

Supplementary Terms of Reference

Participant Data Sharing Group

Remit of the proposed working group

To facilitate the implementation of data sharing good practice across the UKCRC registered CTU network, to provide advice and support to CTUs about data sharing, and to liaise with external organisations regarding data sharing.

Aim

To help every UKCRC registered CTU implement, or develop a plan for implementation of good practices for sharing data from clinical trials.

Members

Member	Organisation
Catrin Tudor Smith (Chair)	Liverpool Trials Collaborative
Roger Stafford	CRUK/UCL CTU
Nicola Howe	Newcastle CTU
Sally Kerry	Barts Pragmatic CTU
Steff Lewis	Edinburgh CTU
Matt Sydes	MRC CTU @ UCL
Kate Fenton	NIHR
Jennifer O'Callaghan	Wellcome Trust
Sharon Kean	Glasgow Clinical Trials Unit
Carrol Gamble	Liverpool Clinical Trials Collaborative
Gill Booth	Leeds Clinical Trials Research Unit
Stuart Douglas	Participant/Patient Representative
Julie Hepburn	Participant/Patient Representative

Proposed activity

The working group would meet approximately 3 times a year by teleconference and communicate in between via e-mail. The proposed outputs would be:

1. Establish a list of data sharing contacts at each of the CTUs and invite them to contribute to the working group and help disseminate information within their CTU.
2. Establish a repository of data sharing policies and procedures from across the CTU network.
3. Establish a forum for CTUs to share experiences and questions regarding data sharing.
4. Investigate the practical costs of data sharing for the CTU network.
5. Develop and disseminate exemplar data sharing policies and procedures that could be implemented at CTUs.
6. Discuss ways in which the CTU network could align its data sharing activities with other initiatives as future external developments are made.

7. Submit application to the MRC HTMR to fund at least one training/dissemination workshop to help CTUs develop appropriate systems for data sharing.

Support required from the CTU Network

The main support required would be to pay for teleconferences and to provide administrative support to organise meetings and liaise with CTUs. Funding to host at least one training/dissemination workshop (activity number 7 above) will be requested from the MRC HTMR. However, the North West Hub for Trials Methodology Research has already confirmed their commitment to fund a workshop if this request is unsuccessful.

References

1. Hopkins C, Sydes M, Murray G, Woolfall K, Clarke M, Williamson P, Tudur Smith C. Clinical trial data sharing and access from publicly-funded Clinical Trials Units' perspectives: an opinion survey. 2015;Submitted
2. Good Practice Principles for Sharing Individual Participant Data from Publicly Funded Clinical Trials. Tudur Smith C, Hopkins C, Sydes M, Woolfall K, Clarke M, Murray G, Williamson P. April 2015.
<http://www.methodologyhubs.mrc.ac.uk/pdf/Datasharingguidance2015.pdf>