## **Topic Guide for pwCF**

**Current care**

* What generally happens when you have an exacerbation or start to get symptoms of a chest infection?
* Who do you see/speak to?
* Where do you have to go?
* What tests are done?
* Do you get the results? How are the results communicated to you?
* How long does it take?
* What sort of sample is taken?
* Is there a pre-sample taking process (e.g. physio required, …)?
* Where is the [sample] taken?
* Are infections ever picked up in your routine check-ups even when you are not experiencing any symptoms?
* If ‘yes’ how are they identified, frequency, follow-up process and tests?
* Do you get any treatments?
* Does the treatment or test come first?
* If empirical (best guess) treatment: Does the test result change treatment?
* Are any other tests taken (blood tests?) to check if your treatment is working safely?
* What happens if you get better, what happens if you aren’t getting better?
* How long does the process take?
* How often do you experience exacerbations or suspected chest infections?
* Would you get these checked out in addition to your regular CF check-ups? If they were close to a scheduled check-up, would they get replaced? Is that always your experience? Have you noticed other ways?

**TPP elicitation & unmet needs**

* When thinking about new tests for exacerbations and infection for patients with CF, what sort of things do you think would work well?
* What would the test need to show?
* *[indication]*
* What samples should the test use?
* e.g., Sputum (mucus coughed up from the lungs), cough swab, something else?
* What are the pros and cons of different samples?
* Which are most acceptable for patients?
* Where should the test be done, where should the sample be taken?
* At-home? Pharmacy? GP? Hospital?
* How would this impact you? What are the pros and cons of preferred method?
* How long do you think a test can take?
* How long until the doctors get the results?
* How would this change your care? i.e., time to results, faster treatments?
* Would you want to get the results too?
* What sort of information should be given to patients?
* If we look at all the characteristics of a test, (accuracy, speed, sample type, location it can be done, cost to the NHS, and any other things you could think of), what aspects are most important to you and other people with CF?
* *[prompt: top three most important characteristics?]*

* Thinking about the pathway as a whole, from exacerbations/symptoms of infection to you feeling well again…
* What do you think works well in that process?
* Why?
* And where do you think improvements could be made?
* *[prompt: Speed? Flexibility? Who is available to speak to…?]*

**AOB/Closing Remarks**

* Thank you very much for sharing your experiences with us.
* As a final question, is there anything that you think is important to let us know, or to keep in mind, that perhaps we didn’t get around to asking you about today? – Anything you think ‘ah, I wished they’d asked about this…’
* Finally. If any of you would be interested in speaking to us further about CF care and patient perspectives, please do let us know, or send us an email at *[add email in chat]*