# Report of the
# Urology Services Inquiry

Inquiry Website: www.urologyservicesinquiry.org.uk

They wish to acknowledge the contribution of the Inquiry's Assessor, Mr Damian C Hanbury MS FRCS (Urol) to the work of the Inquiry and his assistance to the authors of this work.

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## Contents – Volume 1

# The Inquiry Team

## Chair of the Inquiry

### Christine Smith CBE KC

Christine was called to the Bar of Northern Ireland in 1985. She worked in general practice before specialising in criminal law. She took Silk in 2011 and was a member of the Coroners' Senior Counsel Panel since 2016 and of the Northern Irish Government Legal Services Senior Counsel Panel since 2017, until taking up her role in the Inquiry.

From November 2012 to January 2017, she acted as Senior Counsel to the Inquiry into Historical Institutional Abuse which examined whether there had been systemic failings by institutions or the State in the residential care of children in Northern Ireland between 1922 and 1995. She was Senior Counsel for the Department of Finance in the Inquiry into the Renewable Heat Incentive (RHI) in Northern Ireland and, following its conversion to a statutory inquiry, was appointed as Senior Counsel to the Independent Neurology Inquiry. Until May 2021 she was a Criminal Cases Review Commissioner. She is a Bencher of the Inn of Court of Northern Ireland.

## Inquiry Panel Member

### Dr Sonia Swart MD FRCP FRCPath

Independent Advisor – Former Consultant in Clinical Haematology and then Medical Director and Chief Executive of Northampton General Hospital. Sonia practiced as Consultant haematologist in acute hospitals for 25 years and was gradually drawn into medical leadership and management through a desire to improve the quality and efficiency of services.

Following a range of medical management roles, she became Medical Director and then CEO of Northampton General Hospital where she was passionate about improving the quality of care, improving the governance of clinical services and focussing on the link between quality of training and research and quality of care for patients. Having always retained a close link with front line staff and patients and felt the privilege of a career in healthcare, Sonia now works as an independent coach, mentor and advisor aiming to support medical leaders and managers.

## Assessor to the Inquiry

### Mr Damian C Hanbury MS FRCS (Urol) – Consultant Urologist

Damian qualified at The London Hospital, Whitechapel in 1980; Junior Surgical Posts at Whipps Cross and Gloucester leading to FRCS (Eng) in 1986. Urological Training at Cambridge, Norwich and Oxford leading to an MS (London) by Thesis in 1992 and FRCS (Urology) in 1993.

Now 25 years in consultant practice with interests in general and diagnostic urology, urinary tract infection, kidney cancer, laparoscopic and open kidney and adrenal surgery. Since 2017 he no longer undertakes major surgeries but mainly has an outpatient and diagnostic practice.

Currently Honorary Visiting Senior Lecturer at University of Hertfordshire and College Assessor for the Royal College of Surgeons of England.

## Secretary to the Inquiry

### Alasdair MacInnes

Alasdair joined the Northern Ireland Civil Service in 1988. He worked in what is now the Department of Agriculture, Environment and Rural Affairs in a range of policy and operational posts. He was Deputy Director of the Northern Ireland Executive's office in Brussels between 2006 and 2011, before moving to the Department of Health. He worked for several years in the Department's Family and Children's policy teams, including as head of the Child Protection unit, where he was involved in the Department's input to the Historical Institutional Abuse Inquiry and the preliminary work on Mother and Baby homes. Most recently, he was head of the Department's Health Protection Policy team.

## Solicitor to the Inquiry

### Anne Donnelly

Anne worked early in her career for the Equality Commission dealing with discrimination and harassment claims and working with employers on good employment practices. She worked for several years in private practice dealing with civil litigation, representing a large trade union and specialising in employment law matters. Anne has worked for many years for the Crown Solicitor's Office dealing most recently with legacy litigation and inquests. She has worked on several public inquiries to date including the Historical Institutional Abuse Inquiry.

## Counsel to the Inquiry

### Martin Wolfe KC – Senior Counsel

Martin was called to the Bar of Northern Ireland in 1994 and took Silk in 2014. Prior to his appointment to the Inquiry, he specialised in inquest law and civil litigation and had developed a particular interest in the field of clinical negligence. Additionally, he is a regular practitioner in the area of disciplinary and regulatory law and is the current Chair of the Bar's Professional Conduct Committee. He has extensive public inquiry experience having acted as Junior Counsel to the Hyponatraemia Inquiry and as counsel for parties in the Robert Hamill Inquiry, the Historical Institutional Abuse Inquiry and the RHI Inquiry.

