

# Reducing the risk of adrenal crisis: a service improvement project assessing education on adrenal insufficiency.

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# Background

Patients who suffer from adrenal insufficiency are at risk of developing adrenal crisis due to prolonged and decreased cortisol levels <sup>1,2,3</sup>. This results in the patient suffering from persistent vomiting, severe muscle weakness and decreased blood pressure, and can develop into shock <sup>1,2,3</sup>.

Parents/carers of children with adrenal insufficiency routinely receive training on the provision of emergency hydrocortisone. This is based on the NHS Tayside guidelines which states that the dose of steroids given needs to be doubled in mild illnesses (such as the common cold), tripled in moderate illnesses and given intramuscularly by injection in severe illnesses with admission to hospital for intravenous access for fluids and further steroids.

### <u>Aim</u>

This service improvement project aims to assess patient and parent knowledge on their sick day rules, in NHS Tayside, with a view to improving the delivery of this information.

## Method

A 24 item postal questionnaire was constructed and distributed to parents of children with adrenal insufficiency. This included 11 sick day scenarios, where respondents provided their best answer via extended matching items. Responses were pseudo-anonymised and Caldicott guardian permission was obtained.

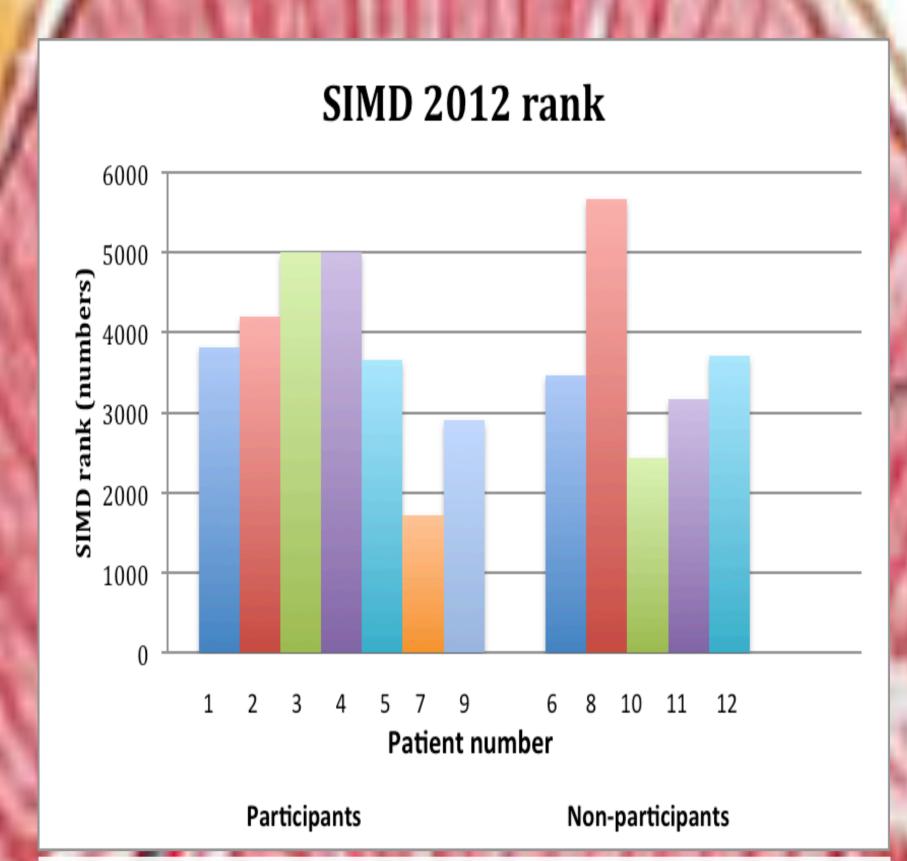


Figure 1: shows SIMD rank of the 7 patients that participated in the study on the left of the graph compared to the 5 who didn't. It shows that the majority of the children invited to take part in the study had a SIMD rank between 3000 and 4000. The least deprived patient was found to have not taken part in the study, with a rank of 5662, however the most deprived, with a rank of 1723, did participate.



Figure 2: shows the 7 participants total score for the 11 questions asked relating to sick day rules in the study. It shows that the minimum score was 35 and maximum of 62. The median score was 53.9 out of a total of 66, with an interquartile range of 5.5.

