**FAQs compiled from researcher teleconferences.**

Participant assessment

* **TICS-m and MOCA- do you administer both of these in person and over the phone?**
	+ The TICS-m and MOCA should both be done at the baseline (in person) assessment and the follow up (either in person or over the phone).
	+ TICS was originally designed as a phone assessment the TICS is done face to face at baseline and the 4-8 week follow up (if possible).
	+ Some of the MOCA e.g. cube and clock can’t be done over the phone but you should try to do the remainder if the patient is willing.
	+ Ignore the Trails on the MOCA to avoid duplicating data.
* **MoCA done by therapist**
	+ If a MoCA has recently been completed by an OT, use this version rather than asking to patient to repeat it.
	+ However if this was completed more than a week before the R4VaD assessment, do ask the patient to repeat it.
* **Change in the MoCA version**
	+ New version of the MoCA 7.2 with a different language section and different verbal fluency letter (S instead of F) should still be used and transferred to the database in the relevant sections rather than making the patient repeat the older version used for R4VaD.
	+ The same should apply if versions such as the blind MoCA are used. Make a note of this in the notes section.
* **Visual and hearing problems**
	+ Guidance on scoring visual problems: ask the patient themselves and then check on their electronic records for any mention of vision problems (e.g. glaucoma, doesn’t include glasses)
	+ Hearing problems and phone follow up: if the patient can’t be seen in person try to do as much as you can over the phone. If hearing problems mean that they cannot do any assessments over the phone, then there is the option to send some of the questions in the post.
	+ There is an option to visit the person at home- that will vary depending on local guidelines.
* **Drawing tasks with patients with weakness in hands**
	+ Encourage patients to attempt to draw the clock and cube even if their dominant hand is badly affected by their stroke.
	+ If they are willing to use their other hand encourage them to do this.
	+ Some patients may not be able to hold a pen or may refuse to use their other hand.
	+ Make a note in the comments section if non dominant hand is used or if drawing tasks aren’t completed because of weakness.
* **Trail Making A&B**
	+ Unclear for people with visual problems- particularly 8 and B which may artificially inflate time taken.

**Action: This has been edited and made clearer.**

* **Zung depression scale**

**What is the best way to approach these questions asking about how the patient feels that day?**

* Certain questions are difficult/awkward for the patient to answer in relation to that day specifically. For example:
	+ *‘Morning is when I feel best’-* may be difficult to ask this question if you are seeing the patient in the morning as they won’t know how they will feel that afternoon.
	+ *‘I find it difficult to make decisions’*- they may not have had to make decisions yet that day.
* In these the cases the patient can be asked in relation to recent thoughts/feelings. i.e. ‘recently have you had difficulty making decisions’ or ‘are you usually a morning person’.
* If the patient replies ‘I am usually a morning person but this morning I feel awful’ or ‘usually I can make decisions but today/this week I haven’t had difficulty’, use the answer that refers to that morning/day.
* *‘I get tired for no reason’*- the patient may feel tired as a result of the testing and this may affect their answer.
	+ This is fine. Their tiredness may be affected by several reasons which you can’t control, such as seeing them in the morning vs afternoon or after a particularly difficult PT session.
	+ Part of this question is to examine whether they are easily tired and this may be as a result of the assessment.
* **Timing of Barthel, Lawton ADL’s and clinical frailty at baseline**
	+ At baseline Barthel and ADL’s refer to functioning before the stroke.
	+ Clinical frailty is assessed at time of assessment.
* **Unknown time of stroke**
	+ If the specific time of stroke is unknown use 12.00.
* **Medications**
	+ Current medication are medications at the time of the assessment.
* **Blood pressure measurements: what to do if you cannot get repeat BP measurements?**
	+ If the patient is in hospital you can use BP measurements from medical records.
	+ Use BP measurements from the past 48 hours.
* **What if patient is not able to sign the consent form?**
	+ Encourage the patient to sign/initial as much as they are able to, even if it isn’t very legible.
	+ If patient is not able to do this then you can use a witness. This should be someone impartial to the research study e.g. nurse/OT who signs somewhere on the consent form with their name etc., to confirm that the patient has consented.
	+ If a witness is used make a file note on the consent form documenting why.
	+ **Action: witness line will be added to the consent form**

**Follow up**

* **Trouble contacting people for follow up**
	+ Try phoning, sending letters/assessment by post. Contact GP to check patient is ok.
* **People can find the baseline assessment very long and are therefore reluctant to come back for follow up.**
	+ Do not try and do too much at baseline if the patient is tiring. Make sure to use the stopping points in the CRF if necessary.
	+ If the patient is reluctant to come back, suggest that the assessment can be as short as 15/20 minutes. During the assessment just do up to the first stopping point on the follow up CRF and get as much information from their medical records as possible.
* **Postal/phone follow up**
	+ Face-to-face or phone assessments are preferred for completeness of data. However if reluctant for a phone follow up agree to send the forms in the post.
	+ In the initial phone conversation attempt to collect any data not possible in the postal follow up (mainly the cognitive data). Sometimes people are willing to answer a few questions over the phone even if they don’t want to do the full follow up.
	+ Follow up any patients who don’t return the forms within a few weeks with a phone to remind them.
	+ Use the date you posted the forms as the date of assessment.
* **Postage costs for postal questionnaires**
	+ If postal costs are problem you can either contact Rosalind and she will send stamps to your site, or send an invoice/bill to Edinburgh periodically for postage costs.

Informant assessments

* **MRS, Barthel and ADL: patient or informant?**
	+ These measures can be obtained from either the patient or the informant.
	+ Try and get as much information from the patient.
	+ If this is not possible or too burdensome for the patient, get the information from the informant or medical records.
	+ If you get the information from the informant enter the data onto the patient and informant eCRF.
* **What to do if the information from the patient and the informant differ?**
	+ Take what the patient says as the truth.
	+ If patient has dementia use own judgement to determine whose answers are more accurate.
* **Can you consent the informant at the follow up rather than baseline?**
	+ Yes, as long as you stress that the baseline questions relate to before the stroke and the follow up questions relate to functioning since the stroke.
* **Reporting recruitment of informants when they have the same participant number as the patient**
	+ Report the informant number as the same as the patient number with the addition of –in (e.g. C001-00001-AA-in).
* **If obtaining all information from the informant do you also enter data onto patient CRF?**
	+ Yes enter the data onto the patient form and the informant CRF rather than leaving it blank.
* **If a consultee gives permission for you to take blood from someone lacking capacity should you?**
	+ Yes unless patient indicates they don’t want to.
* **If you can contact the informant but not the patient at follow up should you withdraw the patient?**
	+ No, do not withdraw the patient unless they request you to do so. If the informant is willing, collect all informant data, and then collect as much information as possible from the patients’ medical records.
* **IQ code**
	+ Contradiction between manual and CRF- 12 months vs 10 years.

**Action: This will be changed to 12 months and instructions will be made clearer on the CRF.**