### Laura McMahon KC – Junior Counsel

Laura was called to the Bar of Northern Ireland in 2005. She specialises in public law and inquests. Her practice has involved acting both for and against government departments. Since 2012 she has been a member of the Government Civil Panel of Junior Counsel and since 2016 she has been a member of the Coroners Panel of Counsel. She took silk in 2024.

## Legal Team

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## Acknowledgements

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Dr Fiona Marshall

Ms Rachel White

Ms Celine Boyd

Ms Pamela Rea

Mr Noel O’Brien

Mr Phillip Montgomery

A final word of thanks goes to the staff of Bradford Court for the courteous and professional service they provided to the Inquiry Team.

## Urology Services Inquiry Terms of Reference

The Urology Services Inquiry (the Inquiry) was established under the Inquiries Act 2005 and will be chaired by Christine Smith QC. The Inquiry will be wholly independent and not accountable to the Department of Health, the Executive, the Assembly, or any public body.

The Terms of Reference for the Inquiry are outlined below.

(a) To review the Southern Health and Social Care Trust's (the Trust) handling of relevant complaints or concerns identified or received prior to May 2020 and its participation in processes to maintain standards of professional practice. The Inquiry shall determine whether there were any related concerns or circumstances which should have alerted the Southern Trust to instigate an earlier and more thorough investigation over and above the extant arrangements for raising concerns and making complaints.

(b) To evaluate the corporate and clinical governance procedures and arrangements within the Trust in relation to the circumstances which led to the Trust conducting a "lookback review" of patients seen by the urology consultant Mr Aidan O'Brien (for the period from January 2019 until May 2020). This includes the communication and escalation of the reporting of issues related to potential concerns about patient care and safety within and between the Trust, the Health and Social Care Board, Public Health Agency and the Department. It also includes any other areas which directly bear on patient care and safety and an assessment of the role of the Board of the Trust.

(c) To examine the clinical aspect of the cases identified by the date of commencement of the Inquiry as meeting the threshold for a Serious Adverse Incident (SAI) and any further cases which the Inquiry considers appropriate, in order to provide a comprehensive report of findings related to the governance of patient care and safety within the Trust's urology specialty.

(d) To afford those patients affected, and/or their immediate families, an opportunity to report their experiences to the Inquiry.

(e) To review the implementation of the Department of Health's "Maintaining High Professional Standards Policy" by the Trust in relation to the investigation related to Mr O'Brien. The Inquiry is asked to determine whether the application of this Policy by the Trust was effective and to make recommendations, if required, to strengthen the Policy.

(f) To identify any learning points and make appropriate recommendations as to whether the framework for clinical and social care governance and its application are fit for purpose.

(g) To examine and report on any other matters which the Chairman considers arise in connection with the Inquiry's investigations in fulfilment of these Terms of Reference.

The clinical practice of Mr O'Brien is being investigated by the General Medical Council (GMC) and it would, therefore, be inappropriate for the Inquiry to encroach on the GMC's remit.

The Inquiry shall submit a report as soon as practicable to the Minister for Health. Should the Inquiry as part of its investigation establish any issue of concern which it believes needs to be brought to the Minister's immediate attention, then this will be done.

## Glossary

| | |
|---|---|
| AD | Associate Director |
| ADT | Androgen Deprivation Therapy |
| ALB | Arm's Length Body |
| AMD | Associate Medical Director |
| AoMRC | Academy of Medical Royal Colleges |
| AR | Additional Responsibility |
| ATICS | Anaesthetics, Theatres and Intensive Care Services |
| BAUS | British Association of Urological Surgeons |
| BAUN | British Association of Urological Nurses |
| BCH | Belfast City Hospital |
| BMJ | British Medical Journal |
| BSO | Business Services Organisation |
| CAH | Craigavon Area Hospital |
| CaPPS | Cancer Patient Pathway System |
| CD | Clinical Director |
| CEO | Chief Executive Officer |
| CHKS | UK provider of healthcare intelligence and quality improvement services |
| CL | Clinical Lead |
| CMO | Chief Medical Officer |
| CNO | Chief Nursing Officer |
| CNS | Clinical/Cancer Nurse Specialist |
| CP | Core Participant |
| CRG | Clinical Reference Group |
| CSCG | Clinical and Social Care Governance |
| CURE | Craigavon Urology Research and Education |
| DARO | Discharge Awaiting Results Outpatients |
| Datix | Risk Management Information System |
| DCC | Delivery of Clinical Care |
| DHH | Daisy Hill Hospital |
| DHSSPS | Department of Health, Social Services and Public Safety |
| DLS | Departmental Legal Services |

