INTRODUCING THE STEROID PATIENT INFORMATION SURVEY (SPINS)- A SURVEY OF KNOWLEDGE OF SICK DAY RULES AMONGST PATIENTS ON LONG TERM STEROID TREATMENT

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1 BACKGROUND

An increasing number of patients take long-term maintenance doses of steroids for a variety of conditions. During periods of illness, steroid treatment should not be discontinued and daily doses need to be doubled. (1,2,4) Thus, patients should be routinely given advice on how to manage their steroids during illness, the so-called sick day rules. Poor sick day management increases morbidity, and may lead to hospital admission with associated costs to the NHS. In Wales, an average of about 200 admissions each year are primarily due to adrenal insufficiency, accounting for an average 750 bed days per annum. (5)The most serious cases result in an adrenal crisis, a potentially fatal medical emergency, in which the body's production of cortisol is critically impaired.

2 GUIDELINES AND PRACTICE

Current NICE guidance (4) states that at diagnosis of adrenal insufficiency, patients should be provided with an emergency therapy card and information regarding sick day rules. However, clinic encounters have identified that not all patients on long-term steroids are adequately educated on sick day rules.(4) Thus, improving knowledge of sick day rules amongst patients will improve patient well-being and prevent hospital admissions. Ultimately, this will align our practice in Cwm Taf Morgannwg University Health Board with national recommendations.

3 AIM

The Steroid Patient Information Survey (SPINS) aims to ensure our current service provide appropriate advice and education to patients on long term steroids including oral and high dose inhaled steroids.

4 METHODOLOGY

Inclusion Criteria:
Any patients taking any of the following medicines:
- Oral Prednisolone
- Oral Hydrocortisone
- Oral Budesonide
- Oral Dexamethasone
- High dose Inhaled corticosteroids (ICS)

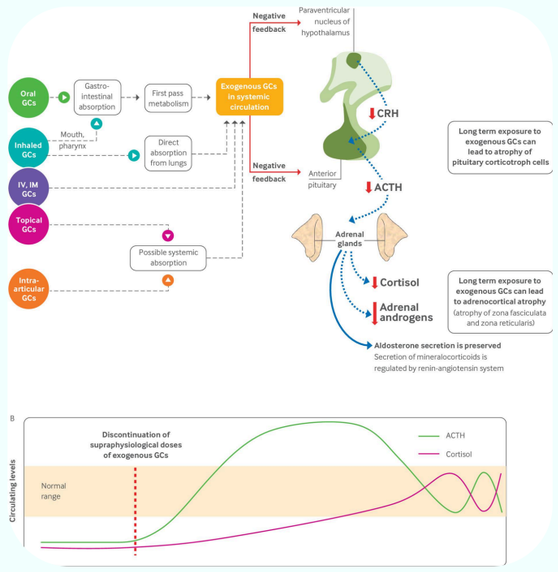

Figure 1 (Ref 3) Taken from BMJ Demonstrates glucocorticoid induced hypothalamic-pituitary-adrenal axis (HPAA) suppression and recovery

Exclusion Criteria:
- Patients with terminal disease.
- Cognitive decline/dementia/Learning disability
- Non-English speaking (we may look to translate survey in the future)

Primary care data

- Searches will be run in primary care using EMIS WEB or Vision to identify patients that meet the inclusion criteria.
- These patients will be sent a pack containing information on steroid sick day rules, a questionnaire and an alert card.
- Completed questionnaires can be posted back in pre-paid envelopes.

Secondary care data

- Patients who meet the inclusion criterial will be identified by the team on the ward or in clinic and offered to participate in the project. Patients will be offered a pack containing information on steroid sick day rules, a questionnaire and an alert card.
- Completed questionnaires are placed in a sealed box until review by the project team.

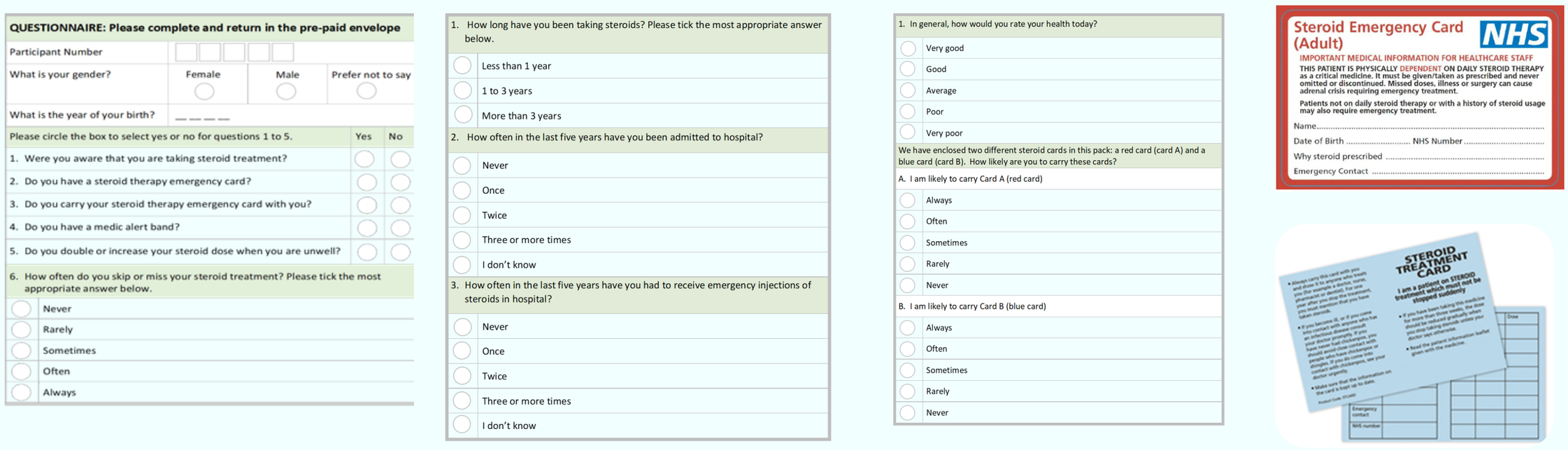

Figure 2 (3) Shows part of the questionnaire and emergency steroid cards offered to patients as part of the pack.

5 PROGRESS

SPINS is currently ongoing. A trial of a small group of patients at one GP practice and patients in secondary care was conducted between February and May 2024. Based on the results from the pilot the questionnaire was refined to allow for more qualitative data to be captured.
Expected Impact of the study:

- Improved education amongst patients on steroid sick day rules. The survey findings will support the design of a simple consistent educational package for patients on long term steroids which will be implemented at the initiation of steroid therapy and reinforced at subsequent clinical encounters throughout CTM.
- Reduced admissions to hospital due to adrenal crisis.
- Patients are educated appropriately at initial point of contact in line with NPSA/NICE guidance.

References:

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