

**Supplementary file 1. Study questionnaire and interview guide****To be filled by patient:**

Dear Sir/Madam, thank you for taking time out of your day to fill in this questionnaire. Please feel free to ask us any questions along the way. Your data will be anonymized.

**Part 1: General Information**

<b>Age:</b>					
<b>Gender:</b>	Male		Female		
<b>Race:</b>	Chinese	Malay	Indian	Caucasian	Others
<b>Highest Education Level:</b>	Primary School	Secondary School	Junior College, polytechnic or ITE	Bachelor Degree	Masters or Doctorate

**Usage of topical steroids (TCS)**

This part of the questionnaire is for us to understand your progress and the factors that influence the treatment for your skin condition.

<b>Factors affecting Adherence</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
I use TCS more often than what is prescribed				
I use TCS less often than what is prescribed				
I often miss applying TCS because I forget/too busy/inconvenient				
I often miss applying TCS because I consciously decide not to				
The creams/TCS prescribed for my skin condition is too expensive				
I am too busy to comply with the treatment for my skin condition				



**TOPICOP® score**

This part of the questionnaire is for us to understand your knowledge and beliefs, fears and behaviour towards the usage of topical steroids (TCS).

<b>Topical Steroids (TCS)</b>	<b>Totally disagree</b>	<b>Not really agree</b>	<b>Almost Agree</b>	<b>Totally Agree</b>
TCS pass into the blood stream				
TCS can lead to infections				
TCS make you fat				
TCS damage your skin				
TCS will affect my future health				
TCS can lead to asthma				
I don't know of any side effects but I'm still afraid of TCS				
<b>Regarding TCS/steroid creams</b>	<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
I am afraid of applying too much cream (TCS)				
I am afraid of putting cream (TCS) on certain zones like the eyelids where the skin is thinner				
I wait as long as I can before treating myself with TCS				
I stop treatment as soon as I can				
I need reassurance about TCS				

<b>This section aims to measure how much your skin problem has affected your life OVER THE LAST WEEK.</b>					
	<b>Very much</b>	<b>A lot</b>	<b>A little</b>	<b>Not at all</b>	<b>NA</b>
Over the last week, how <b>itchy, sore, painful</b> or <b>stinging</b> has your skin been?					
Over the last week, how <b>embarrassed</b> or <b>self conscious</b> have you been because of your skin?					
Over the last week, how much has your skin interfered with you going <b>shopping</b> or looking after your <b>home</b> or <b>garden</b> ?					
Over the last week, how much has your skin influenced the <b>clothes</b> you wear?					
Over the last week, how much has your skin affected any <b>social</b> or <b>leisure</b> activities?					
Over the last week, how much has your skin made it difficult for you to do any <b>sport</b> ?					
Over the last week, has your skin prevented you from <b>working</b> or <b>studying</b> ?	Yes		No		NA
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If 'No', over the last week, how much has your skin been a problem at <b>work</b> or <b>studying</b> ?	A lot	A little	Not at all		NA
	<b>Very much</b>	<b>A lot</b>	<b>A little</b>	<b>Not at all</b>	<b>NA</b>
Over the last week, how much has your skin created problems with your <b>partner</b> , or any of your <b>close friends</b> or <b>relatives</b> ?					
Over the last week, how much as your skin caused any <b>sexual difficulties</b> ?					
Over the last week, how much of a problem has the <b>treatment</b> for your skin been, for example by making your home messy, or by taking up time?					

**TEN-ITEM PERSONALITY INVENTORY-(TIPI)**

Here are a number of personality traits that may or may not apply to you. Please write a number next to each statement to indicate the extent to which you agree or disagree with that statement. You should rate the extent to which the pair of traits applies to you, even if one characteristic applies more strongly than the other.

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree a little
- 4 = Neither agree nor disagree
- 5 = Agree a little
- 6 = Agree moderately
- 7 = Agree strongly

I see myself as:

1. \_\_\_\_ Extraverted, enthusiastic.
2. \_\_\_\_ Critical, quarrelsome.
3. \_\_\_\_ Dependable, self-disciplined.
4. \_\_\_\_ Anxious, easily upset.
5. \_\_\_\_ Open to new experiences, complex.
6. \_\_\_\_ Reserved, quiet.
7. \_\_\_\_ Sympathetic, warm.
8. \_\_\_\_ Disorganized, careless.
9. \_\_\_\_ Calm, emotionally stable.
10. \_\_\_\_ Conventional, uncreative.