# Volume 1 – Glossary

| | |
|---|---|
| DNAR | Do Not Attempt Resuscitation |
| DoH | Department of Health |
| DSO | Departmental Solicitor’s Office |
| EBRT | External Beam Radiation Therapy |
| EHL | Electrohydraulic Lithotripsy |
| ENT | Ear, Nose and Throat |
| ERG | External Reference Group |
| FLO | Family Liaison Officer |
| FSS | Functional Support Services |
| GDC | General Dental Council |
| GIRFT | Getting it Right First Time |
| GMC | General Medical Council |
| GMP | Good Medical Practice |
| GP | General Practitioner |
| HOS | Head of Service |
| HR | Human Resources |
| HROD | Human Resources and Organisational Development |
| HSC | Health and Social Care |
| HSCB | Health and Social Care Board |
| HSSIB | Health Service Safety Investigations Body |
| IEAP | Integrated Elective Access Protocol |
| IHRD | Inquiry into Hyponatraemia-related Deaths |
| INI | Independent Neurology Inquiry |
| IOG | Improving Outcome Guidance |
| IR1 | Incident Report Form |
| IRM | Invited Review Mechanism |
| IVT | Intravenous Therapy |
| LHRH | Luteinising Hormone-Releasing Hormone |
| MCHP | Model Complaints Handling Procedure |
| MDM | Multidisciplinary Meeting |
| MDT | Multidisciplinary Team |
| MHPS | Maintaining High Professional Standards |
| NED | Non-Executive Director |

# Volume 1 – Glossary

| | |
|---|---|
| MSSU | Mid Stream Specimen of Urine |
| NICE | National Institute for Clinical Excellence |
| NICaN | Northern Ireland Cancer Network |
| NIECR | Northern Ireland Electronic Care Record |
| NIMDTA | Northern Ireland Medical and Dental Training Agency |
| NIPACS | Northern Ireland Picture Archiving and Communications System |
| NIPSO | Northern Ireland Public Services Ombudsman |
| NPSA | National Patient Safety Agency |
| OG | Oversight Group |
| OHS | Occupational Health Service |
| PAs | Programmed Activities |
| PAS | Patient Administration System |
| PCC | Patient and Client Council |
| PDP | Personal Development Plan |
| PHA | Public Health Agency |
| PICC Line | Peripherally Inserted Central Catheter |
| PPA | Practitioner Performance Advice (formerly NCAS) |
| PPI | Personal Public Involvement |
| PSA | Prostate-Specific Antigen |
| PSIF | Patient Safety Incident Framework |
| RBC | Referral and Booking Centre |
| RCA | Root Cause Analysis |
| RCS | Royal College of Surgeons |
| RO | Responsible Officer |
| RQIA | Regulation and Quality Improvement Authority |
| SA | Service Administrator |
| SAI | Serious Adverse Incident |
| SCRR | Structured Clinical Record Review |
| SEA | Significant Event Audit |
| SEC | Surgery and Elective Care |
| SEHSCT | South Eastern Health and Social Care Trust |
| SHSCT | Southern Health and Social Care Trust |
| SID | Senior Independent Director |

| | |
|---|---|
| SLT | Senior Leadership Team |
| SMDM | Specialist Multidisciplinary Meeting |
| SMT | Senior Management Team |
| SOW | Surgeon of the Week |
| SPA | Supporting Professional Activity |
| SPPG | Strategic Planning and Performance Group |
| SWAH | South West Acute Hospital |
| ToR | Terms of Reference |
| TURP | Transurethral Resection of the Prostate |
| WHO | World Health Organisation |
| WHSCT | Western Health and Social Care Trust |
| UAG | Urology Assurance Group |
| UTI | Urinary Tract Infection |
| rUTI | Recurrent Urinary Tract Infection |
| UoW | Urologist of the Week |
| VTE | Venous Thromboembolism |

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## Contents - Executive Summary

# Executive Summary

## Purpose and Scope

This Inquiry was set up following a series of Serious Adverse Incidents (SAIs) involving one consultant urologist in the Southern Health and Social Care Trust (the Trust).

