Domain A
Do you get sharp, intense pain around the anus because of your fistula(s)?
Do you get a dull / background discomfort around the anus because of your fistula(s)
Do you take painkillers for pain or discomfort related to your fistula(s)?
Do you get any type of discharge from your fistula(s)?
Do you need to use pads or gauze for the discharge from your fistula(s)?
Do you get sore skin around your fistula(s) because of discharge?
Is sitting, standing or walking restricted by your fistula(s)?
Do you get urinary tract (bladder) infections that you believe are caused by your fistula(s)?

Domain B
I am bothered by the side effects from the medication I take for my fistula
I am bothered by the side effects of surgery I had for my fistula (e.g. scarring, appearance, wound problems)
My seton (stitch/string/loop) causes me pain/discomfort/irritation
I feel that my seton is not helpful
I don't understand the treatment I am receiving for my fistula
Understanding the treatment I get for my fistula is important to me
I am not sure that my current fistula treatment is right for me
Anything else about your symptoms or the effects of your current treatment you want to say:

Domain C
My sleep is disturbed because of my fistula
I avoid getting physically close to another person (hugging, sitting next to each other etc.) because of my fistula
I do, or would avoid getting into new relationships because of my fistula
My sexual activity is (or would be) restricted because of my fistula
My socialising (meeting friends going to parties, other social events) is restricted because of my fistula
My exercise / activities (e.g. swimming, cycling, running) that I would like to do are restricted because of my fistula
My travelling (driving, taking the train/plane etc.) is restricted because of my fistula
Having a fistula causes me embarrassment / shame
I am concerned that others may find out that I have a fistula
My ability to work or study is restricted because of my fistula
My ability to advance in my education / career is limited because of my fistula
I have lost out financially because of my fistula
Because of my fistula, I worry about finding or needing the toilet (‘toilet mapping’) when I am away from home
Because of my fistula, I only go to places where I know there’s a clean toilet and washing facilities
Because of my fistula, I have to take spare underwear and wipes with me when I go out
It is hard for me to keep myself feeling clean because of my fistula
I am concerned that other people may be able to smell the discharge from my fistula
I feel anxious or depressed, down or hopeless because of my fistula
I worry that my fistula will never be cured
I worry I might one day need to have a stoma because of my fistula
I worry about my temporary stoma becoming permanent because of my fistula

Appendix 1 - Item reduction overview – items highlighted in grey were removed from the final draft of the CAF-QoL scale following consensus within the PPI representatives / study steering group.