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### Development of medical alert cards using structured data to assist in the management of children with Anorectal Malformation, Cloaca, and Cloacal Exstrophy

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# Development of medical alert cards using structured data to assist in the management of children with Anorectal Malformation, Cloaca, and Cloacal Exstrophy

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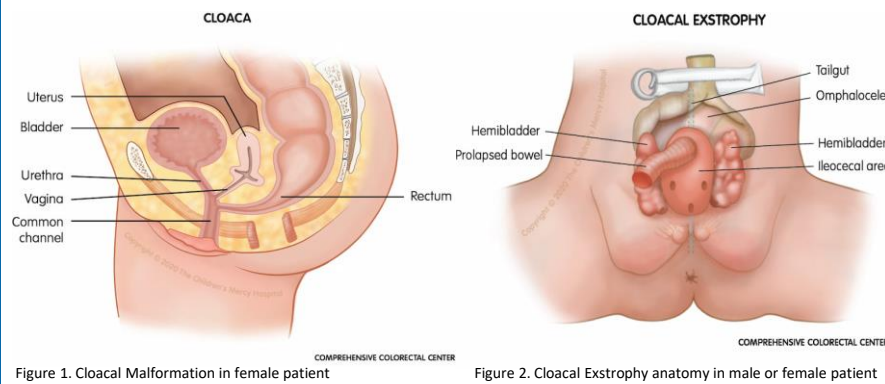
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### Introduction

- Anorectal malformations are present in 1 in 5000 children
  - Includes children with cloaca and cloacal exstrophy (1 in 50,000)
- ARMs result in variant anatomy at different stages of reconstruction and healing
- Emergency situations
- Anatomic variation requires specialized knowledge and equipment in management

### Aim

Design a medical alert card that raises awareness among providers and caregivers of variant anatomy and management for patients with anorectal malformation



### Methods

- Single institution study
  - Dedicated colorectal center
  - Multidisciplinary (Surg, GI, Gyn, Urol, Psych)
- Survey:
  - Iterative review -questions and concerns
- Cards:
  - Collection of common anatomic, procedural, and surgical information
  - Collection of VACTERL anomalies
  - Notation of special equipment required
  - Contact information

### Results

**Components of card** - selected through drop down menus to create an individual card

- Condition (ARM, cloacal, cloacal exstrophy)
- VACTERL associated conditions
- Anatomic variations
- Surgeries (ex: colostomy with blind ending mucous fistula) as these can lead to complications of their own
- Bowel management (Ex: utilizes enemas)
- Urinary system (catheterization techniques, equipment, channels)
- Contact information (phone and website links)

#### Antegrade Colonic Access

- Channel type (appendicostomy vs. cecostomy)
- Catheter specifications
- Flush ingredients
- What to do if tube falls out
- Concerning symptoms
- Diagnostic imaging and labs
- Link/QR code to website

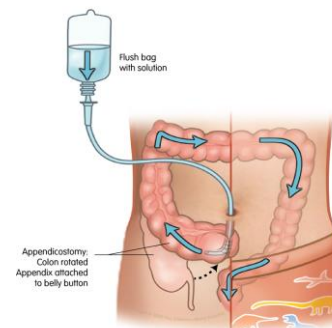


Figure 3. MACE or Malone Antegrade Continence Enema. Note the channel, catheter, and flush

### Conclusion

#### ARM specific medical alert cards:

- Are valuable communication tools proven to enhance medical care in multiple medical settings
- Raise provider and family awareness of anatomic variation
- Provide easy to access patient/provider specific information and resources
- Help understand unique variations for routine procedures and provide anticipatory guidance to manage care
- May lead to prompt recognition of symptoms, diagnosis and earlier implementation of appropriate management