The Inquiry looked at the harm or potential harm caused to patients, explored how that occurred and why the scale of harm was not fully appreciated. As a result and in fulfilment of its Terms of Reference (ToR), the Inquiry's work has been predominantly concerned with leadership and governance at the Trust.

The Inquiry could not determine civil or criminal liability and was more focused on improving patient safety than concerned with the attribution of blame.

Although the events described apply to the care delivered by one consultant in one department in one Trust in the Health and Social Care system in Northern Ireland, the lessons from this Inquiry are important not only for Northern Ireland but for the whole of the health service in the UK.

## Methodology

The Inquiry gathered documentary evidence and heard from witnesses in order to answer the questions posed by its ToR. We also had regard to findings from other health care inquiry reports, both from Northern Ireland and elsewhere in the UK. Our work exposed failures in leadership and governance that allowed patients to be harmed. Those failures continued over a number of years. While shining a light on those failures, the Inquiry also sought to understand what lessons had already been learned and what improvements had been made, both at the Trust and more widely in Northern Ireland, by the Department of Health (the Department). In this Report we have endeavoured to identify those areas which continue to require improvement.

## Chapter Findings

### Patients

From patient evidence we learned that:

- Failure to triage referrals created avoidable safety risk. The accounts of Patient 10 and Patient 13 illustrate how missed triage could lead to significant delay, anxiety and a risk of worse outcomes.
- Stent management was inadequately controlled. The evidence from Patients 84 and 16 shows prolonged delays in stent removal or replacement, absence of a reliable tracking mechanism and lack of agreed protocols, despite longstanding awareness of the risk.
- Patients frequently could not access timely clinical advice. Several accounts described repeated attempts to obtain reassurance, a date, a plan or an explanation, but contact was limited to administrative staff. There was no clear route to a clinician or delegated member of the medical team. This amplified distress for the patients.
- Communication with patients was often poor, delayed or non-reciprocal. Patients and families repeatedly described not being kept informed, not understanding what was happening, not receiving clear written explanations and learning important facts only after reading SAI reports or other material provided by the Inquiry. The absence of structured written communication following consultations and incidents only compounded a sense of frustration.
- Patient involvement in treatment decisions was inconsistent. Patient 18's evidence suggests a failure to present options fully, discuss MDT outcomes clearly and support informed choice.
- Communication across Trust departments was unreliable. The evidence in Patient 16's case highlights missed letters, correspondence not copied to the right team, incomplete visibility of records and poor coordination between oncology and urology.
- The SAI process was often experienced as remote, slow and insufficiently patient-centred. Families described limited explanation of what an SAI was, little

or no involvement in setting terms of reference, long periods without updates, delay in reporting and in some cases no meaningful post-report discussion. The governance and management systems failed to address the immediate learning required to protect patient safety and failed to ensure that agreed actions were completed in a timely way.

- There was insufficient organisational emphasis on learning, identifying themes and monitoring of agreed actions. As a result, improvements were delayed even when there were recurrent well-recognised problems as, for example, with the management of stents. In this case there was a failure to introduce reliable systems with suitable control measures.
- Complaints handling did not consistently address the substance of concerns. Patients described responses that focused on peripheral issues, relied heavily on service pressure as explanation, or did not engage directly with the central complaint. In a number of cases, the process itself became a source of further frustration and distress.
- Patient experience was in itself a source of intelligence about the possible risks to patient safety. The patient evidence demonstrates that accounts of confusion, being ignored, being unable to get an answer, or being left without a plan are not merely service-quality issues; they can be early indicators of clinical risk and weak governance.
- The Inquiry has not sought to examine each case before it with the aim of determining appropriateness of treatment or to apportion blame. Instead, the Inquiry considered the problems with governance and leadership that allowed harm and potential harm to happen.

## MHPS (Maintaining High Professional Standards)

A formal MHPS process in respect of Mr O'Brien was eventually instigated by the Trust. While the Inquiry considers that the MHPS process was handled badly, examination of the process and events prior to its being instigated evidenced a number of matters.

- Concerns about aspects of Mr O'Brien's practice were known for many years before 2016, including triage delays, record-keeping failures, storage of patient notes at home, delayed dictation, non-standard prescribing and other clinical and administrative concerns.

- The Trust repeatedly failed to convert known concerns into structured investigation or sustained corrective action. Responses were commonly ad hoc, delayed, informal and insufficiently escalated.
- Medical and operational management did not consistently recognise that issues labelled as ‘administrative’ could amount to significant patient safety risks.
- Clinical governance systems were underdeveloped and did not reliably identify poor practice. In several areas, routine audit, comparative metrics, escalation pathways and follow-through were absent or ineffective.
- Managers and colleagues often resorted to workarounds rather than resolving the underlying problem.
- The Trust was aware of repeated concerns about the handling and location of patient notes yet allowed the practice to continue for years despite recognising it as a governance issue.
- Known concerns about delayed review of test results and undictated clinic outcomes created avoidable risks to continuity of care, timely diagnosis and clinical decision-making.
- The prolonged failure to triage referrals properly created a clear risk that urgent cases, including cancer cases, would not be identified or escalated in time.
- The handling of the IV antibiotics issue demonstrated that firmer action was possible once the issue was escalated to senior leadership; however, it also showed resistance to guidance, slow resolution and weak internal governance before senior intervention.
- The Trust ought to have recognised that Mr O’Brien was at points a doctor in difficulty and managed him as such, with a formal support and improvement plan, rather than repeated tolerance of unresolved risk.
- Where routine management measures proved ineffective, MHPS or equivalent formal mechanisms should have been triggered earlier, with earlier involvement from medical leadership and HR.

## Clinical Aspects

In assessing the clinical aspects of cases, the Inquiry looked to see whether there were significant departures from expected practice and professional standards. We considered if governance arrangements created risks to patient safety and quality of care. The Inquiry did not determine criminal or civil liability, nor make findings on fitness to practice. Instead, it looked at the cases and thematic evidence to assess whether governance systems, leadership arrangements, administrative controls and team actions were sufficient or sufficiently applied to prevent, detect and respond to risk. There was both a failure of individual responsibility as well as systemic failures. Failure of management, leadership, governance and demand/capacity mismatch were all factors. The Inquiry found:

- Governance systems were not sufficiently robust, proactive or coherent to detect unsafe practice, recurring administrative failures or accumulating risk reliably. Key issues often came to light through exceptional events or external challenge rather than normal assurance mechanisms.
- Patient safety was not embedded strongly enough in organisational culture and decision-making. Leadership and management were not consistently patient-safety focused, and operational pressures, service demand and focus on target delivery contributed to a degree of institutional blindness.
- There was a sustained mismatch between demand and capacity in the urology service. Longstanding shortages in consultant workforce, theatre access and wider support capacity contributed to excessive waiting times, service fragility and a heightened risk environment.
- Triage failures were a major patient-safety issue. The evidence shows there was a repeated failure by Mr O’Brien over many years to complete triage within required timescales. This was despite repeated attempts by others to address this, leading to a temporary improvement before further failure. Other consultants worked under similar pressures but managed to adapt their practices to ensure that triage was completed.
- Mr O’Brien’s administration of his practice as well as follow-up processes were unsafe in important respects. Delayed or absent triage, failures to review

investigation results promptly, non-dictation of letters, poor record keeping and retention of notes outside the hospital created direct risks to patients and undermined continuity of care.

- Systems for managing radiology, pathology and follow-up results were inadequate. The Report identifies failures to review and act on abnormal results, contributing to delayed diagnosis and harm. The Trust also lacked sufficiently reliable safety-net systems to ensure abnormal findings were escalated and acted upon.
- Outpatient and surgical waiting-list management exposed patients to avoidable risk. Excessive waits for first appointments, follow-up appointments and surgery resulted in delayed diagnosis, delayed treatment and deterioration in patient condition. There was insufficient systematic reprioritisation of patients whose conditions worsened while waiting.
- Management of planned procedures, particularly time-critical cases such as insertion or removal of stents, was deficient. The absence of robust scheduling and recall arrangements created foreseeable safety risks.
- Team-based working and clinical challenge were insufficient. The Urology Service did not function consistently as a unified team around agreed methods, shared standards and open challenge. In particular, it was difficult to secure agreement on common ways of working where one clinician resisted adaptation or challenge.
- Medical leadership and escalation were often too limited, informal or delayed. Several witnesses accepted in hindsight that more formal intervention, earlier escalation and fuller use of available management processes should have occurred.
- Professional standards were not consistently upheld. The Report identifies departures from expected professional practice, including failures to follow guidance, reluctance to adapt practice, insufficient collaboration, poor administrative discipline and inadequate insight into the consequences of those behaviours.
- The Inquiry recognises recent steps by the Trust to improve culture, oversight, triage monitoring, results management and waiting-list controls. These actions were necessary corrective steps.

