

### INTRODUCTION AND BACKGROUND

Spina Bifida (SB) is the most prevalent congenital defect of the central nervous system. Ireland shows a higher rate of 6.3 per 10,000 live births (Mc Donnell *et al* 2015) compared with 3.63 per 10,000 in the USA (Mai *et al* 2019). Life expectancy has increased resulting in a growing adult population. 85% of affected children are now expected to survive into adulthood. Bladder dysfunction is common in Spina Bifida individuals, highlighting the importance of ongoing urologic care. As patients transition from paediatric to adult services, many practitioners are faced with the challenge of treating this medically complex group of patients.

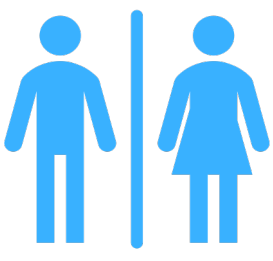
**PROBLEM:** Urologic care for those with Spina Bifida is dynamic and ever changing and symptoms can vary considerably. There is limited long-term outcome evidence on bladder management strategies available to help guide best practice for this group of patients.

**AIM:** Describe the urological management of an adult Spina Bifida population attending a nurse-led neuro-urology clinic in a rehabilitation setting, to better understand their issues and needs and improve long-term outcomes for this population.

**METHODOLOGY:** Exploratory retrospective chart review of 40 (random sample) adult Spina Bifida patients attending a nurse-led urology clinic. Data includes demographics, presenting complaints, bladder management, medication use, urodynamic studies, imaging, and laboratory results.

### RESULTS

#### DEMOGRAPHICS



Male n=22  
Female n=18



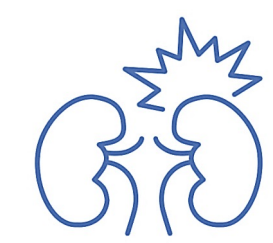
Age between 18-71 years.  
Mean age = 47



