

ONLINE SUPPLEMENTARY DATA

Supplementary Table 1. Focus group and interview questions and prompts.

Research priorities (four allocation exercises)

Each participant will allocate 10 tokens

We have given you a tokens and I want you to imagine that each one is worth \$1 million and that you are in charge and have to decide what to give the money to.

There is limited resources and money available to distribute, decisions have to be made, with your 10 tokens provided, place them on the areas you think are more important and less tokens to the ones you think are less important. You can place more than one token on an option.

We have provided a survey with a list of research areas in lupus, identify which you think are more important and less important.

Four allocation exercises

- Research topics – Medical management, Prevention and diagnosis, lifestyle and psychosocial
- Research questions
 - Medical management.
 - Prevention and diagnosis
 - Lifestyle and psychosocial

After each topic is completed

Is there any other research question or research topic you would add, that you believe is important?

Can you explain why you chose priority x as the highest priority? Can you explain why priority y was given the least amount of tokens?

If you were to remove one token that allocated, which one would that be and why?

For focus group only

After hearing others discuss their prioritisation, would you change any of your selections?

Healthcare priorities (one allocation exercise)

Each participant will allocate 10 tokens and a survey with a list of healthcare services

Lupus can affect in different people in different ways and sometimes people with lupus have to see different doctors, nurses, and other health experts.

We have listed 11 different health experts and problems they treat or the issues they help with. The exercise is similar to the ones above.

After exercise is completed

Are there any other specialties you would add, that you believe is important?

Can you explain why you chose priority x as the highest priority? Can you explain why priority y was given the least amount of tokens?

If you were to remove one token that allocated, which one would that be and why?

For focus group only

After hearing others discuss their prioritisation, would you change any of your selections?

Supplementary Table 2. Healthcare specialties and research questions list.

Research questions/ research topics

1) Research topics

- Medical management
- Prevention and diagnosis
- Lifestyle and psychosocial
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2) Medical management

- What diets and lifestyle help control lupus?
 - How can treatment of lupus be tailored to the individual patient?
 - How can we effectively manage lupus flares?
 - How can weight gain from treatment be minimised?
 - How do we effectively treat lupus related skin rashes?
 - How do we effectively treat lupus related kidney disease?
 - How do we effectively treat lupus related arthritis?
 - What is the best treatment/management strategy for fatigue/tiredness?
 - What is the best treatment to manage pain?
 - How can infection risk from treatment be minimised?
 - How can cancer risk from treatment be minimised?
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3) evention and diagnosis

- What are the causes of lupus?
 - What diets and lifestyle can help prevent lupus?
 - How can lupus best be diagnosed?
 - Is there any medication to prevent lupus?
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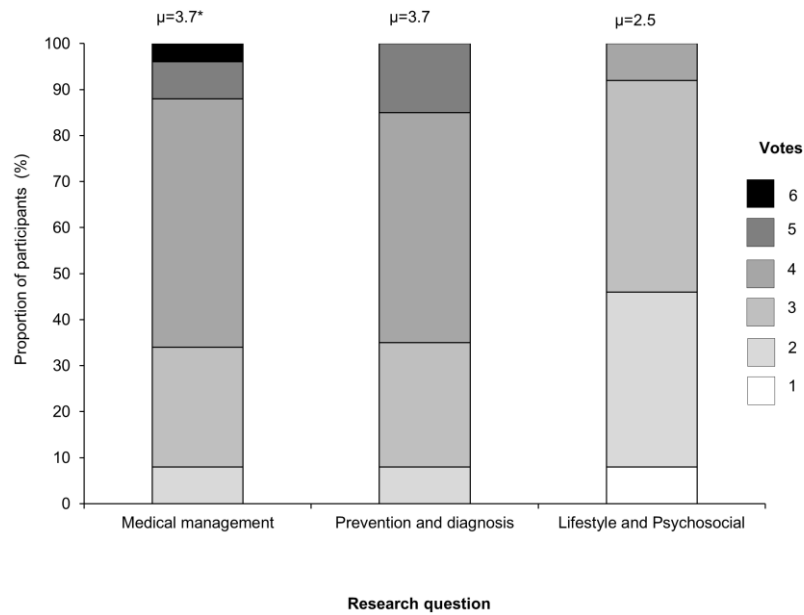
4) Lifestyle and psychosocial

- What impact does lupus have on patient's psychosocial health?
- What impact dose lupus have on patient's relationships with families and friends?.
- What information/education would be the most effective in improving the knowledge of lupus patients?
- What management/treatments can improve pregnancy outcomes for lupus patients?