- The evidence disclosed several key risks to patient safety: delayed cancer diagnosis; delayed treatment; missed or unreviewed abnormal results; unsafe waiting-list prioritisation; loss of patients to follow-up; inadequate oversight of unusual or non-standard practice; inequity of access; and reduced resilience where the service relied excessively on individual clinicians.
- Mr O'Brien disputed a number of criticisms of his practice. We noted these views but conclude that they do not excuse his unwillingness to adapt his practice or displace the central governance and patient-safety failings identified.

## Governance

The chapter on Governance is the lengthiest chapter of the Report. It does not examine urology in isolation but rather used what occurred in that service to examine the wider governance arrangements of the Acute Directorate, the Senior Management Team, the Trust Board and the broader Northern Ireland health and social care system. At all times the Inquiry was cognisant of important contextual factors: severe operational pressure; workforce shortages; financial constraint: increasing demand-capacity gaps, and the complexity of regional oversight arrangements. Our findings are that:

- The Trust did not sufficiently 'join the dots' across complaints, incidents, appraisal information, professional concerns, waiting list issues and governance signals. Risks were often visible in part but rarely brought together into a comprehensive picture of threat to quality and safety.
- Warning signs in the Urology Service and the wider Acute Directorate were recognised by some staff and managers over many years, but were not escalated, triangulated or acted on with the urgency required.
- Board oversight of quality and safety was weaker than required. The Board did not receive sufficiently rich, integrated or challenging information to provide robust assurance on the safety and effectiveness of services.
- There was significant instability in senior leadership, including turnover at Board and executive level. This reduced continuity, institutional memory and the consistent follow-through of concerns and actions.

- Clinical governance functions were under-resourced and, at times, rudimentary. Key areas such as clinical audit, standards and guidelines, incident management, thematic learning and data triangulation were not developed sufficiently to support proactive assurance.
- Information flows were fragmented. Governance arrangements depended heavily on local escalation rather than systematic, trust-wide processes for drawing risk information upward and across organisational boundaries.
- Operational and financial pressures dominated organisational attention. Performance against ministerial targets was measured in detail and discussed frequently, whereas quality and safety metrics were far less visible and less systematically scrutinised.
- The Inquiry found insufficient clinical representation and challenge at Board level, particularly in relation to the scale and complexity of the Trust's service responsibilities.
- There was limited evidence of a mature, organisation-wide approach to learning from incidents and serious adverse events. Learning was not consistently thematic, strategic or translated into sustained improvement.
- The management of governance in the Acute Directorate and Urology Department reflected wider weaknesses in role clarity, leadership support, handover, induction and accountability.
- The Inquiry found evidence that governance posts and functions were vulnerable to financial pressures, without adequate assessment of the resulting risk to quality and patient safety.
- There was not enough sustained attention to building an open and just culture, that provided psychological safety and effective routes for staff to raise concerns with confidence that action would follow.
- In summary, there were clear failures in Board leadership, governance and medical management. The Board did not fully understand its duties to oversee and assure effective governance. There was no clear focus from the Board on safety and quality of care. Governance systems did not detect signals of harm or act sufficiently when harm was detected.

### Medical Management and Leadership

While the Trust recognised the importance of medical leadership, for much of the period examined it underinvested in the structure, time, training, governance support and development needed to make that leadership effective.

- Leadership was not well developed at the Trust.
- Medical management and leadership was poorly supported.
- The Trust and medical managers failed to act effectively to ensure that problems were detected and corrected as they should have been.
- The available tools of medical management were not used to best effect. This includes the use of the MHPS framework.

The Inquiry considers that Mr O'Brien should have been supported to change his approach and understand his professional duties as a doctor and Trust employee.

The Inquiry recognises that since it began, immediate improvements have been put in place in each of these areas.

We note that the Trust has demonstrated a willingness to embrace the need for cultural change.