Regular attendees n=31  
New referrals n=9



Wheelchair user n=29  
Ambulant n=11



Chronic kidney disease n=2



Solitary kidney n=3

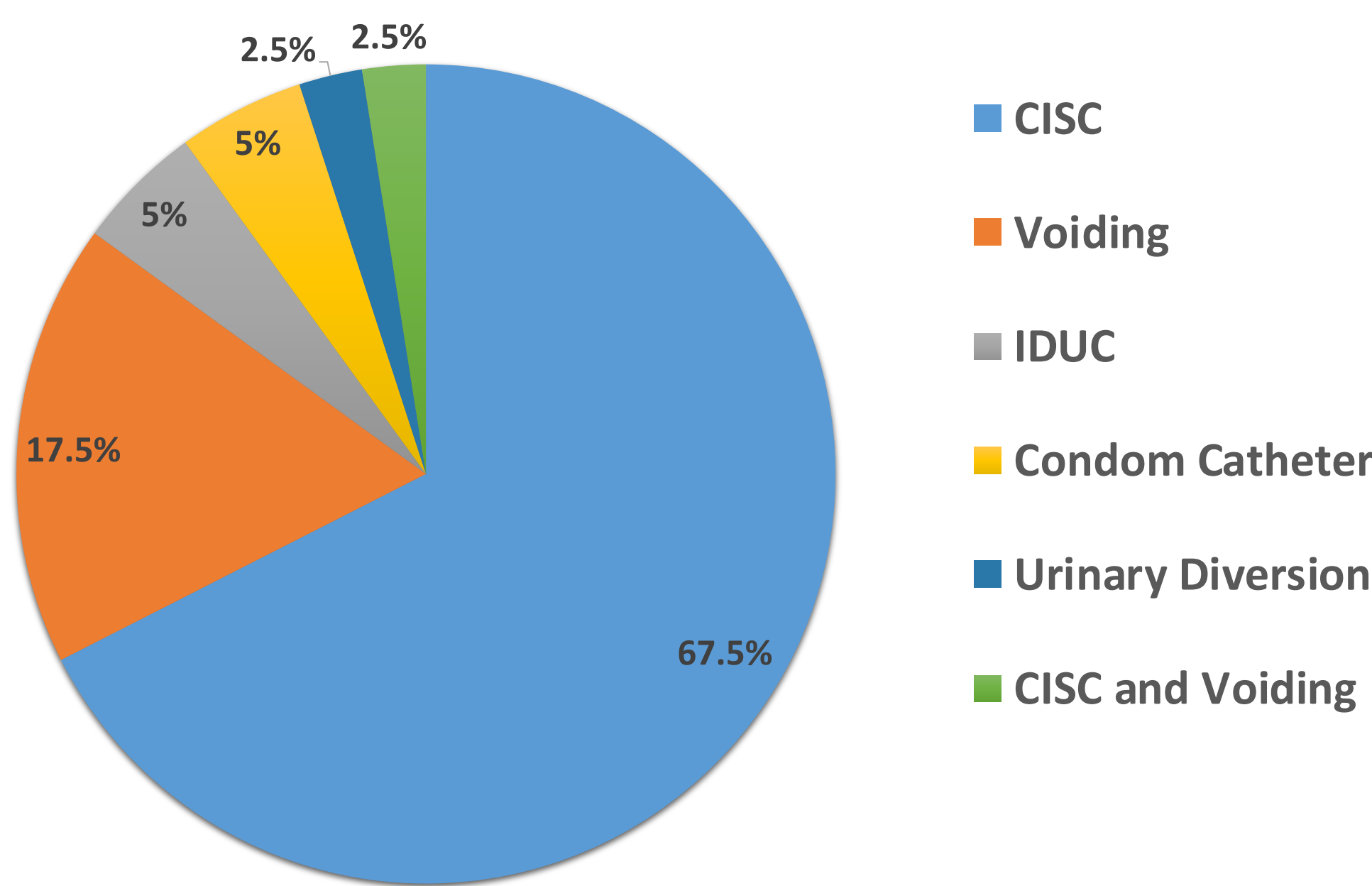


History of bladder tumour n=1



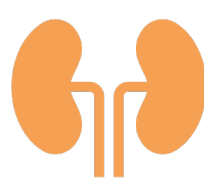
Total reporting urinary incontinence n=22

#### BLADDER MANAGEMENT



(CISC = Clean Intermittent Self-Catheterisation. IDUC = Indwelling Urethral Catheter)

#### CHRONIC BLADDER CHANGES / HYDRONEPHROSIS / RENAL & BLADDER CALCULI SEEN ON ULTRASOUND



History of hydronephrosis n= 14



History of renal / bladder calculi n=11



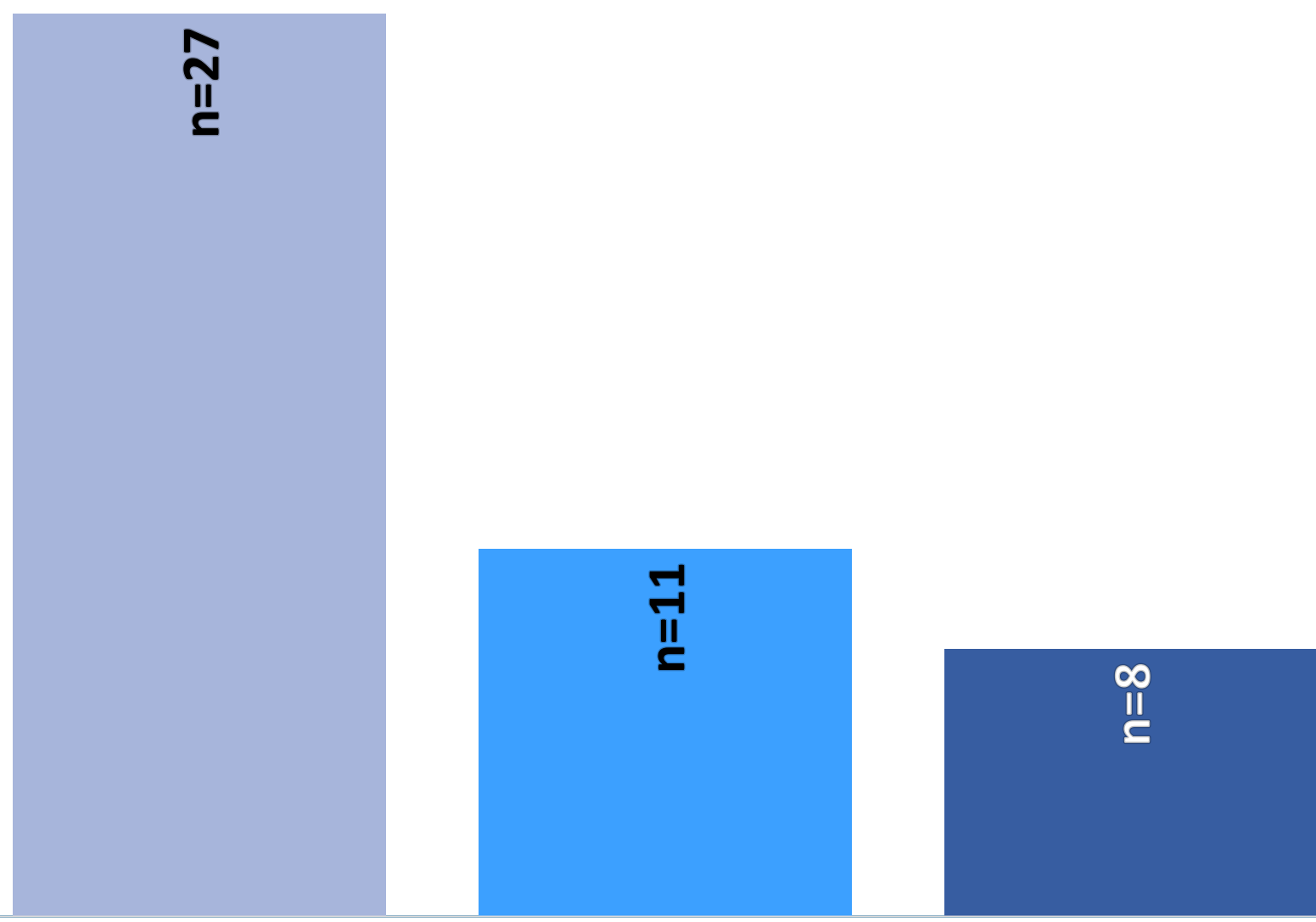
Bladder wall trabeculation /diverticula n=18

#### URODYNAMICS (UDS)

■ UDS

■ Repeat UDS

■ Change in clinical management as a result of repeat UDS



#### 3 sample UDS tracings below demonstrate where repeat UDS resulted in a change of management in order to establish a stable bladder and maintain continence:

Fig 1. Marked detrusor overactivity and associated incontinence requiring anticholinergic medication. Patient voiding.

Fig 2. Reduced compliance with OAB and incontinence requiring the addition of Mirabegron in combination with an anticholinergic. Patient self-catheterizing.

Fig 3. Intractable overactive, hostile bladder with high leak point pressures and possible DSD. Hydronephrosis on ultrasound. Patient self-catheterizing and required intravesical Botulinum toxin A (OAB = Overactive Bladder. DSD = Detrusor Sphincter Dyssynergia)

Fig 1.

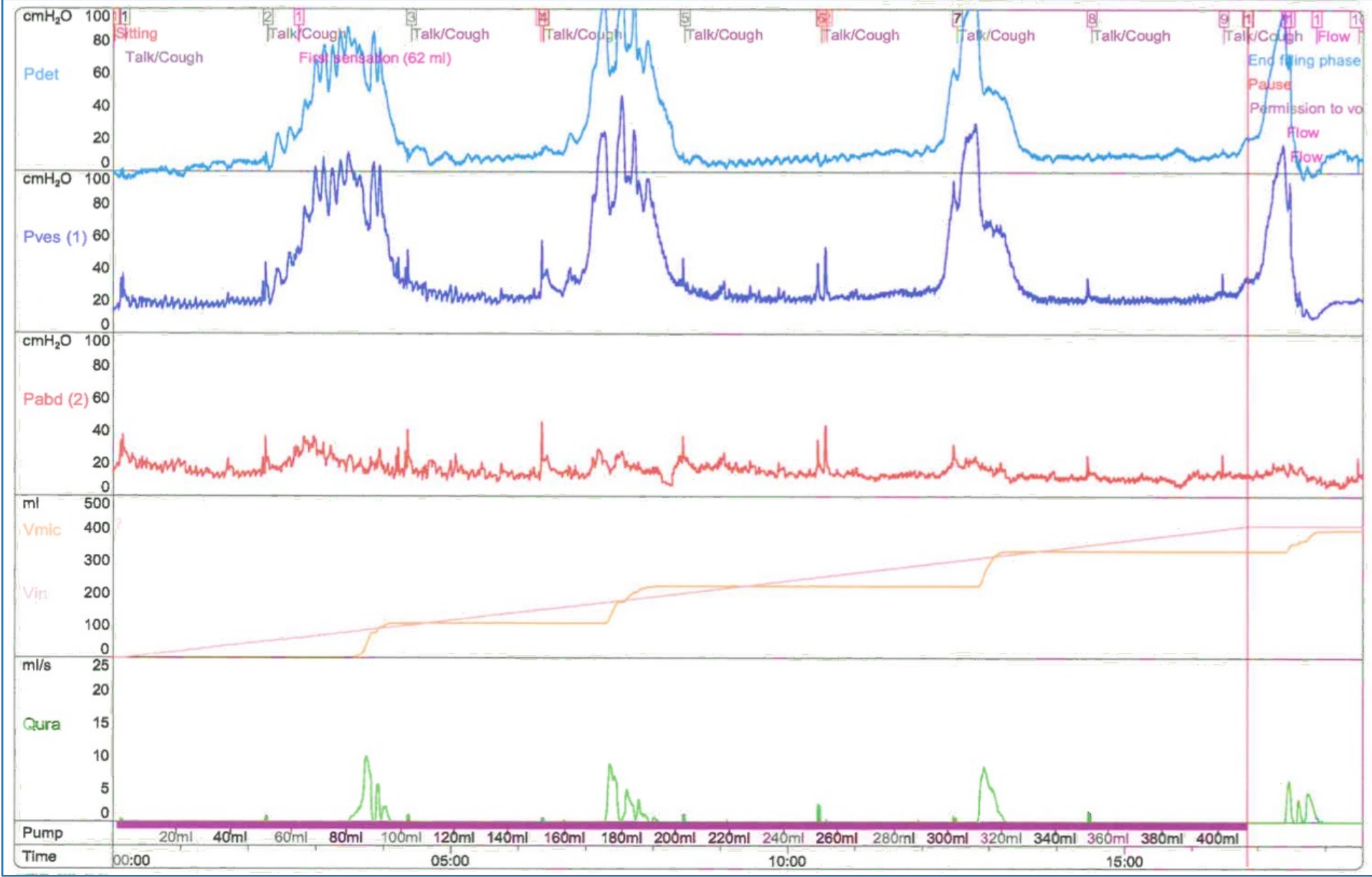


Fig. 2.

