SECTION C – Details of concerns raised/complaints reported

1. Please provide full details of any concerns and/or complaints raised by you, specifying the nature of those concerns in as much detail as possible.

We are submitting this questionnaire on behalf of our late husband and father, Patient 1. The following account is a recollection of Patient 1's experience with Urology Services based on our discussions with him, our own interactions with those services and contemporaneous diary entries made by Patient 1 from diagnosis in Spring 2019 until his death in Personal Information redacted by the USI. The relevant diary entries are available for inspection upon request.

In the spring of 2019 Patient 1 watched a BBC Newsline segment which was focusing on the importance of males being vigilant with respect to the early signs and symptoms of male specific cancers. It noted the importance of regular PSA checks – one of the main indicators of Prostate Cancer.

He discussed this with his GP (Dr Personal Information redacted by the USI and a PSA test was carried out on 30th May 2019. A high reading was recorded and on foot of that reading Dr Personal Information redacted by the USI made a referral to Urology Services on 13th June 2019.

An MRI scan was carried out on 10th July 2019 and Patient 1 met with Mr Aidan O'Brien, Consultant Urologist on 22nd July 2019 at the South West Acute Hospital (SWAH). He was informed a malignancy was present in the prostate gland and that he would be referred to Craigavon and to the Cancer Centre in Belfast City Hospital for treatment,

A biopsy was taken at Craigavon Hospital on 20th August 2019 and a CT Scan at SWAH on 21st August 2019.

Patient 1 met again with Mr O'Brien on 23rd September 2019 and was informed that cancer was present in the prostate gland (with no spread). He was advised his cancer was of "intermediate risk" and that he would be referred for hormone treatment and radiotherapy. He was prescribed 150mg Bicalutamide and Tamoxifen.

On 25th November he commenced his medications. Almost immediately the medication did not agree with him. He started to feel dizzy and it was affecting his ability to drive. He has reported in a diary entry of 9th October 2019 reporting dizziness to a "specialist nurse" who advised him to take the medication at night-time to try and eliminate some of the worst of the symptoms.
He reports receiving a phone call from Mr O'Brien on 14th October from Mr O'Brien. He reports that he agreed that Patient 1 could stop taking both medications.

On 17th October he reports attending for a PSA test at GP.

On 28th October 2019 he reports attending for a CT scan at SWAH

On 31st October 2019 he reports attending for a bone scan at Craigavon Hospital.

On 1st November 2019 he reports starting a reduced dosage (50mg) of Bicalutamide and to continue not taking Tamoxifen.

On 11th November 2019 he reports attending again with Mr Aidan O'Brien at SWAH. A PSA test was done. He notes in his diary that he intended asking the following questions

- Can I stop Proscar?
- Take Bicalutamide at night?
- Stop all medication 'till after holiday?
- Take every other day?

18th November 2019 he records that he is stopping all medication for 1 week.

19th November 2019 there is an entry "Aidan O'Brien – Armagh". It is unclear what this entry is referring to.

22nd November 2019 – He records that he sought Mr O'Brien's permission to "leave out cancer tablet before flying – (OK'd by O'Brien)"

16th December 2019 he records Getting PSA checked.

23rd December 2019 he recorded "Appointment Line Craigavon Radiology Dept."

7th January 2020 he recorded "PSA level checked GP".

27th January he recorded attending with Mr O'Brien @ SWAH. He recorded being referred to an Oncologist at City Hospital.

6th March 2020 he recorded a PSA level check at GP
1
9th March 2020 he records "Seem to have lost control of my bladder."

23rd March he contacted Patient 1's daughter at work and asked her to A&E (his GP was unable to see him because of the COVID 19 situation) He was seen and prescribed muscle relaxants.

24th March 2020 he records "Really bad night – pain"

1st April 2020 he records "Started 150mg again"

2nd April 2020 he records "Really bad night!!"

3rd April 2020 he records “Progressively getting worse??”

4th April he records “Scared to go to A&E – worst night of my life!!”

5th April 2020 he records “Serious discomfort all night – absolutely no sleep.”

6th April 2020 he records “Night of hell with pain.”

7th April 2020 he records “Got to A&E – Got catheter fitted A&E

14th April 2020- Got catheter removed A&E, PSA test done – fingers crossed

19th April 2020 – Got new catheter fitted A&E

20th April 2020 – PSA checked @SWAH

22nd April 2020 – Get PSA checked

27th April 2020 – Aidan O’Brien @ SWAH 10:50am. (**this appointment never took place Patient 1 had been informed it would be over the phone – never happened**)

29th April 2020 – Prescribed Mirtazapine tablets (anti-depressant)

30th April 2020 – Commenced Mirtazapine – 150mg. New Bag for catheter. Visit of Kathy Travers.

1st May 2020- he records “I’m struggling – I’ve hit the old proverbial wall. Need help! Visit from Kathy Travers – informed Mr an O’Brien”.

4th May 2020 – Email sent to A O’Brien Personal information redacted by USI. A&E for pain.

5th May 2020 – Visited A&E – Got antibiotics for infection under foreskin and injection.