## Conclusions

The consultant urologist at the centre of this Inquiry did not set out to harm patients and was known as a hardworking, well-respected clinician who had contributed to the establishment of the department of urology and was committed to his patients. He chose, however, to practice in a way that sat outside of accepted practice and as a result not all his patients received the required standard of care.

From the outset it was clear that concerns had been raised about the consultant on a number of occasions over many years, but there had been a failure to appreciate that some very significant administrative issues might be indicative of broader clinical issues. To some extent managers at every level, both clinical and non-clinical, were apparently blinded by a culture that was too heavily reliant on deference to seniority and especially medical seniority.

There was an underdeveloped use of information systems and data to act as warning signals and a pressurised working environment where the focus on ministerial targets dominated much discretionary effort. The result was that issues on some occasions were not detected and when they were detected they were tolerated for too long.

Positive improvement action has been taken by both the Department and the Trust in seeking to learn from the Inquiry as it progressed. We recognise and commend the many improvements that have been set in train but believe that both the Department and the Trust need to do more.

## Recommendations

The Inquiry recommends three key changes to improve patient safety and the quality of care in our health service:

- The formal **declaration** of **patient safety** as the dominant and primary purpose of health provision.
- A comprehensive **leadership development** programme.
- Investment in **data and information**.

More details of the areas that need to be addressed under these overarching recommendations are set out in the Conclusion and Recommendations Section of the Report. The Inquiry does not call for more activity in the abstract; it calls for clearer purpose, stronger leadership, better information and disciplined implementation. Senior leaders should therefore treat this Report as both a warning and an opportunity: a warning about the consequences of fragmented assurance and tolerated risk, and an opportunity to align current reform efforts around a patient-safety led model of governance and improvement.

**Christine A Smith CBE KC**
**Dr Sonia Swart MD FRCP FRCPath**
**June 2026**

## Contents - Introduction

## Introduction

1. Public Inquiries are set up to investigate matters of public concern. In the case of this Inquiry the concerns relate to the issue of patient safety within our healthcare system, specifically relating to what occurred within the Urology Department of the Southern Health and Social Care Trust (SHSCT) (the Trust).

2. This Inquiry is, sadly, one of several statutory and non-statutory inquiries[1] into aspects of the health care system in recent years, both in Northern Ireland and further afield. The fact that such inquiries have been required is in itself cause for concern and begs many questions about the state of our healthcare systems. It is beyond the remit of this Inquiry to answer all of those questions. Nonetheless, where our investigations have raised questions or issues that bear greater examination, we have noted them in the Report.

3. Like the Independent Neurology Inquiry (INI), the catalyst for this Inquiry was the identification that the work of an individual consultant employed in one of our health trusts failed patients in his care. The care of a number of patients of consultant urologist, Mr Aidan O'Brien was the subject of Serious Adverse Incident (SAI) investigations in the Trust. Individual reports into the care relating to nine patients were produced together with an overarching report.[2]

4. The Overarching Serious Adverse Incident report summed up the issues uncovered by the investigation:

> "The primary duty of all doctors, nurses and healthcare professionals is for the care and safety of patients. Whatever their role, they must raise and act on

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[1] INQ-10001 to INQ-10729 (The Inquiry into Hyponatraemia-related Deaths); INQ-10730 to INQ-10971 (Independent Neurology Inquiry).
The Thirlwall Inquiry identified a total of 31 previous Inquiries into Healthcare Issues in England. See "Review of the Implementation of Recommendations from Previous Inquiries into Healthcare Issues prepared by the Thirlwall Legal Team", 15 May 2024. At: https://thirlwall.public-inquiry.uk/documents/
UK wide inquiries include: The Infected Blood Inquiry, At: https://www.infectedbloodinquiry.org.uk/

[2] DOH-00001 to DOH-00013; DOH-00026 to DOH-00135

> concerns about patient safety. This did not happen over a period of years resulting in MDM[3] recommendations not being actioned, off guidance therapy being given and patients not being appropriately referred to specialists for care. Patients were unaware that their care varied form [sic] recommendations and guidance. They could not and did not give informed consent to this."[4]

5. In some respects, many of the issues identified in the INI echo the evidence which was seen and heard in this Inquiry. Both inquiries were concerned with issues of governance in health and social care trusts and many of the recommendations made by that Inquiry are supported by this Panel.