Healthcare specialties

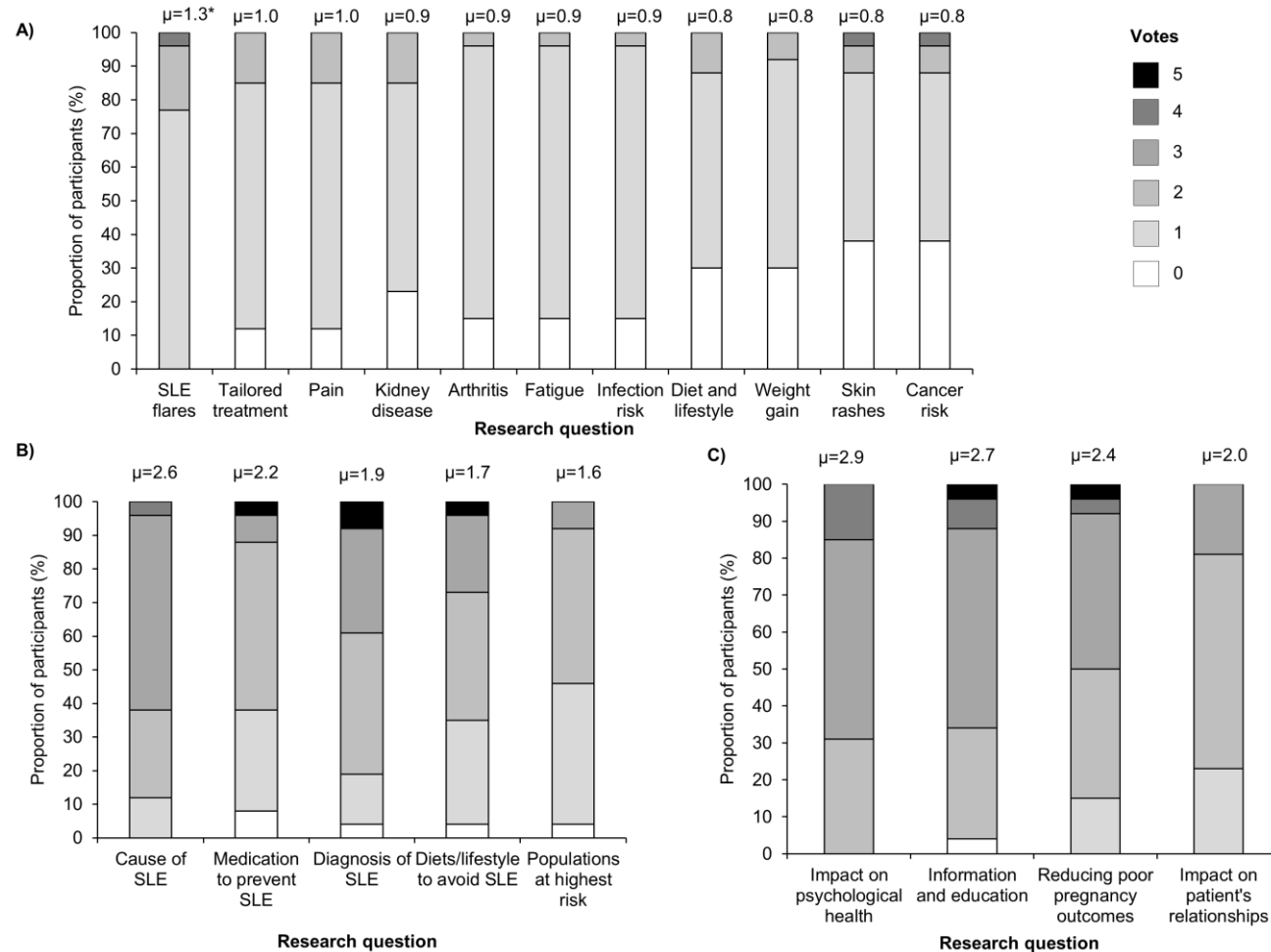
- Cardiologist – treatment of lupus related heart problems.
 - Dietician – educate and provide meal plans for patients
 - General practitioner – monitoring and providing prescriptions for patients.
 - Haematologist – treatment of lupus related blood problems, for example clotting etc.
 - Nephrologist – treatment of kidney disease
 - Mental health professional – treatment of stress, anxiety, depression
 - Neurologist – treatment of lupus related brain problems.
 - Nurse – educate, resource, co-ordinate care and support for patients with lupus
 - Occupational therapist/physiotherapist – treatment to improve fitness, mobility and getting back to normal daily living.
 - Rheumatologist – treatment of inflammatory conditions, and lupus flares
 - Social worker – advise on financial issues, education and employment
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Supplementary Figure 1. Allocation of votes to broad research topics for young patients with SLE.