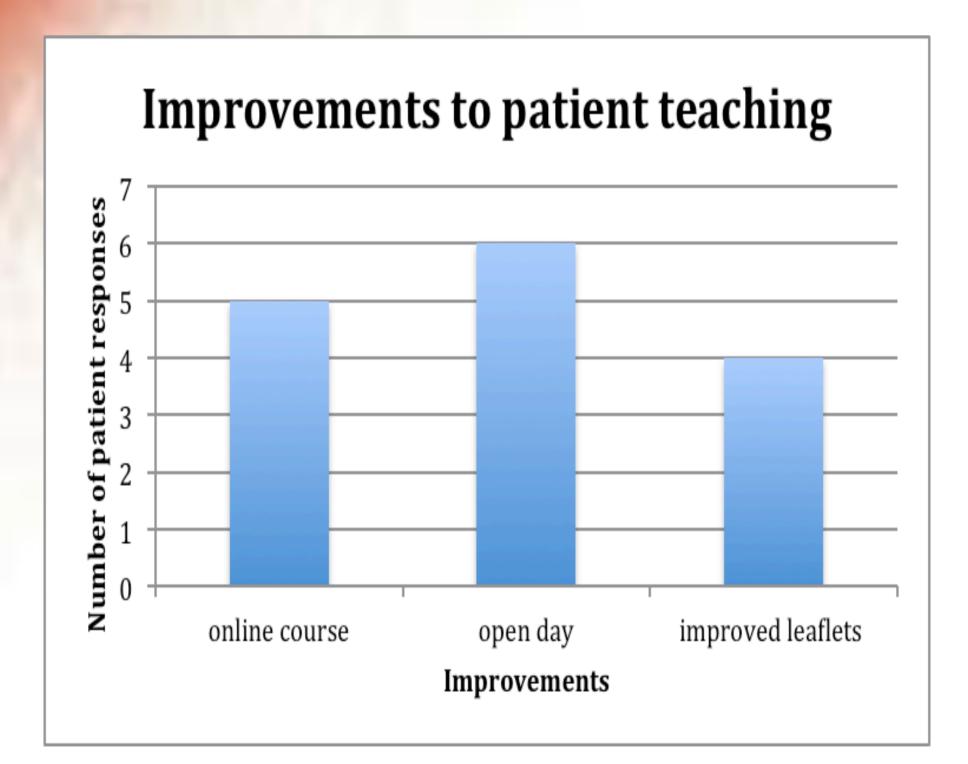


Figure 3: shows the responses of the 7 participants to ways in which patient education can be improved. It shows that the patients thought that all 3 methods would be beneficial with an open day being the most highly thought of method for patient education about sick day rules.

# Results

13 children were identified as having adrenal insufficiency, of which 7 responded (54%), with all having received training on sick day rules. Of the patients who filled out the questionnaire 6 of them were in the 3<sup>rd</sup> quintile for deprivation or higher with only one patient being in the 2<sup>nd</sup> quintile based on the 2012 SIMD guidance. Again, when assessing these patients deprivation based on their postcodes, none of the 7 that filled out the questionnaire fell into the most deprived percentile.

Sick day rule knowledge was good based on the 11 questions they were surveyed on, with a mean score of 82% (54 out of a possible 66, range 32-62). The questions they were asked related to the following illnesses: cold, fever, broken bone, tummy bug, cut, toothache, chest infection, skin or nail infection, simple faint, requiring surgery and when unable to take any food or fluids by mouth. 2 children completed the questionnaire themselves with significantly lower scores than the other participants (mean score 44/66, 67%, p<0.05).

The participants were also asked about new ways to educate both the parents and children on the sick day rules. They were receptive to the idea of an online educational course and open days to reinforce knowledge. Participants also felt that there was a lack of awareness on adrenal insufficiency amongst other medical specialities.

### Conclusion

We have demonstrated that parental sick day knowledge is currently good. Consideration should be given to how this information is delivered to children (especially as they transition into adulthood and have more control over their management) as well as colleagues within other areas of the healthcare system.

### References

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Background Image taken from: Forsyth Surgical Associates. Adrenal Surgery [homepage on the internet]. No date [cited 2015 Oct 14]. Available from: