



# A cross-sectional analysis of paediatric urologists' current practices, opinions and areas of perceived importance in the delivery of adolescent & transitional care

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## Summary

### Introduction

Complex urological anomalies often require continued care as patients reach adulthood. Adequate transition for adolescents with ongoing urological care needs is critical to allow for seamless care in adult hospitals. Studies have shown that this can lead to improved patient and parental satisfaction, and lower utilisation of unplanned inpatient beds and emergency department visits. There is currently no ESPU-EAU consensus on the adequate mechanism and very few individual papers examining the role of urological transition for these patients in a European setting. This study aimed to identify current practice patterns in paediatric urologists providing adolescent/transitional care, to assess their opinions towards formal transition and to look for variations in care. This has implications for long-term patient health and specialist care.

### Methods

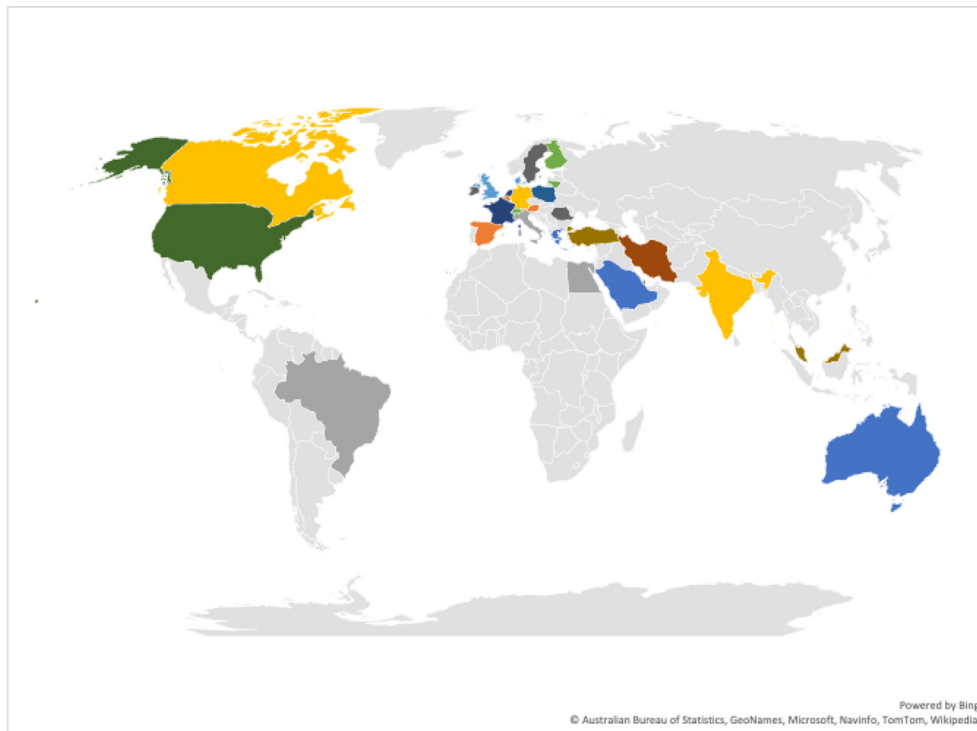
An 18-item cross-sectional survey was compiled and pre-approved through the EAU-EWPU and ESPU board offices prior to dissemination to all registered ordinary members affiliated with the ESPU. This was created using a mini-Delphi method through the EWPU research meetings to provide current semi-quantitative data relating to current opinions and attitudes of this cohort.

## Results

A total of 172 respondents (55% paediatric general surgery; 45% urology) across 28 countries completed the survey. The majority of respondents were in practice >10 years and spent >80% time in paediatric urology. There was no formal transition process according to 50% respondents and over half of those that did have less than 1/month, with <10% using validated questionnaires. More than two-thirds respondents continued to provide care after transition, as >70% units had no designated corresponding adult service. Furthermore, 93% paediatric believe a formal transition service to be very important, using a multidisciplinary framework. A pareto chart demonstrated 10 specific conditions to be of most interest in transition to adulthood.

