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Acta Dermato-Venereologica

APPENDIX S1 Study questionnaire

logo

Panelist ID fields

Q0. Before starting this questionnaire, please confirm your agreement to the collection and analysis of your health data by us. We remind you that the data you provide to us will never be processed individually, but will always be processed anonymously and aggregated with that of other respondents.

1 ☐ Yes, I agree to answer this survey ➔ Switch to Q1

2 ☐ No, I refuse to answer. ➔ This questionnaire has been completed

YOU AND YOUR HEALTH

Q1. Have you ever had or do you currently have one or more actinic keratosis lesions? These are crusty or rough lesions to the touch and are also called solar keratosis lesions. *Only one answer*

1 ☐ Yes, I currently have or have had them in the past

➔ Proceed to Q2

2 ☐ No, I have never had actinic keratosis

➔ This questionnaire is over

Q2. Has your actinic keratosis lesion(s) been diagnosed by a doctor? *Only one answer*

1 ☐ Yes..... ➔ Proceed to Q3

2 ☐ No ➔ Skip to Q17

Q3. Your diagnosis of actinic keratosis was made ... *Only one answer*

1 ☐ Less than 6 months

2 ☐ Between 6 months and less than one year

3 ☐ Between one year and less than 3 years

4 ☐ 3 years and up

Q3b. Which doctor diagnosed these actinic keratosis lesions? *Only one answer*

1 ☐ General practitioner ➔ switch to Q3d

2 ☐ Hospital Dermatologist

3 ☐ Dermatologist in his office

4 ☐ Other physician (specify: _____)

Q3c. What were the conditions of the diagnosis? *Only one answer*

- 1 ☐ During a consultation, on my initiative, with a dermatologist to talk about these lesions
 2 ☐ During a consultation with a dermatologist for another reason
 3 ☐ My doctor advised me to go see a dermatologist
 4 ☐ Other condition (specify: _____)

Q3d. Before getting the diagnosis, did a pharmacist give you advice on how to go see a general practitioner or dermatologist?

- 1 ☐ Yes 2 ☐ No

ACTINIC KERATOSIS SINCE YOUR DIAGNOSIS

Q4. How many months or years have passed between the appearance of your first actinic keratosis lesion(s) and the diagnosis made by the doctor?

|_|_|_| Month OR |_|_|_| Years

Q5. At the time of diagnosis by your doctor, on which part(s) of the body was your actinic keratosis lesion(s)? *Several possible answers*

- | | |
|---|---|
| 1 ☐ Face, indicate on which areas precisely: | 2 ☐ Scalp |
| a ☐ forehead /temples | 3 ☐ Back of Hands |
| b ☐ chin | 4 ☐ Forearm / Arm |
| c ☐ nose | 5 ☐ Ears |
| d ☐ cheeks | 6 ☐ Neck |
| | 7 ☐ Legs / Feet |
| | 8 ☐ Other (specify: _____) |

Q6. At the time of diagnosis by your doctor, how many visible or palpable lesions (roughness to the touch) of actinic keratosis did you have in total? *Only one answer*

- 1 ☐ Less than 3 actinic keratosis lesions 4 ☐ More than 25 actinic keratosis lesions
 2 ☐ Between 3 and 10 actinic keratosis lesions
 3 ☐ Between 11 and 25 lesions of actinic keratosis

Q6b. At the time of diagnosis or afterward, did you feel the need to have explanations/advice about actinic keratosis from your doctor ?

- 1 ☐ Yes, I felt the need and I received all the necessary explanations and advice, → go to Q7
 2 ☐ Yes, I felt the need but no one gave me any explanations/advice → go to Q7
 3 ☐ No, I never felt the need to have explanations/advice → go to Q8

Q7. What explanations/advice were they? *Several possible answers*

- 1 ☐ The origin of your actinic keratosis lesion(s)
 2 ☐ The importance of protecting yourself from the sun

- 3 ☐ The importance of following medical prescriptions
- 5 ☐ Adverse effects of treatments
- 6 ☐ The possible consequences of actinic keratosis on your health
- 7 ☐ Other (specify: _____)

MEDICAL MANAGEMENT OF YOUR ACTINIC KERATOSIS

Q8. Since your diagnosis of actinic keratosis, has a doctor prescribed one or more treatments (medication or other type of treatments) for your actinic keratosis lesion(s) and at what period? *Only one answer*

1 "Yes, I had one or more treatment(s) ONLY before January 2021 → Skip to Q10

2 "Yes, I had one or more treatment(s) ONLY after January 2021 → Skip to Q10

3 "Yes, I had one or more treatments, before AND after January 2021 → Skip to Q9

4 "No, I have never had a treatment → go to Q17

Q9. If you had one or more treatments, before AND after January 2021 (code 3 to Q8), report the code(s) of each of the treatments you took from your diagnosis to December 2020 from list A. *Several possible answers*

1 ☐ / 2 ☐ / 3 ☐ / 4 ☐ / 5 ☐ / 6 ☐ Other, specify _____

→ Then move on to Q10 answering for the treatments you have had since January 2021

Q10. In the table below, you are asked to answer questions Q10b to Q16, for each treatment you had. Fill in one column per treatment, **always starting with the oldest treatment and ending with the most recent.**

If you have had more than 3 treatments, please complete this table for the last 3 treatments you have had.

Q10b. Post the code for the A list processing <i>Start with the oldest</i>	Processing code (oldest): / _ / _ / → Then go to Q12	Processing Code: / _ / _ /	Processing code (most recent): / _ / _ /
Q11. For what reason(s) have you been prescribed another treatment? <i>Several possible answers</i>		1 ☐ My lesions have not disappeared 2 ☐ My lesions have come back 3 ☐ To avoid having new lesions 4 ☐ Other reason (specify: _____)	1 ☐ My lesions have not disappeared 2 ☐ My lesions have come back 3 ☐ To avoid having new lesions 4 ☐ Other reason (specify: _____)
Q12. Regarding this treatment, which doctor prescribed it to you? <i>Only one answer possible</i>	1 ☐ General practitioner 2 ☐ Community dermatologist 3 ☐ Hospital dermatologist 4 ☐ Other (specify: _____)	1 ☐ General practitioner 2 ☐ Community dermatologist 3 ☐ Hospital Dermatologist 4 ☐ Other (specify: _____)	1 ☐ General practitioner 2 ☐ Community dermatologist 3 ☐ Hospital Dermatologist 4 ☐ Other (specify: _____)

	_____)	_____)	_____)
Q13. Regarding this processing, For list A codes from 1 to 9, indicate the duration of the prescription, in days OR weeks. For list codes A 10 to 13, indicate the number of sessions	/ _ / _ /OR/ _ / _ / Days Weeks / _ / _ /Sessions	/ _ / _ /OR/ _ / _ / Days Weeks / _ / _ /Sessions	/ _ / _ /OR/ _ / _ / Days Weeks / _ / _ /Sessions
Q14. Regarding this treatment, have you... <i>Only one answer possible</i>	1 ☐ Respected the duration AND the number of doses/applications/sessions indicated on the prescription 2 ☐ Complied only with the statute of limitations 3 ☐ Respected only the number of takes/applications/sessions 4 ☐ Neither respected the duration nor respected the number of takes/applications/sessions	1 ☐ Respected the duration AND the number of doses/applications/sessions indicated on the prescription 2 ☐ Complied only with the statute of limitations 3 ☐ Respected only the number of takes/applications/sessions 4 ☐ Neither respected the duration nor respected the number of takes/applications/sessions	1 ☐ Respected the duration AND the number of doses/applications/sessions indicated on the prescription 2 ☐ Complied only with the statute of limitations 3 ☐ Respected only the number of takes/applications/sessions 4 ☐ Neither respected the duration nor respected the number of takes/applications/sessions
Q14b. Regarding this treatment, did you stop it before the lesions disappeared? <i>Only one answer possible</i>	1 ☐ Yes → Skip to Q15 2 ☐ No → Skip to Q16	1 ☐ Yes → Skip to Q15 2 ☐ No → Skip to Q16	1 ☐ Yes → Skip to Q15 2 ☐ No → Skip to Q16
Q15. For what reason(s) did you stop this treatment before the lesions disappeared? <i>Several possible answers</i>	1 ☐ Termination of Prescription/Treatment 2 ☐ Problem of tolerance to treatment 3 ☐ Ineffective treatment 4 ☐ Duration of treatment too long 5 ☐ Treatment that is too restrictive/complicated to take 6 ☐ Other (specify: _____)	1 ☐ Termination of Prescription/Treatment 2 ☐ Problem of tolerance to treatment 3 ☐ Ineffective treatment 4 ☐ Duration of treatment too long 5 ☐ Treatment that is too restrictive/complicated to take 6 ☐ Other (specify: _____)	1 ☐ Termination of Prescription/Treatment 2 ☐ Problem of tolerance to treatment 3 ☐ Ineffective treatment 4 ☐ Duration of treatment too long 5 ☐ Treatment that is too restrictive/complicated to take 6 ☐ Other (specify: _____)

Q16. After this treatment... <i>Only one answer possible</i>	1 ☐ My doctor has renewed my prescription 2 ☐ My doctor prescribed/offered me another treatment 3 ☐ My doctor didn't give me a new prescription 4 ☐ I haven't seen my doctor again 5 ☐ Other (specify: _____) ☐ Processing still in progress ➔ Skip to Q17 <i>If you had another treatment after this one, fill in the second column. If not, go to Q17</i>	1 ☐ My doctor has renewed my prescription 2 ☐ My doctor prescribed/offered me another treatment 3 ☐ My doctor didn't give me a new prescription 4 ☐ I haven't seen my doctor again 5 ☐ Other (specify: _____) ☐ Processing still in progress ➔ Skip to Q17 <i>If you had another treatment after this one, fill in the third column. If not, go to Q17</i>	1 ☐ My doctor has renewed my prescription 2 ☐ My doctor prescribed/offered me another treatment 3 ☐ My doctor didn't give me a new prescription 4 ☐ I haven't seen my doctor again 5 ☐ Other (specify: _____) ☐ Processing still in progress ➔ Skip to Q17
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Q17. In the past, or currently, are you or have you been... *Several possible answers*

