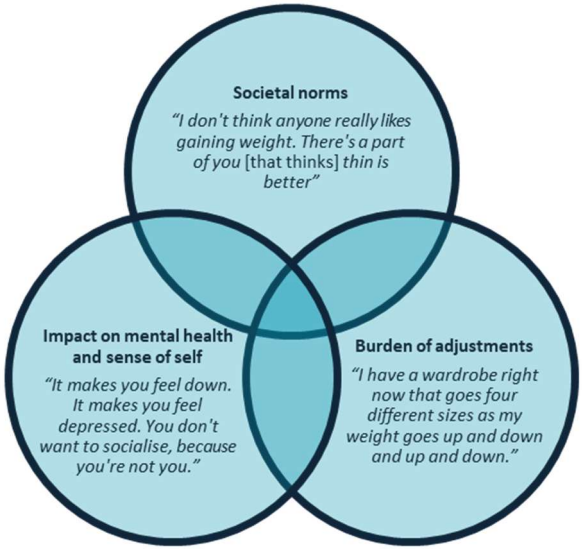
Perspectives on the impacts of appearance and weight changes due to long-term steroid use

I'm Stephanie Lax, a researcher from the University of Nottingham alongside Dr Fiona Pearce and Alice Muir in the RECORDER team. You might remember Alice's lovely double pager in the Autumn 2024 newsletter about her Guided Imagery project. Her YouTube resources on the Vasculitis UK website here: https://www.vasculitis.org.uk/imagery-techniques-for-people-living-with-vasculitis.

It's also been my pleasure to join Dr Jo Robson at UWE Bristol and colleagues on a project about the impacts of appearance and weight changes due to long-term steroid use. Previously, Jo's team had interviewed 60 patients with lots of different rheumatic conditions, including vasculitis, about the general impacts of steroids on their lives. I looked at the original interviews with fresh eyes and pulled out everything participants said about how steroid-related appearance and weight changes affected them.

Three main issues came out:

- Firstly, participants shared the pressures they felt about their appearance because of cultural expectations and unhelpful comments received from others when their appearance changed. This was across weight, skin, and hair changes.
- Secondly, participants explained how appearance changes had a negative impact on their mental health and sense of identity.
- Thirdly, we drew up a list of all the adjustments people said they had to make to cope with steroid-related appearance changes. They included changes to diet, physical activity, and social interactions. We realised many were associated with increased financial costs, which some people would find easier to afford than others.

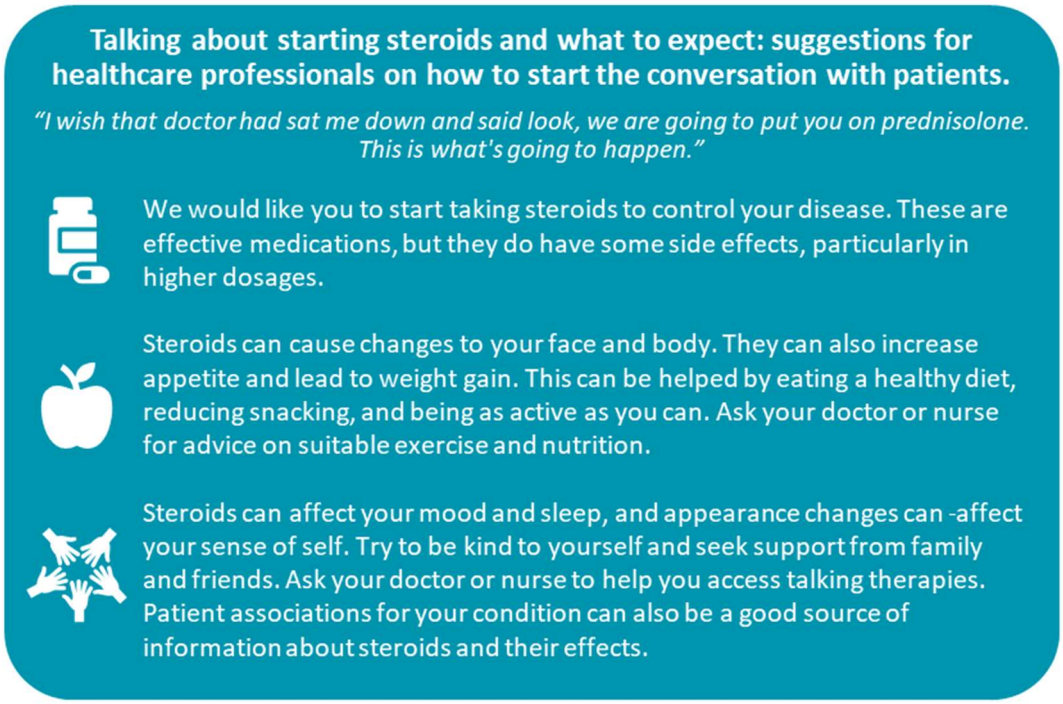


Something that surprised us was the mention of hair thinning. That's because doctors and researchers typically think of steroids as causing hair gain, rather than loss. It's an area that needs further work to fully understand.

Some participants indicated more support and information about steroids would have helped them prepare themselves better, which is something the patient partners on our team agreed with. Drawing on the research, we came up with some advice for healthcare professionals talking to patients who are starting to take steroids. A postcard is available to print from https://www.nottingham.ac.uk/research/groups/recorder/documents/steroid-project-20250313-updated-postcard.pdf.

If you have any comments about this work, would like to hear more about our research, or live in the East Midlands and would be interested to join our Public Partnership, please email RECORDER@nottingham.ac.uk. Please also contact Jo Robson at UWE Bristol for further information about the original Steroid PRO project (Jo.Robson@uwe.ac.uk).

Suggested wording based on participant interviews and patient partner feedback:



Images are from our paper: Lax SJ, et al. Patient perspectives on the impact of appearance and weight changes attributed to systemic glucocorticoid treatment of rheumatic diseases, *Rheumatology*, 2025; https://doi.org/10.1093/rheumatology/keaf121.