

APPENDIX S1: Participant's clinical characteristics¹

Age (years), mean +/- SD, range	62 +/- 14, 35-82
Female, n (%)	16 (76)
ECOG performance status ² , n (%)	
0	2 (10)
1	10 (50)
2	5 (25)
3	3 (15)
4	0 (0)
Ulcer location, n (%)	
Lower extremities	16 (80)
Abdominal/ peristomal	1 (5)
Buttock, groin, anogenital	3 (15)
Other (upper limb, upper trunk)	2 (10)
Time since diagnosis (years), n (%)	
<1 year	1 (5)
1-5 years	11 (55)
>5 years	8 (40)
Delay to diagnosis (months), n (SD, range)	13.8 (24.8; 0.5-96)
Current systemic therapy, n (%)	
Prednisolone	18 (90)
Non-biologic DMARD	14 (70)
Biologic	5 (25)
IVIG	3 (15)
Ulcer recurrence during disease course, n (%)	15 (75)
DLQI ³ score, mean (SD; range)	10.7 (8.2; 1-28)
DASS21 ⁴ score, mean (SD; range)	17.9 (17.0; 0-47)
DCQ ⁵ score, mean (SD; range)	5.4 (5.1; 0-15)

¹ 1 of the 21 participants failed to return the clinical characteristics questionnaire due to hospitalisation

² Eastern Cooperative Oncology Group (ECOG) Performance Status

³ Dermatology Life Quality Index (DLQI)

⁴ Depression Anxiety and Stress Scale 21 (DASS21)

⁵ Dysmorphic Concern Questionnaire (DCQ)

APPENDIX S2: Interview Schedule

“When discussing your experiences and perspectives, please ensure to avoid any information that could potentially make any person identifiable.”

1. To begin our interview, I'd like to start by asking you to tell me about what it is like to have pyoderma gangrenosum.
2. Can you tell me about your biggest challenges or concerns about your pyoderma gangrenosum?
3. How does the pyoderma gangrenosum function within your day-to-day life?

Follow up with:

- *How about in your school/ work/ retirement/ responsibilities/ roles?*
- *How about in your social life/ relationships?*
- *How about on your finances?*
- *How about managing the dressing needs?*

4. To what extent do you feel the pyoderma gangrenosum impacts on your quality of life?

If it impacts... ask to elaborate.

5. To what extent do you feel the pyoderma gangrenosum impacts on your mental health and wellbeing?

If it impacts... ask to elaborate.

6. What do you find are the most useful strategies for dealing with your pyoderma gangrenosum day to day?

If patient describes strategies, ask how/ why it is helpful.

Follow up with - have you used alcohol, smoking or other substances/ drugs or habits to cope?

7. A. What treatments have you had for the pyoderma gangrenosum?

- B. How does the treatment of the pyoderma gangrenosum impact on your life?

If needing prompting then:

- a. *Positives of treatment?*
- b. *Negatives of treatment?*

8. What feedback/ suggestions would you give to health professionals and health services in terms of helping patients manage pyoderma gangrenosum?

9. Is there anything else you would like to add?