British Society for Paediatric Endocrinology & Diabetes

RESEARCH and INNOVATION AWARD FINAL REPORT

As per the agreed conditions of the Grant, the BSPED requires a written report from the award winner demonstrating how the grant benefited the applicant/home institution and how the funding has enabled advances in endocrinology/science/medicine as a whole. The final written report is due two years after the grant is awarded detailing final findings, whether positive or negative. The report should include details of any publications resulting from the funding and will be published on the BSPED website.

A final written report (600-1000 words) is due detailing final findings, whether positive or negative. The report should include details of any publications resulting from the funding and will be published on the BSPED website.

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Title of project	Collaborative development of education standards and resources for the emergency management of Adrenal Insufficiency: A mixed method, multi-phase project
Year of award commencement	2024
Date of report	01.04.2026
Method	**Research aim:** To investigate the perceptions of young people with adrenal insufficiency (AI) and their caregivers regarding education and information on managing emergency episodes. **Design:** Online surveys and group discussions were used to gather quantitative and qualitative data in this sequential multi-method two phase study. Six parents/carers from key patient organisations, were consulted via a group videocall to help inform the planned recruitment and

	data collection methods. Parent/carers shared their views on the design, content and delivery of the survey and flyer. **Sample and recruitment:** A flyer was distributed via relevant charities and support groups to recruit young people with AI (ages 10-16) and their parents/carers (ages 0-16). **Data collection:** An online survey for parents/carers (34 questions) and an online survey for young people (19 questions), both using closed and open questions, were designed for this study. Young people with AI and caregivers participated in separate online group discussions. **Data analysis:** Descriptive analysis was used for the quantitative survey data, and content analysis for the qualitative open text responses. Thematic analysis was used to analyse the group discussion data. Multiple team members cross-checked codes and key messages. The key findings from each dataset were then synthesised into themes.
Results	**Participants:** The survey was completed by 12 young people (aged 10-16 years, mean 13) and 108 parents (mean age of child: 9.6). Online group discussions were attended by 9 young people (aged 12-15 years, mean 14), and 13 parents (mean age of child: 12.4) The young people and parents' children had a range of diagnoses including Addisons, Congenital Adrenal Hyperplasia, Septo-optic dysplasia and Hypopituitarism. Young people's survey responses linked to education are reported out of 8, as 4 of the 12 young people reported not having received any education on adrenal insufficiency from a health professional. **Initial education and information from health professionals about managing adrenal crisis and sick day rules** Many parents in the group discussions and open text survey responses highlighted the importance of initial education: "I think knowledge is power. I think they should arm you with all the knowledge at the beginning" (Parent 4; focus group). However, 4/12 young people surveyed had not received any education on adrenal insufficiency from a health professional. 73% (n=78) of parents found the information delivered at initial education easy or very easy to understand, compared to only 38% (n=3/8) of young people. One-third of parents (36%, n=39) said that initial education did not provide them with the knowledge to recognise signs of adrenal crisis. Many parents and young people described that initial education could have been more comprehensive, young people commented that information was often "*directed at my mum more than me*" (YP3; survey) and did not always feel able to engage in the

	sessions as they were “*too shy to ask healthcare professionals questions*” (YP11; survey). Some parents commented that the information provided was “*overwhelming*” (P5; focus group) and “*a lot to take in, in one sitting*” (P1; focus group). Around half of parents reported receiving education on their own (54%, n=58), and half received education alongside their child (46%, n=50). Being educated with their child was helpful for some parents however, others expressed concerns about their child receiving all the detailed risks. Regarding the administration of the hydrocortisone injection, 89% (n=96) of parents reported receiving a demonstration, whereas only 69% (n=74) reported having had the opportunity to practice. **After the initial health professional education** Most parents (70%, n=76) reported not receiving any updates or refreshers from health professionals following their initial education. Instead, many parents reported having to look for information on charity websites and young people described how they had had to rely on their parents for information. Only 82% (n=88/108) of parents and 54% (n=6/11) of young people reported being confident in managing sick-day dosing. Parents and young people spoke about the ambiguity around the meaning of ‘unwell’ and discussed the importance of updating their knowledge and skills, particularly when it came to administering injections. Both parents and young people discussed how they lacked information or guidance on the ‘wider aspects’ of living with AI, such as mental health and sharing the condition with friends. Young people reported that their concerns could be ‘brushed off’ by professionals.
Conclusion	The study shows that there are missed opportunities to ensure young people and parents have accessible information at the right time to ensure they have the knowledge and skills to manage a sick day or adrenal crisis. Young people were often excluded from education, and the timing of the initial education session was problematic for some young people and their parents. The study also highlights the ongoing uncertainties of parents and young people in administering sick-day dosing and the hydrocortisone injection.
Publications	A paper has been drafted ready for submission to a peer reviewed academic publication (expected to be submitted by June 2026). A first draft has already been reviewed by the research team. An abstract of the output was presented as a poster in the joint ESPE-ESE meeting in 2026. Prof Bray presented the output as an

	update of the project at BSPED 2025. We plan to submit the full results as an abstract to BSPED 2026. The results of this research directly informs the work of the BSPED Working Group on Standards of Education of Sick Day Management of Adrenal Insufficiency led by Dr Wong; Prof Bray and Prof Ng are also members of that working group. Those standards have been finalized following a modified Delphi process and expected to be launched later in 2026.
Benefit to applicant	This project expanded the existing body of work of **Prof Bray**, by enhancing her portfolio of work related to health literacy in children and young people living with long-term conditions. The project also strengthened research partnerships with **Dr. Wong**, **Prof. Ng**, and built a working relationship with the BSPED. In addition, further funding has been awarded by patient groups (Addison's Disease Self Help Group, Pituitary Foundation and Living with CAH-funds awarded to **Prof Bray**/Edge Hill University) to co-develop resources to meet the identified information gaps that can be used as national educational resources for sick day management.
Benefit to department/ institution	The project has been part of the programme of work linked to the children, young people and families research theme at Edge Hill University. This collaboration with the team and with the patient organisation has enhanced the university's standing as a leader in healthcare education and has promoted interdisciplinary collaboration between the university and the NHS.

Please email all reports to bsped@endocrinology.org