## Conclusion

This is the first study to assess the requirements of paediatric urologists for adequate transitional care, however due to the nature of the survey's distribution, this was a non-scientific poll based on a convenience sample of respondents. It is critical that dual-trained or adult-trained urologists with a specific interest in paediatric urology work with current paediatric urologists in a multidisciplinary fashion to facilitate early transition based on the adolescent's developmental and biopsychosocial requirements. National urological and paediatric surgical societies need to make transitional urology a priority. The ESPU and EAU should collaboratively consider developing transitional urology guidelines to allow a framework by which this can occur.



Australia	3	Italy	9
Austria	4	Lithuania	1
Belgium	4	Malaysia	5
Brazil	9	Netherlands	7
Canada	11	Poland	6
Denmark	8	Qatar	2
Egypt	9	Romania	2
Finland	1	Saudi Arabia	3
France	7	Spain	4
Germany	11	Sweden	2
Greece	3	Switzerland	1
India	11	Turkey	5
Iran	10	UK	8
Ireland	2	USA	24

**Summary Figure** Illustration of respondent countries of paediatric urologists who completed the survey.

## Introduction

The transition from adolescence to adulthood is a challenging time of biological, psychological, and social change. Adolescents with underlying urologic conditions and any mental health issues which accompany them must also need to deal with changes in care that is provided to them as they move to adult services. They are furthermore expected to exercise a greater role and independence in the management of their own conditions. Thus it is imperative for health care systems to adequately meet the needs of these adolescents and young adults during this time of flux in order to ensure that there is no deterioration in health which can have long-standing consequences for them [1,2]. Patient reported surveys have also reported adolescent as a time where an increased number of interventions are required prior to transition to adult services to minimise risk of deterioration [3,4].

The term transitional care was defined 30 years ago as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems” [5]. This definition described the metaphor of moving from the pond into the sea and has been a focus of medical specialties ranging from diabetes to cystic fibrosis to sickle cell care to adult congenital heart disease, but a concerted effort in urology has only come under the spotlight relatively recently in urology due to significant advances in anaesthesiology, critical care, radiology and nephrology. Even in the latter half of the 20th century, most babies born with bladder exstrophy died in childhood and approximately 60% of those born with spina bifida died before the age of 40 years [6]. However, recent advances in neurosurgery, genitourinary surgery, gastroenterology, and physical medicine and rehabilitation have contributed to improve survival such that 75–85% of individuals with spina

bifida now survive into adulthood [7]. Transitional care in urology is a multi-faceted process designed to encourage a patient who is able to accept full responsibility for medical decision-making and care with an adult urological care team. It is recommended that this process of transition should begin around 12 years of age with the goal to provide uninterrupted, developmentally appropriate transfer of medical care to an adult - care model [8]. There is however, no silver bullet to prescribe this process. In a study in Indiana it was demonstrated that only 40% of patients transitioned successfully from a multidisciplinary spina bifida clinic with a number of these patients re-presenting after 2 years of having no structured care, however, those patients followed by a urologist were less likely to present to the emergency department [9]. Similarly, in another cohort of transitional spina bifida adolescents, failing to adequately transition patients led to an increase in emergency department, inpatient, and surgical costs [10]. As such, borrowing from the example of specialized centers in the United States and Canada and with recommendations from the American Academy of Pediatrics and the American College of Physicians, transitional units began to be established in North America in the last decade to try to tackle this issue [11]. Similar units in Europe have developed in an *ad hoc* manner, however there is an increasing awareness of the necessity to drive this initiative to optimize patient outcomes in this population and to increase collaboration between adult and paediatric healthcare providers. It is also understood that those providing adolescent and transitional care should have an interest in the long-term care of these patients and understand the idiosyncrasies of congenital urological conditions.

This study's primary aims were to identify current practice patterns in paediatric urologists providing adolescent/transitional care, to assess their opinions towards formal transition and to look for variations in care. The secondary aims were to compile which case-mix was of most interest in transition and how they deemed this was best facilitated.

## Methods

An 18-item cross-sectional non-validated Google Forms survey was compiled using a mini-Delphi method in collaboration between the European Association of Urology (EAU) Working Group in Paediatric Urology (EWPU), the EAU Young Academic Urologists (YAU) office and the European Society of Paediatric Urology (ESPU) and was approved by each board (Appendix 1). These questions related to current practice patterns, variations in transitional care, and opinions regarding transitional care in urology and took approximately 8 min to complete. The survey was dissemination by the ESPU to all affiliated paediatric urology department chairs, to all YAU members through opt-in contact lists and through Twitter links on social media including @EAUEWPU and @EAU\_YAUPedsUrol. A further invitation was emailed 1 month later to encourage enrolment. A limit was placed to prevent the same IP (internet protocol) address being used more than once. The survey consisted of multiple-choice questions with free text options and included information about 16 complex genitourinary conditions including spina bifida, bladder exstrophy,

cloacal exstrophy, cloacal anomalies, posterior urethral valves and disorders of sex development.

Inclusion criteria for the target population were adult urologists who undertook regular paediatric or adolescent work and general paediatric general surgeons who considered themselves to be paediatric urologists. Exclusion criteria were those who did not undertake any paediatric urological work or did so infrequently (<50% of the time as per the questionnaire). Questions were set as mandatory except for initial demographic questions. There were no interventions in this observational study.

**Table 1** Survey responses regarding current care patterns in transition clinics for adolescent urology patients.

Parameter	n	% respondents
<b>Residency Type</b>		
Adult Urology	95	55
Paediatric General Surgery	77	45
<b>Paediatric Urology Experience (years)</b>		
<5	18	11
5–10	46	29
11–20	78	49
20+	18	11
<b>Paediatric Urology Practice (%)</b>		
<50	10	6
50–80	21	12
80+	139	82
<b>Number of Transition Clinics (per month)</b>		
<1	19	12
1–2	122	77
3–4	17	11
<b>Average Number of Patients Transitioned (per annum)</b>		
<10	16	10
10–20	109	66
21–50	32	20
>50	7	4
<b>Use of a Validated Transition Framework/Checklist</b>		
Yes	19	11
No	148	86
Not Sure	5	3
<b>Routine discussion of Sexual Function/Fertility</b>		
Yes	129	75
No	33	19
Not Sure	10	6
<b>Routine discussion of Pregnancy/Contraception</b>		
Yes	88	51
No	65	38
Not Sure	9	11
<b>Encouragement of Independent Appointment Attendance</b>		
Yes	118	70
No	35	21
Not Sure	15	9

In those situations where questions were left unanswered, calculations were based on the those who did answer the question. Statistics were predominantly descriptive in nature. The study was deemed not to require ethics approval by the hospitals research and ethics committees.