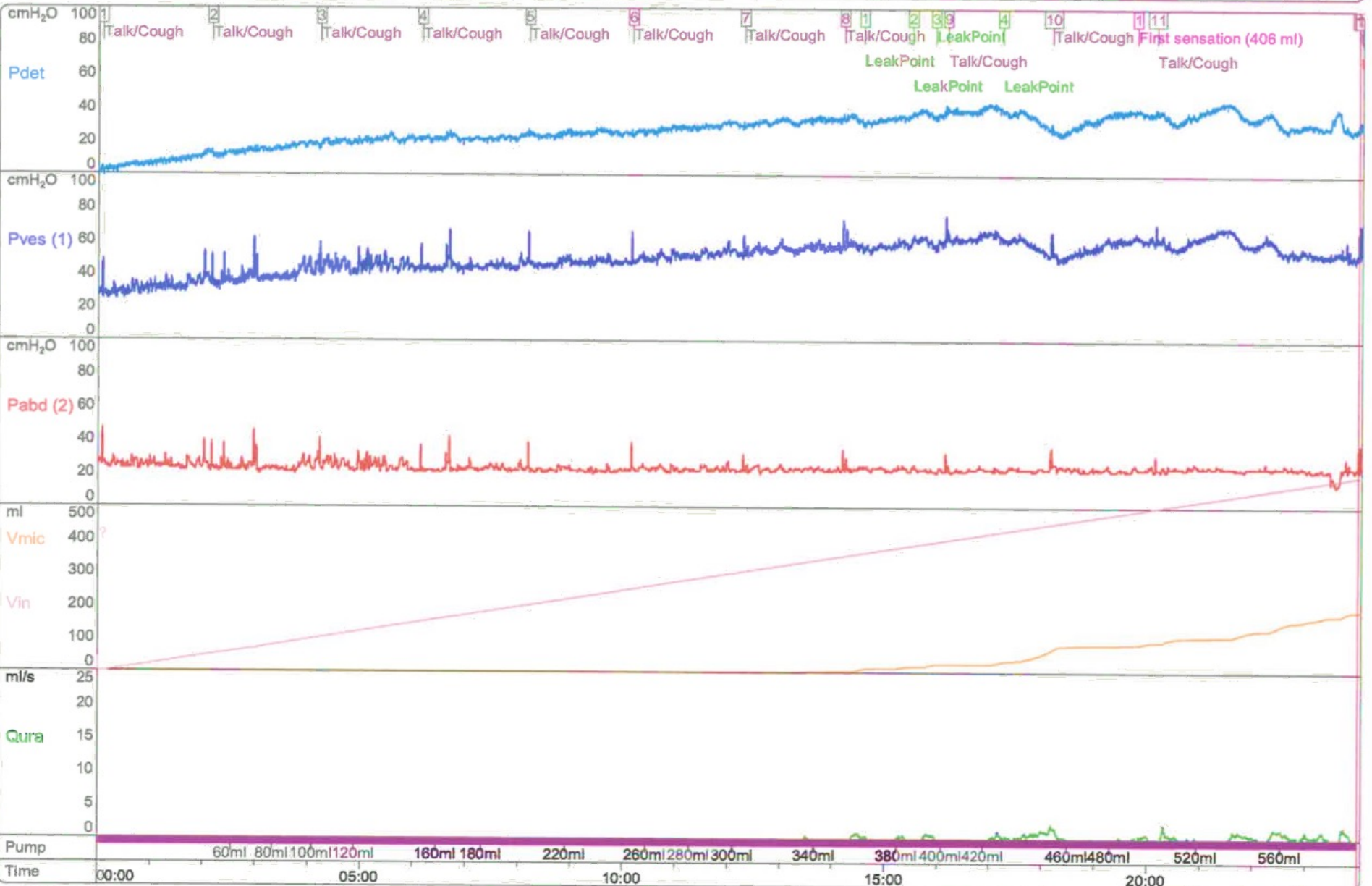


Fig 3.



#### RESULTS SUMARRY

- 45% of patients had chronic bladder changes on ultrasound
- 27.5% had a history of renal/bladder calculi
- 100% of new referrals required intervention, 89% needing UDS
- 55% report a degree of incontinence
- Two patients had recognised CKD

#### CONCLUSION

- Spina Bifida patients are at risk for progressive renal damage due to recurrent UTIs and high bladder pressures (Joseph *et al* 2020)
- They require ongoing observation and renal function monitoring
- Support is needed to achieve bladder management independence and enhance QoL into adulthood (Ouyang *et al* 2015)
- Continence is not stable throughout the lifetime of these patients. Regular follow-up and discussion with urologic Health Care Professionals in relation to urinary incontinence and complications is recommended (Schechter *et al* 2015)
- The increased lifespan of patients with Spina Bifida highlights the importance of transitioning care from the caregiver to the young adult, and from the paediatric urologist to the adult urologist (Joseph *et al* 2020) (CKD = Chronic Kidney Disease. QoL = Quality of Life)

#### RECOMMENDATIONS

- Annual urological follow-up (EAU 2022, Joseph *et al* 2020, NICE 2012) and smooth transition into adult services
- A neuro-urology, nurse-led clinic is best placed to offer this care, with access to a consultant urologist and specialised bowel management and sexual health services
- A multidisciplinary team approach is advisable
- Further longitudinal data is needed to determine best practice

#### REFERENCES

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