* μ = mean number of votes allocated to each research topic
Research topics are ordered from highest to lowest number of total votes received from participants (n=26)

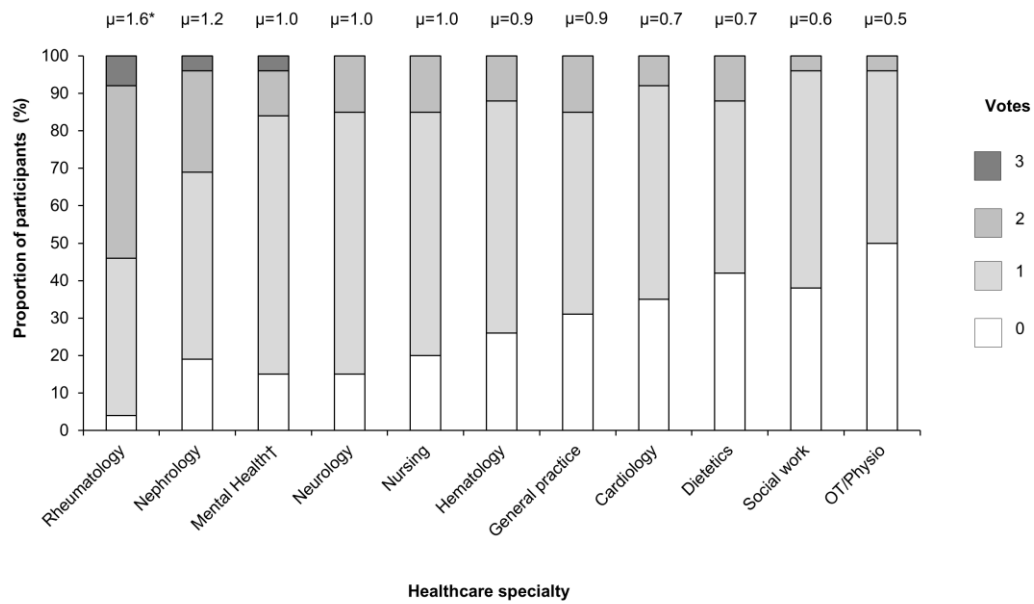
Supplementary Figure 2. Allocation of votes to research topics for young patients with SLE **A)** Medical management **B)** Prevention and diagnosis **C)** Lifestyle and psychosocial.



* μ =mean number of votes allocated to each research question

Research questions are ordered from highest to lowest number of total votes received from participants (n=26).

Supplementary Figure 3. Allocation of votes to healthcare specialties for young patients with SLE.



* μ = mean number of votes allocated to each healthcare specialty

† Mental health = healthcare professionals from psychiatry or psychology

Healthcare specialties are ordered from highest to lowest number of total votes received from participants (n=26).