**To be filled by doctor or patient:**

Disease condition: \_\_\_\_\_ Duration of disease: \_\_\_\_\_ years  
Highest potency topical steroid: \_\_\_\_\_ Duration of topical steroid use: \_\_\_\_\_

## Interview Guide Version 1

### Interview Guide

Good afternoon and welcome to the session. Thank you for taking the time to share with us about your skin condition.

My name is \_\_\_\_\_. I am a doctor at the National University Hospital. Assisting me is \_\_\_\_\_. The purpose of this interview is to gain an understanding into possible factors influencing usage of moisturisers and steroid creams. We are having discussions like this with other patients and groups.

There are no wrong or right answers. We expect that different people will have different opinions. Please feel free to share your point of view, even if it differs from what others have said.

We will be audio recording this session as we do not want to miss any of your comments. This information will be kept confidential, and no names or identifiers will be used in any reports. The information shared by participants in this group should be kept confidential and not disclosed or discussed outside of this group.

#### Opening

1. Tell me about yourself
2. Tell me about your skin condition
3. Tell me about your current treatment

#### Steroid concern/steroid phobia

1. What are your thoughts towards using creams to treat your skin?
2. What are your thoughts towards using topical steroids?
  - a. Elaborate more
  - b. What do you think about the safety of topical steroids
    - i. Why do you think it might be \_\_\_\_ (dangerous/thin the skin/cannot use too long/whatever they suggest)
    - ii. Describe your worry towards topical steroid use (to understand whether its a knowledge thing, an innate fear that cannot be shaken etc)
  - c. Do you worry when using topical steroids?
    - i. Why yes and no
    - ii. What made you worried about topical steroids (if worried)
    - iii. What made you not worried about topical steroids (if not worried)
1. What do you think about when you use topical steroids
2. What do you feel after applying TCS
3. What do you feel if you do not apply TCS
4. How would you describe your mindset towards using topical steroids
5. What has contributed to this mindset
6. Has anyone tried to change your mindset/thoughts towards topical steroids (friends/family/doctors), how did they do it
  - a. What is your response to them?

- b. If doctors have tried to tell you about s/e topical steroids/safety of use > how did you feel after that
- c. How much did your views towards TCS change

#### Adherence to topical treatment

1. How compliant are you with your topical treatment/TCS
2. (If not compliant) Could you share reasons why you are not able to comply with treatment adequately?
3. (If compliant) What are some factors that motivate you to comply with your treatment?

#### Closing

Thank you very much for sharing with us your thoughts. Is there anything else that you would like to share?

**Interview Guide Version 5 (last version)**

*\*Modifications were made to the interview guide in an iterative fashion to reflect the learnings gained from earlier interviews and to explore new insights.*

Good afternoon and welcome to the session. Thank you for taking the time to share with us about your skin condition.

My name is \_\_\_\_\_. I am a doctor at the National University Hospital. Assisting me is \_\_\_\_\_. The purpose of this interview is to gain an understanding of the effects and usage of moisturisers and steroid creams. We are having discussions like this with other patients and groups.

There are no wrong or right answers. We expect that different people will have different opinions. Please feel free to share your point of view, even if it differs from what others have said (if focused group, not relevant if 1:1).

We will be audio recording this session as we do not want to miss any of your comments. This information will be kept confidential, and no names or identifiers will be used in any reports. The information shared by participants in this group should be kept confidential and not disclosed or discussed outside of this group.

