Appendix 4 – Interview topic guide

1. Can you please tell me about your experience of getting a diagnosis of lupus?

> Follow up: What symptoms prompted you to seek care?, How long did it take to get a referral for testing/diagnosis?, Did you receive any misdiagnoses?

2. Was there anything positive or particularly well-handled throughout your experience of getting a diagnosis?

3. Is there anything that could have been improved about your experience of getting a diagnosis?

4. Has lupus impacted your daily life, including work, relationships or day-to-day activities in any way?

> Follow up: Can you explain how it has impacted [xyz]?

We're going to move on now and talk about the care you receive to monitor and manage your lupus.

5. Can you tell me about the healthcare professionals you see on a regular basis to help monitor and manage your lupus?

> Follow up:
> A: *Do these appointments meet your needs? Why/Why not?*
> B: *Is there anything that you think is done well in terms of managing your lupus?*
> C: *Is there anything that could be done better about managing your lupus?*

6. How would you describe the coordination of your lupus care among different healthcare providers (GP, specialists, and other).

7. How do you currently self-manage your lupus and flare ups, and do you find any particular strategy especially helpful/effective?
Prompts: Medication, lifestyle changes, alternative therapies.

8. How involved do you feel in making decisions about how to manage your lupus?

9. Where do you normally go to get information or advice on your lupus?
Prompts*: Do you think you have been provided with enough information about lupus and how to manage it from healthcare professionals?,* What could be improved?

10. Do you feel like you receive enough support for the emotional impact of lupus?
Prompts*: What sources do you currently rely on for emotional support? [Online/forum/support group],* How do you think this could be improved?

11. Would you prefer to access care for your lupus locally, or would you be willing to travel further for specialist care?

Now, I'd like to ask about the support that you access when you experience a flare up.

12. Who, if anyone, do you contact if you are experiencing a flare up? Does this meet your needs?

13. What support would you like to have available during a flare up?
Prompt*: A 24-hour helpline, emergency pack, or a specialist nurse?*

Finally, I want you to think more hypothetically about the type of care you would like to receive for your lupus in an ideal world.

14. What would be the one thing you would change about how the NHS provides care for people with lupus?

15. Do you have any further comments on how lupus care could be improved in Wales?