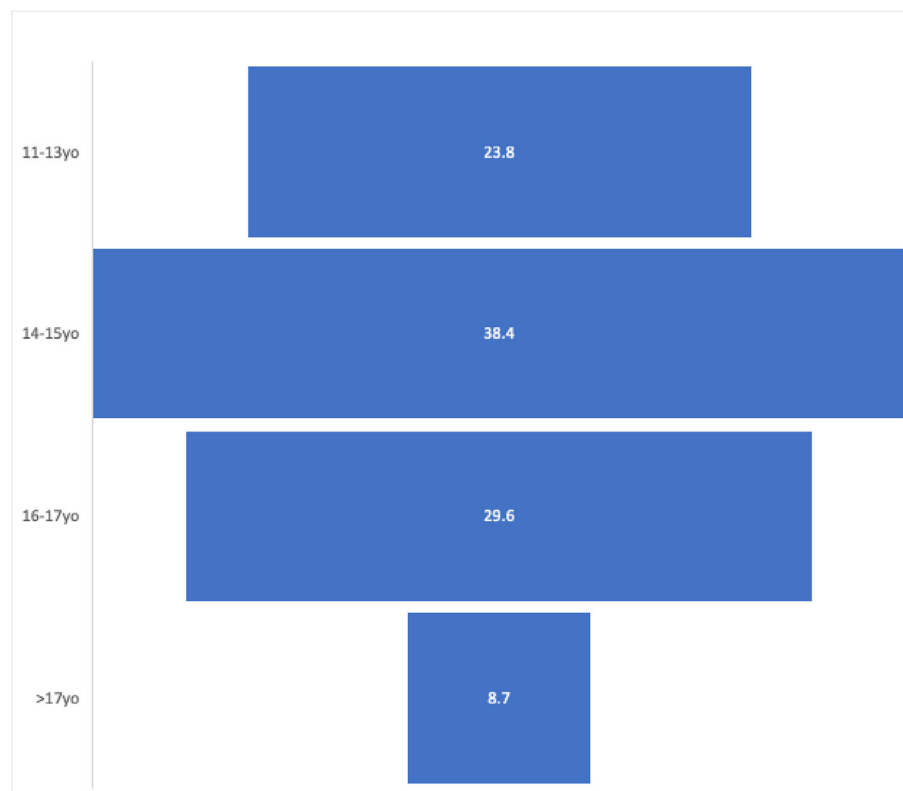
## Results

A total of 172 respondents (55% paediatric general surgery; 45% urology) across 28 countries completed the survey (Appendix 2). The majority of respondents (60%) were in practice >10 years and 82% spent >80% time in paediatric urology. Not all questions were answered by all respondents and in those cases responses were based on those totals accordingly. There was an overall full completion rate of the survey of 91.3%. Questions which remained unanswered related to responder demographics. Those who practiced paediatric urology <50% of the time were also excluded. This amounted to 14 surveys which were not used in the analysis.

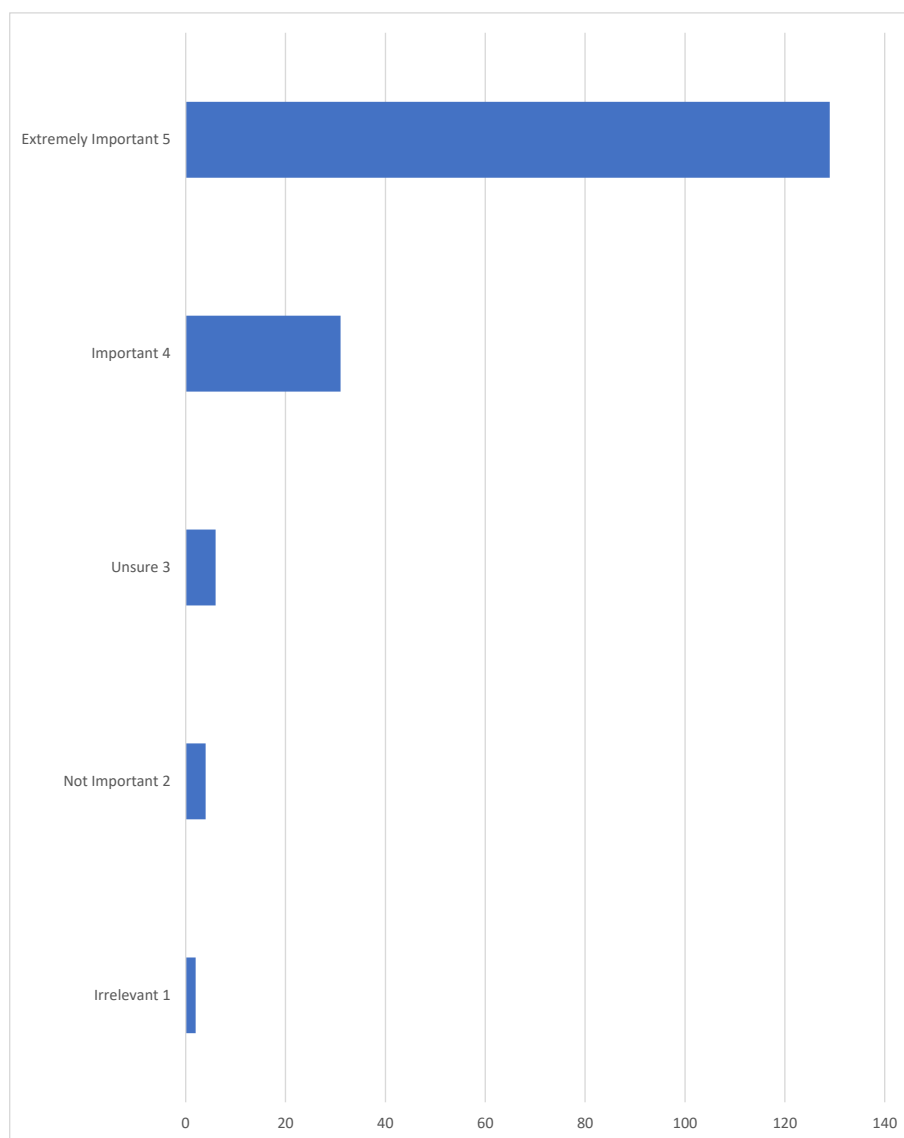
The majority of respondents were in practice >10 years and spent >80% time exclusively in paediatric urology. The overwhelming majority of respondents (82%) managed </ = 2 transition clinics per month with 76% transitioning </ = 20 patients per year to adult services (Table 1). Of those that did have dedicated transition clinics, 86% didn't use a formal transition framework and of those that did, the majority responded that they used the Transition