**Opening**

1. Tell me about yourself
2. Tell me about your skin condition
  - a. Explore how does it affect their quality of life e.g. occupation, circumstances where it is problematic
  - b. How long have you had your condition
  - c. How has your condition evolved over time
3. Tell me about your current treatment

**Steroid concern/steroid phobia**

1. What are your thoughts towards using creams to treat your skin?
2. What has been your experience with using topical steroids?
3. Do you worry when using topical steroids?
  - a. Why yes and no
  - b. What made you worried about topical steroids (if worried)
  - c. What made you not worried about topical steroids (if not worried)

**Explore knowledge seeking behaviour (for those who did)**

1. Could you share why you started to search for more information
2. Could you share the process by which you obtained information on TCS

**Explore founded vs unfounded fears**

1. What are some side effects that you know of
  - a. Have you experienced any
  - b. Why do you say you have skin thinning/how do you know you have skin thinning
  - c. Why is skin thinning bad?



2. Exploring addiction/dependence/reliance
  - a. Could you share with us your journey with TSW. How did you know that you were going through TSA/TSW (if relevant)
  - b. What are your thoughts towards steroid addiction or steroid withdrawal? > do you think its something that everyone gets if they use TCS for long enough period, or only some people get it?
  - c. What are some features that might suggest a person is 'addicted' to TCS
  - d. Is there a difference between physical reliance vs mental reliance
3. What are your thoughts/mindset towards using topical steroids?
4. Explore the changes in mindset and opinion over time/usage
  - a. What factors influenced this change/contributed to this mindset
  
1. Has anyone tried to change your mindset/thoughts towards topical steroids (friends/family/doctors), how did they do it
  - a. What is your response to them?
  - b. How did you feel
2. What might change your belief (for those who hold stronger beliefs). Do you think anything can convince you to use steroids again/safety of topical steroids? (for steroid phobic patients)
3. If doctors have tried to tell you about s/e topical steroids/safety of use > how did you feel after that
4. How much did your views towards TCS change
5. Exploring "natural" treatment options (if relevant/raised)
  - a. What do you consider natural
  - b. Why is natural better

**For those who belong to a TSW/TSA community**

1. What led you to speak up/share about your journey with TSW?
2. Do you mind sharing with us more about the TSW/TSW community
3. What do you think is the relationship most people with TSW have with their dermatologists
4. How do you think the medical community/dermatologists can support people with TSW/TSA?
5. Why do you think some/many dermatologists/doctors reject the idea of TSW (If raised)

**Adherence to topical treatment**

1. How frequently do you use your topical treatment/TCS
  - a. What influences how much and how often you choose to apply
2. Could you share reasons why you apply your creams (regularly/not regularly)
  - a. If adherent > what motivates you to apply your creams regularly
  - b. If non adherent > why

**Factors associated with steroid concerns**

1. Why do you think some people have more/less fear about steroid side effects ?
2. Why do you think some people use steroid creams and seem to be okay?

#### **Where do you get information on TCS from**

1. Where is most of your information about TCS/TSA from?
2. How is the message different on these different sources/How is the consistency of information about TCS/TSA/TDW
3. Which source do you trust the most? If there are differing opinions on \_\_ vs \_\_\_\_, which would you choose to believe
4. What determines whether you trust the information
5. What determines whether that information influences your beliefs
6. What determines whether that information/beliefs influence your actions (usage/adherence)

#### **Personality and demographics**

1. Can you describe your personality?
  - How do you think your personality influences your acceptance/rejection of topicals steroids
2. How does your personality influence your acceptance of the information given by doctors/information you read on internet
  - How does your personality influence your view towards using TCS
3. How does personality influence decision making
4. Do you think there is a gender, age difference in steroid phobia?
5. Do you think males and females may have different concerns towards steroid concerns? Why
6. Do you think patients who are older/young may have different concerns towards steroids? Why
7. Do you think there's a difference based on how long a person has been using TCS for?
8. Do you think there is a difference based on the severity of disease, impact on quality of life?
  - How does your severity of your condition at a particular point influence your decision to use TCS
  - How does your decision to use TCS affect your severity
  - Which one influences which (do you think your decision affects severity more, or severity affects decision more)

#### **Relationship with dermatologist**

1. How is your relationship with the dermatologist?
  - How much do you trust the doctor?
  - Does your relationship and trust influence your view and decision to use TCS?
  - What are some things you hope or expect from the doctor?
  - What kind of information, support would you want

#### Closing

Thank you very much for sharing with us your thoughts. Is there anything else that you would like to share?