- 1 ☐ Treated with chemotherapy and/or radiotherapy and/or immunotherapy
2 ☐ Treated for skin cancer (melanoma, cutaneous or basal cell carcinoma)
3 ☐ Transplanted
4 ☐ Treated for another dermatological disease (specify: _____)
99 ☐ None of the above

ACTINIC KERATOSIS CURRENTLY

Q18. Currently, where is your actinic keratosis lesion(s) located? *Several possible answers*

1 ☐ Face, indicate on which areas precisely:

a ☐ forehead /temples

b ☐ chin

c ☐ nose

d ☐ cheeks

2 ☐ Scalp

3 ☐ Back of Hands

4 ☐ Forearm / Arm

5 ☐ Ears

6 ☐ Neck

7 ☐ Legs / Feet

8 ☐ Other (specify: _____)

99 ☐ I no longer have actinic keratosis currently → How many months or years have you not had actinic keratosis lesions /__/__/

OR /__/__/

Months years

→ Then, skip to Q21

Q19. Currently, how many visible or palpable lesions (roughness to the touch) of actinic keratosis do you have in total? Only one answer

1 ☐ A single lesion of actinic keratosis

2 ☐ Between 2 and 3 lesions of actinic keratosis

3 ☐ Between 4 and 10 lesions of actinic keratosis

4 ☐ Between 11 and 25 actinic keratosis lesions

5 ☐ More than 25 actinic keratosis lesions

Q20. Currently, on a scale of 0 to 10, how would you rate the impact of your actinic keratosis injury(s) on your quality of life? 0 means that the impact of your actinic keratosis lesion(s) on your quality of life is zero and 10 that its/their impact on your quality of life is very important. Intermediate grades are used to nuance your judgment. |_|_|_|

PERCEPTIONS, EXPECTATIONS AND EXPERIENCES RELATED TO ACTINIC KERATOSIS

Q21. Here are some statements reported by people with actinic keratosis. Indicate the extent to which you agree with each of them. On a scale of 0 to 10, rate between 0 and 10.

0 means you strongly disagree and 10 means you strongly agree. Intermediate grades are used to nuance your judgment.

	Score from 0 to 10
No matter what is done, actinic keratosis lesions recur (are chronic)	_ _
Treatments are effective in treating actinic keratosis	_ _
Treatments for actinic keratosis are restrictive	_ _
Actinic keratosis is a precancerous disease	_ _
Actinic keratosis is due to the cumulative dose of UV received throughout life	_ _
Actinic keratosis is a disease that can be cured	_ _
Actinic keratosis is inevitable as we age	_ _
Actinic keratosis requires protection (cream, clothing, etc.) every day from the sun	_ _

Q22. Here are some suggestions that could improve the management of actinic keratosis. Indicate how much you agree with each of them by giving a score between 0 and 10.

0 means you strongly disagree and 10 means you strongly agree. Intermediate grades are used to nuance your judgment.

	Score from 0 to 10
Hearing about actinic keratosis in the media	_ _
Inform about the risks of untreated actinic keratosis	_ _
That the doctor regularly suggests a skin examination	_ _
Having medications/treatments with few adverse effects on their health	_ _
Have medications/treatments that are taken over a short period of time	_ _
Involving pharmacists in the prevention of actinic keratosis	_ _
Better reimbursement of drugs/treatments for actinic keratosis	_ _
Have actinic keratosis medications/treatments that make the lesions disappear	_ _
Have easy-to-use medications/treatments	_ _
Have cheaper actinic keratosis medications/treatments	_ _

Q23. Here are some life experiences reported by people with actinic keratosis. Indicate how much you agree with each of them by giving a score between 0 and 10.

0 means you strongly disagree and 10 means you strongly agree. Intermediate grades are used to nuance your judgment.

	Score from 0 to 10
There is a long wait to make an appointment with a dermatologist	
My lesions did not disappear after my treatment(s)	
I went through a period of medical wandering before finding a treatment that cured me	
It took several consultations before my actinic keratosis was diagnosed	
I am unfamiliar with medications and other treatments for actinic keratosis	
Some treatments have caused a crusty, red, painful and unsightly appearance on my treated areas (face in particular)	

Q24. Here are different attitudes that some people may adopt because of their actinic keratosis injuries. For each one, indicate how often you adopt them. *One response per line*

	All the time	Often	Rarely	Never
I avoid exposing myself between 10 a.m. and 4 p.m.				
I avoid exposing myself to the sun at any time				
I only expose myself to the sun if I have protection (sunscreen, hat...)				
I no longer go on holiday with friends/family				
I avoid lunches outside				
I no longer practice any sports or outdoor activities				
I apply a sunscreen every morning				

IN THE END

Q25. From the photos on the attached sheet, how would you describe your skin when choosing a photo from A to F?

Only one answer

/ __ /