co-researchers may undertake similar or specific roles within the research project.

Potential risks

- Patient confidentiality
- Data protection and information governance
- Principles of GCP (if a CTIMP)
- Record keeping and data integrity
- Reporting of adverse events and incidents
- Understanding standard operating procedures
- Understanding roles and responsibilities
- Consent

Duty of care

For discussion

- Are the roles of SUC different from the rest of the research team?
- Do we as an R & D community understand the implications of SUC as co-applicants, project team members, co-researchers?
- How do we enable all members of a research team, including sponsors, to have sufficient knowledge and expertise?

Contracts

- What do the different sorts of agreement look like for SUC project team members or co-researchers and what are the risks and benefits of each one?
- Should agreements be in the form of a personal honorary contract clear the specific roles and responsibilities
- Should this be more of a collaboration agreement? If the latter how would the indemnity cover for the SUC be provided?
- What are the pros and cons of each scenario and what are the real risks involved?

Liabilities

- What are the liabilities and personal risks for an individual who conducts roles and responsibilities on a project for a grant, with and without an agreement in place with the Sponsor and/or grant holding body?
- What are the liabilities for a Sponsor/grant holding body conducting a study without written agreement with individuals undertaking activities?
- How do the different sorts of agreements mitigate this risk?

Grant funding

- Do grant funders consider service users and carers as potential grant holders and incorporate this into their award literature?
- Is it possible to establish whether any funders are still willing to award funding to individuals who are not based within an institution?
- If a host institution holds a grant award for or with a SUC lead but is not be the Sponsor, what should the agreement between the host and the SUC co-applicant look like?

IP and publication rights

- Are Service User and Carer research leads being considered equally for IP & publication rights?
- Do the different contracting arrangements make any difference to this in anyway?

Next steps

- Further consultation
- Complete position paper
- Work with other stakeholders

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