Readiness Assessment Questionnaire (TRAQ) (55%), followed by the Ready Steady Go Transition program (24%), as well as a minority stating that they used local/national framework guidelines. Approximately 70% units had no formal framework to transition these patients to congenital adult colleagues and 67% respondents continued to provide *ad hoc* care themselves after the national age of majority, of which 63% respondents were paediatric general surgeons. Despite this, 62% respondents believed that the most appropriate age of transition was 15 years or younger (Fig. 1). Only 75% survey respondents stated that they routinely discussed sexual function/fertility with their patients prior to transition with just over half respondents stating that they discussed issues around pregnancy and contraception. In addition, 70% respondents also encouraged independent attendance of patients at their clinics and 93% respondents felt that a structured approach to transition of adolescent urology patients to be (extremely) important and should be carried out through a multidisciplinary approach (Fig. 2).

Using a Pareto Chart of responses to cumulatively rank the importance of specific congenital urological conditions. The most important perceived conditions requiring structured transition to adult services included Bladder/Cloacal extrophy, Disorders of Sexual Development, Cloacal anomalies, Myelomeningocele (MMC), Neurogenic Bladder, Posterior Urethral Valves, Proximal Hypospadias and Prune Belly Syndrome (Fig. 3).



**Fig. 1** Survey respondents views regarding an appropriate age of commencing transition for adolescent patients. Each bar represents the relative percentage of respondents' answers (11–13years old, n = 41; 14–15 years old, n = 66; 16–17 years old, n = 50; >17 years old, n = 15).



