

Determining Care Consensus Guidelines for Life-Long Follow-up Based on Stakeholder Input in Hypospadias

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Introduction: Hypospadias (HS) is one of the most common congenital diseases, affecting 1/150-1/300 males born in the US. Most patients undergo surgical repair at a young age; however, many develop variable future complications. Long-term studies of adults show that many of these complications are related to voiding problems, social problems, and depression. Using previous patient and medical expert data, we have identified the need for a patient-centered care planning tool that is able to longitudinally address patient concerns to personalize their follow-up plan after HS repair. However, there are no points of consensus on long-term patient follow-up. Therefore, this study looks to confirm points of consensus for long-term care of HS across multiple specialties, to develop a patient-oriented web application.

Methods: The Delphi method, which is a structured approach to reaching a consensus on a particular topic or problem using expert opinions, will be used. Medical experts and patient stakeholders were recruited during a previous IRB-approved study. All participants will take part in a process where they will provide feedback on a set of Likert-scale statements addressing potential life-long concerns of HS patients. Statements were created using data from qualitative literature reviews and patient interviews consisting of youth, adolescent, and adult HS patients. Analysis will be run and statements that have more than 60% of respondents select agree or strongly agree to a statement will reach a consensus. The remaining statements will be revised or deleted, and a new round of statements will be sent out along with the comments of other stakeholders. These comments can be used to guide evaluations of the new survey but will be presented anonymously to avoid biases. 4 total rounds will be completed to finalize consensus statements for HS care.

Expected Results: We expect to achieve consensus on over half of the proposed statements. Robust consensus on the proposed statements will yield a short list of screening questions that will aid in the pilot model of a care-planning tool.

Conclusions: HS patients and healthcare providers of HS patients desire an online care-planning tool that is able to effectively address long-term symptoms and follow-up of HS. This study fills a crucial gap in the literature by providing insights into the perspectives of medical experts and HS patients/parents regarding long-term care. The findings will inform the development of a comprehensive care-planning tool, enabling personalized and effective management of HS.

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