

Appendix 5 – Focus group topic guide

Intro question: Would anyone like to start by sharing at what age they were diagnosed, and how long it took to get your diagnosis?

Topic 1: Diagnosis and initial consultation

1. What do you think were the main factors that affected how slowly/quickly you got a diagnosis?

Prompts: Were you referred to the appropriate healthcare professionals? Any misdiagnoses? Sufficient HCP knowledge of lupus?

2. After receiving your lupus diagnosis, did your GP or consultant have a detailed conversation with you about what to expect with your lupus journey? Did this meet your needs at the time?

Prompts: what to expect regarding prognosis/treatment options, impact on QoL, co-morbidities

Follow up: Looking back on it now, what are the main information you would have wanted at that first consultation?

Topic 2: Personalisation and coordination of care

In the next few questions, we'll explore how well your lupus care is tailored to your needs, how effective communication is between your care teams, and your management of flare-ups.

3. During our interviews with people with lupus, we've learned that the condition affects everyone differently, with no two journeys being the same. How well do you feel your care is tailored to your individual needs?

Prompts: care plan, specialist lupus nurse

Follow up: If not, what would you like in place to make it more specific?

4. How do you feel about your relationship with your lupus care team?

Prompts: Do you feel supported and understood?

Follow up: What aspects of the relationship with your lupus care team work well, or could be improved?

5. Some of you have mentioned that multiple departments are involved in your care, such as rheumatology and nephrology. If this is the case, how well do you feel the teams and healthcare professionals communicate with each other?

Follow up:

A: What do they do well that helps you keep track of information and treatments/appointments?

B: If you feel communication isn't well coordinated, what would you suggest to improve communication between teams?

6. I'd like you to think about what happens if and when you experience a flare. How do you manage the flare up, and what services do you turn to in this situation?

Prompts: Helpline, GP, charity support, A&E

Follow up:

A: How could service x/y/z be improved? Is there anything good about x/y/z?

B: In an ideal world, what services would you like to have available during a flare?

Topic 3: Knowledge and sources of information

Now, we're going to talk about the level of knowledge and understanding of lupus among different HCPs in NHS Wales, as well as your own level of knowledge, and where you get your information from.

7. Based on your experiences, how would you describe the level of knowledge about lupus among healthcare providers and your care teams?

Follow up: If you have found that HCPs lack in their knowledge, has this impacted how much you've needed to find information on your own? If so, where you do typically look to find reliable information about lupus?

Prompts: websites, support groups/charities, scientific papers.

8. What resources and information would you recommend to someone at the start of their lupus journey/diagnosis?
9. How informed do you feel about the various factors that contribute to living with lupus such as risk factors, lifestyle/dietary changes etc.?

Follow up: If you don't feel well informed, what would you suggest would help to keep you informed?

Topic 4: Emotional/Mental health support

We will now discuss your experiences with support groups and mental health services related to lupus. We want to know the types of support you find useful, and how important you think having support services is for lupus.

10. Are you involved in any support groups?

Prompts: social media, word-of-mouth, HCP, charities

Follow up: *if yes, which ones? How did you discover them?*

11. How helpful do you find these support groups.

Follow up: If they are helpful, in what ways? If not, how could they be improved?

12. Do you/have you accessed mental health or emotional support services?

Follow up: *Are these sources of support lupus-specific?*

13. How important do you think mental health support is in managing lupus?

Follow up: If you have accessed support, do you feel it was adequate? What improvements would you suggest?