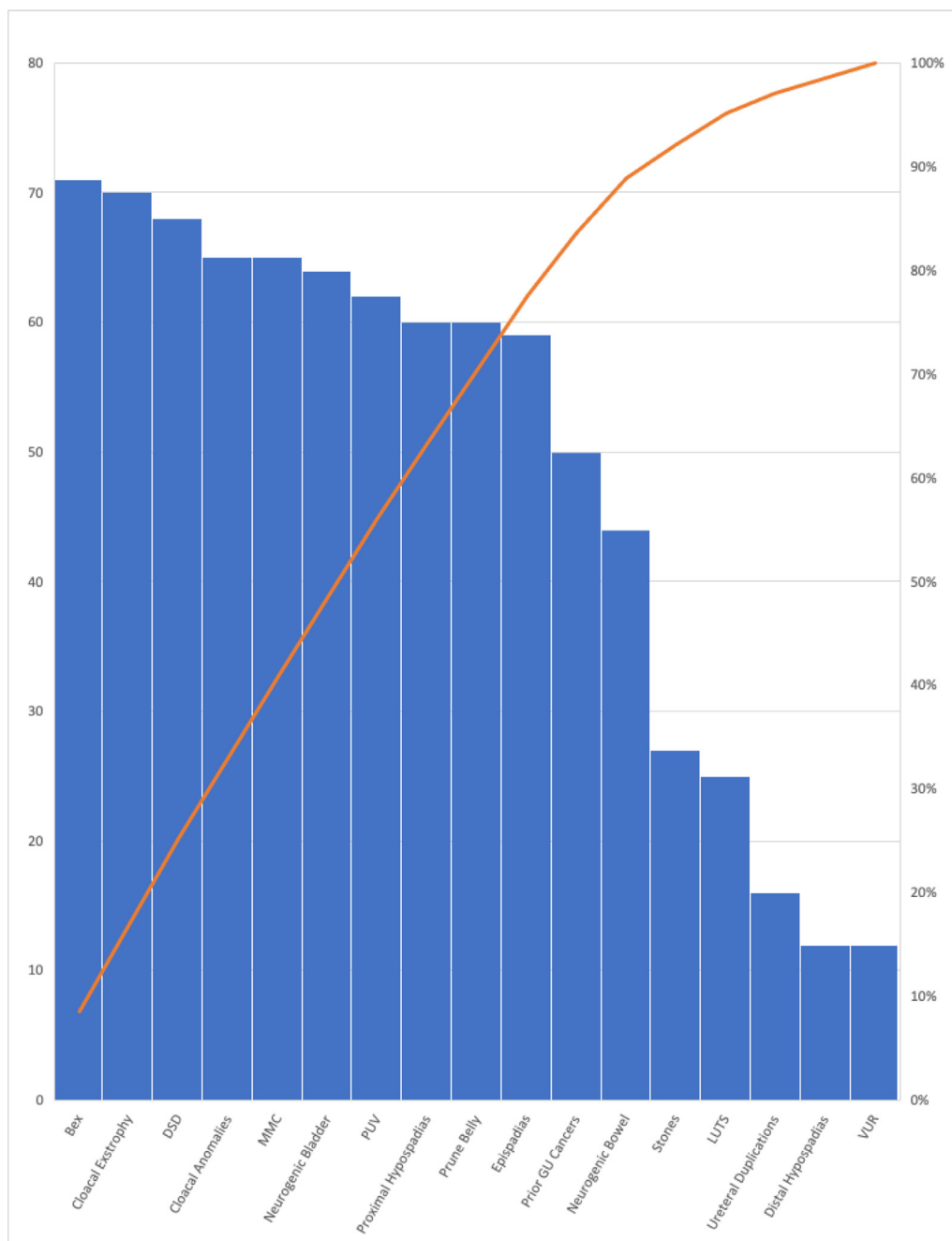
**Fig. 2** Survey respondents views regarding the importance of appropriate, structured transition of adolescent urology patients.

## Discussion

This study describes patterns and variations in care, and opinions regarding transition from a cross-section convenience sample of paediatric urologists in dealing with transitional urology patients. Despite the seniority of the majority of these respondents, there is little harmony in how these patients are managed in individual units, which is both unsurprising and a cause for concern. Many of these patients require continuity of care and there is evidence to suggest that a number of visits in transition clinics could be required to establish levels of trust with the adolescent/transitional service, as such it is important to have transition started at an age where this can be facilitated [12,13]. The use of structured transition frameworks (e.g., TRAQ) can help lead to slight improvements in disease management and transition readiness (process of building the capacity of adolescents and those involved in their care to

prepare for, enter, continue, and complete transition) [14–16].