7th May 2020 – A note of telephone numbers for Mr O’Brien

1st June 2020 – He records “Re contact with ‘A’ O’Brien. Get injection and 150mg Bicalutamide. Will be admitted to Daisy Hill Hospital. Male surgical ward.”

2nd June 2020 – PSA injection GP

16th June 2020 – Covid test

17th June 2020 – Daisy Hill – 5 days. 29th June 2020 – CT scan at SWAH. Patient 1 had received a call from Mr O’Brien in the days after discharge who had confirmed him that there was concern that his cancer had started to travel and that accordingly they needed to take another CT scan.

1st July 2020 – injection at GP. Nurse unable to administer

6TH July 2020 – Collection of new injection

7th July 2020 – Injection and PSA check

9th July 2020 – Scan Craigavon

14th July 2020 –Met with Mr Mark Haynes Urologist for the results of the CT scan. This appointment only happened on foot of pressure by family members as there was obviously anxiety around the results. Mr Haynes informed [redacted], [redacted] and [redacted] that the cancer had spread. He said that there were signs of the disease progression for some time – the first being the requirement for a catheter in March/April. He informed them that the spread was significant. [redacted] was shocked, we simply could not take the news in. A cancer nurse specialist was present who indicated her surprise that [redacted] had never been allocated to a cancer nurse specialist from the outset. We explained that no, from February –June his only access to care was through A&E despite repeated attempts to access Urology Services. [redacted] explained that Mr O'Brien had felt his prognosis was a good one so he really could not believe what he was being told. Mr Haynes explained that he was going to lodge a complaint by in relation to this matter. We weren't particularly interested in that as the reality was, [redacted] was going to die and we had to deal with whether now lay ahead for us. [redacted] asked what his prognosis was and it was explained that it was difficult to say however he was optimistically looking at around 18 months. His only treatment option was likely to be chemotherapy. [redacted] simply could not understand why he was never given radiotherapy and how on earth he had ended up in this position. Mr Hayes explained that treatment options could be discussed in more detail tomorrow with Dr Darren Brady, Consultant Urological Oncologist at the Cancer Centre in Altnagelvin.

15th July 2020 – We attended at the Cancer centre. A 6am start from [redacted]. [redacted] was extremely weak and had to be carried from the car by [redacted] With difficulty, due to Covid protocols, the Cancer Centre agreed that [redacted] could attend this appointment with [redacted]. He was recommended for Abiraterone , an oral drug used to treat advanced prostate cancer. An 18 month prognosis was given. He spoke to [redacted] and [redacted] and told them he felt that he "had been thrown under a bus" by the health care system. He and we simply could not believe that he was now in this position.

22nd July 2020 - Admitted to SWAH for treatment for urinary infection. GP would not visit home due to Coved so [redacted] took a urine sample from the catheter bag and brought it to the GP practice for testing [redacted] advised by GP – Dr [redacted] advised that unless [redacted] was admitted to hospital there was a good chance he would die at home. Visiting was not permitted whilst [redacted] was in hospital and [redacted] was in a lot of distress throughout this period, telephoning [redacted] frequently.

Personal Information redacted by the USI – Patient 1 re-attended at the cancer centre with Dr Brady. Dr Brady was shocked at how he was presenting. He was extremely weak and underweight and was struggling to walk. There was blood in his catheter bag. It was noted that it would be difficult to commence him on his treatment with him at clearly such a low ebb. He was given a half dosage of the recommended mediation.

The period of the next Personal Information redacted by the USI - Patient 1's health took a serious decline. It was clear that he was seriously ill. He was unable to mobilise unaided, he was trying to mobilise but was falling frequently and both Patient 1's wife and Patient 1's daughter (who had been granted leave from her job) had to care for him 24 hours per day. We had no access to carers or district nurses. We contacted Palliative care and an assessment was done. We also contacted Social Services and an assessment was done. No care was forthcoming. Marie Curie were unable to help. The local cancer charities were unable to assist as what they could provide was so restricted during Covid. Family members and neighbours were drafted in and a rota was established to provide 24 hour care but Patient 1's health continued to deteriorate. We wanted to care for him at home as he was terrified that an admission hospital would mean he would never see us again. He developed another very serious infection and Patient 1's daughter organised for the rapid response team to attend at the home and antibiotics were administered 3 times per day intravenously.

Personal Information redacted by the USI – GP – Dr Personal Information redacted by the USI attended and agreed with family that Patient 1 needed to be admitted to hospital. He was still demonstrating signs of infection and was unable to have a bowel movement. Patient 1 was extremely reluctant to go and said he knew if he went he would be “returning in a box”. He was admitted in an ambulance, accompanied by Patient 1's daughter (only 1 person was allowed) who stayed with him for 6 hours in A&E holding his hand as he cried in distress. The following day Patient 1's daughter and Patient 1's wife met with the Consultant and it was agreed that should the antibiotics not be effective and if Patient 1 became unconscious that he would not be resuscitated. Patient 1's condition continued to deteriorate. He was extremely confused and agitated as a result of the ongoing infection, not recognising either Patient 1's daughter or Patient 1's wife when they were allowed to briefly attend with him. He was unable to eat and despite being spoon fed by the Consultant in a final bid to boost his energy levels, it was clear that the person we knew and loved was slipping away.

Personal Information redacted by the USI - 6am urgent call received from SWAH advising Patient 1 was seriously ill and for family to attend as soon as possible.

Date Personal Information redacted by the USI – 1:15 pm Patient 1 died in SWAH.

Date Personal Information redacted by the USI – Social worker contacted Patient 1's daughter to advise that at last a care package has been granted for Patient 1. It was too late.

Date Personal Information redacted by the USI – Patient 1's funeral at Personal information redacted by USI.

In the days following Patient 1's death (she cannot be precise as to the actual date) Patient 1's daughter received a call from Mr O’Brien. The call was within a week of the death.

When I spoke with him by telephone, I found him to be somewhat vague. I do believe that he does have some, probably significant degree of memory loss. He did not appreciate that he had been referred to the Cancer Centre at Altnagelvin Area Hospital, and did not fully appreciate that any radiotherapy would be for the malignancy of his prostate gland. I do believe that there is some global deterioration in cognitive function since I first met him in July 2019. Whether it was denial or lack of insight, he did not particularly wish to have any treatment for his prostatic carcinoma in late 2019, preferring to go on holiday in December 2019, deferring initiation of any treatment until after he returned. While he was able to convince me that he had been taking the Bicalutamide daily recently, he could not remember having that first injection of Leuprorelin during the 1st week of June 2020.

A provisional report of the histopathological examination of recently resected prostatic tissue has found that he now does have Gleason 5+5 adenocarcinoma involving approximately 60% of resected prostatic tissue. I have advised [Patient 1] that his prostatic carcinoma is now appearing to be more aggressive than it had been in August 2019.

In order to ensure that he is administered the Decapeptyl 11.25mgs injection intramuscularly, I took the liberty of contacting your Practice, requesting that the prescription be issued and transferred to [Personal information redacted by USI] Pharmacy. Your receptionist ensured that she would then arrange for [Patient 1] to have the injection administered, and his serum PSA level repeated, by the Practice Nurse during the week commencing Monday the 29th of June 2020.

I do hope that there will be no evidence of any metastatic disease on scanning, and that [Patient 1] may proceed to have radical radiotherapy. I believe that it would be preferable for him to be free of indwelling urethral catheterisation prior to any radical radiotherapy. If [Patient 1] is unable to pass urine following catheter removal, or is unable to achieve satisfactory bladder voiding, it would be preferable for him to be taught self-catheterisation prior to radical radiotherapy. I have written to Kathy Travers, Urology Nurse Specialist asking her to consider introducing [Patient 1] to self-catheterisation in the event of satisfactory bladder voiding not being achieved.

Yours sincerely

Dictated but not signed by

Mr A O'Brien FRCS
Consultant Urological Surgeon

c.c. Sister Kathy Travers,
Urology Nurse Specialist
South West Acute Hospital
124 Irvinestown Rd,
Enniskillen
BT74 6DN

Date Dictated: 26/06/20	**Date Typed:** 02/07/20-NE

PAT-001400

JANUARY 2020

27 Monday
Week 5 · 027-339

Aide O'Brien @ SWAT ?? @ 12:30 p

[redacted]

Referred to Oncologist @ City Hosp.

December						
M		2	9	16	23	30
T		3	10	17	24	31
W		4	11	18	25	
T		5	12	19	26	
F		6	13	20	27	
S		7	14	21	28	
S	1	8	15	22	29	

January 2020						
M		6	13	20	27	
T		7	14	21	28	
W	1	8	15	22	29	
T	2	9	16	23	30	
F	3	10	17	24	31	
S	4	11	18	25		
S	5	12	19	26		

2020 JANUARY

[redacted]

Tuesday
Week 5 · 028-338 28

February						
M		3	10	17	24	
T		4	11	18	25	
W		5	12	19	26	
T		6	13	20	27	
F		7	14	21	28	
S	1	8	15	22	29	
S	2	9	16	23		

March						
M		2	9	16	23	30
T		3	10	17	24	31
W		4	11	18	25	
T		5	12	19	26	
F		6	13	20	27	
S		7	14	21	28	
S	1	8	15	22	29	

PAT-001454

	Date	Clinical Notes
→	27/1/20	[redacted] UROLOGY CLINIC SWAH
Age		
URINE Protein Sugar Acetone		PSA ↓ 2.23 ON 07 JAN 20
WEIGHT kg.		LUTS • NOCTURIA x 2
→		PLAN
Age		• INCREASE BICALUTAMIDE TO 100 MGS DAILY
URINE Protein Sugar Acetone		
WEIGHT kg.		• WRITE TO DR. MITCHELL ? BRACHYTHERAPY
→		? CBRT
Age		? COMBINATION [redacted]
URINE Protein Sugar Acetone		
WEIGHT kg.		
→		
Age		
URINE Protein Sugar Acetone		
WEIGHT kg.		