There are a number of considerations for congenital urological conditions which must be taken into account in this population including renal function, bladder outlet obstruction and function including reservoir perforation and the development of neoplasms as well as the management of stone disease and urinary tract infection. Several studies have reiterated the importance of continued surveillance of patients with congenital anomalies of the kidneys and urinary tract (CAKUT) into early adulthood. In patients with posterior urethral valves, 32% of patients have been shown to have end stage renal disease by the age of 30 years regardless of early management [17]. Scarring of the kidneys can be acquired as a result of vesicoureteric reflux (VUR), especially when complicated by bladder dysfunction and/or recurrent pyelonephritis [18]. Bladder dysfunction may arise from spinal cord (MMC) or brain abnormalities, or be acquired conditions such as from



**Fig. 3** Pareto chart demonstrating views of paediatric urologists of the most important conditions requiring appropriate transition for optimal ongoing urological care (BEX: Bladder exstrophy; DSD: Disorders of Sexual Development; MMC: Myelomeningo-coele; PUV: Posterior Urethral Valves; LUTS: Lower Urinary Tract Symptoms [inc. recurrent urinary tract infections]; VUR: Vesicoureteric reflux).

recurrent UTIs, stones, trauma, chemoradiotherapy, or reconstruction (including augmentation) [19]. Ileum and sigmoid colon are the most commonly used bowel segments for cystoplasty; however their absorptive properties lead to hyperchloremic metabolic acidosis in up to 50% of patients with reservoir stones occurring in greater than 50% patients [20]. Although the rate of neoplasia appears to be the same as controls in those who have undergone augmentation cystoplasty (in the absence of recurrent infections), the

risk of bladder cancer in patients with exstrophy has been reported as increased by more than 600-fold at the age of 40 years compared to the general population [21,22].

This study suggests that despite the abundance of data pertaining to the importance of long-term specialist surveillance and the broad consensus on the need for multi-disciplinary clinics from early teenage years across a number of conditions, there remains little agreement regarding how this should be carried out. A recent scoping



review from Toronto demonstrated that most adolescent patients felt that sexuality and fertility were not adequately tackled during the transition phase, with reported barriers to successful transition including patient, provider, and system factors, including a lack of insurance coverage/financial management, patient preference, trust and communication with the adult provider [23]. This is broadly in line with the findings of this study in that these questions should be addressed during this time. Similarly, in cases of severe penile insufficiency, phalloplasty demonstrated improved psychosexual outcomes but at the price of a high complication rate. In addition, females with epispadias–exstrophy complex were shown to have higher rates of pregnancy complications, including a higher risk of miscarriage [24]. It is thus critical to improve communication with patients in transition clinics around these issues, to prepare for sexual activity and fertility and to have a dedicated team as an important element of this transition [25,26]. Patient and parental education is also important given the relatively low levels of compliance of certain groups with routine follow-up (e.g. MMC) who often fail to visit healthcare providers unless there is an acute urological issue, or similarly do not have the resources or time to travel to specialised centres for specialist care once they reach adolescence [27,28].

The limitations of this study include the self-reported nature of this non-validated questionnaire, however there are no known national registries from which to draw data. Furthermore, due to the nature of the survey's distribution, this was a non-scientific poll based on a convenience sample of respondents, which is almost an unavoidable consequence of utilising social media channels. This study is also limited by a certain risk of inclusion bias and an unknown number of not answered questionnaires for unknown reasons. It could be argued however that there is adequate representation of both paediatric general surgery and adult urology with a 55%/45% respective split. Potential solutions to improve the urological care of this vulnerable population suggest additional national provider resources, standardised international guidelines, standardised adolescent/transitional multidisciplinary clinics, the establishment of national registries and further subspecialist training of paediatric urologists to improve the pathway of care for patients with congenital urological conditions requiring long term care, with a potential added benefit of reducing healthcare provider costs.

## Conclusion

This is the first study to assess the requirements of paediatric urologists for adequate transitional care. It is critical that dual-trained or adult-trained urologists with a specific interest in paediatric urology work with current paediatric urologists in a multidisciplinary fashion to facilitate early transition based on the adolescent's developmental and biopsychosocial requirements. National urological and paediatric surgical societies need to make transitional urology a priority. The ESPU and EAU should collaboratively consider developing transitional urology guidelines to allow a framework by which this can occur.

## Ethical approval

Not applicable.

## Sources of funding

Nil.

## Conflicts of interest

The authors declare that there are no actual or perceived conflicts of interest.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jpurol.2023.04.023>.