6. Error and harm in healthcare are very common with around one in ten patients experiencing an adverse event.[5] Problems related to patient safety have been well recognised since the time of Florence Nightingale who understood that errors in basic care killed more people than the injuries of war. However, the current focus on patient safety in our complex healthcare environment started with the publication of "To Err is Human" in 2000 based on data from the United States.[6]

7. In the UK this was consolidated in Liam Donaldson's Report "An organisation with a memory" (2002 National Institute of Health) which recommended embedding patient safety and clinical governance in every hospital. The management of clinical risk and efforts to improve patient safety have been actively underway since this time.[7]

8. However, in 2016 the Health Service Journal featured an article by James Titcombe entitled: "The NHS is an organisation with amnesia".[8] In that

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[3] MDM is an acronym for Multidisciplinary Meeting

[4] DOH-00128

[5] The Health Foundation (2011). "Levels of harm". At: https://www.health.org.uk/sites/default/files/LevelsOfHarm_0.pdf

[6] Kohn, L.T., *et al* (2000). "To Err Is Human". *Institute of Medicine*. At: https://www.nationalacademies.org/read/9728

[7] Donaldson, L. (2002). "An organisation with a memory". *Clinical medicine, London.* At: https://doi.org/10.7861/clinmedicine.2-5-452

[8] INQ-31377 to INQ-31380

article, James Titcombe focused on the failure to implement recommendations from inquiries into patient safety incidents. His comments relate to the observation that a poor learning culture, a failure to involve families, and poor-quality investigations were resulting in repetition of the same failures. In a further article in the same journal in 2024, entitled “Patient Safety Watch: The NHS remains an organisation with amnesia”, he comments on the failure to embed learning from recommendations of formal inquiries stating that he is struck by the “cyclical nature of the problems and the false dawns.”[9]

9. Failings and avoidable death from unsafe care in acute hospitals continue with estimates of around 11,000 avoidable deaths per year in England.[10] While there are figures available for Northern Ireland these are not directly related to care in hospitals.

10. Increasingly, as healthcare becomes more effective and more complex, the possibilities for errors grow, causing both direct harm and a failure to provide effective care.

11. The Panel has seen work done by the Department of Health (the Department) to pool and implement Inquiry recommendations of recent public inquiries and is aware that the recommendations of this Inquiry will feed into that process.[11] The Inquiry has tried not to duplicate the recommendations of other inquiries but rather to confirm our support for those we would have otherwise recommended.

## Background to the Inquiry

12. The urology service sits within the Trust’s Acute Directorate, and patient care is delivered across multiple Trust sites including Craigavon Area Hospital (CAH),

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[9] Titcombe, J. (2024) “Patient Safety Watch: The NHS remains an organisation with amnesia”. *Health Service Journal*. At: https://www.hsj.co.uk/patient-safety/patient-safety-watch-the-nhs-remains-an-organisation-with-amnesia/7037985.article

[10] Hogan, H., *et al* (2012). “Preventable deaths due to problems in care in English acute hospitals: a retrospective case record review study”. *BMJ Quality & Safety*. At: https://qualitysafety.bmj.com/content/21/9/737

[11] DOH-72381 to DOH-72396: DoH Inquiries Implementation Programme Management Board Assurance Framework Guidelines

Daisy Hill Hospital, South Tyrone Hospital, South West Acute Hospital and Banbridge Polyclinic.[12] The main setting for the provision of the Trust's urology service is Craigavon.

13. An Early Alert sent by the Trust to the Department on 31 July 2020 or 01 August 2020 advised that issues had come to light regarding the practice of Mr O'Brien, who had recently left his employment with the Trust.[13] The Department was told that, on 07 June 2020, the Trust became aware of potential concerns regarding delays in the treatment of Mr O'Brien's surgery patients. The Trust believed that two out of 10 patients listed for surgery under the care of the consultant were not on the hospital's patient administration system at that time. As a result of those potential patient safety concerns, an initial look-back exercise in relation to the consultant's work was conducted to ascertain whether there were other areas of potential concern. It later transpired that the two patients identified were in fact on the patient administration system,[14] however at that point several issues of concern relating to the care of some of Mr O'Brien's patients had been identified.

14. When the Minister of Health, Mr Robin Swann announced the setting up of what has become the Urology Services Inquiry on 24 November 2020, he stated that:

> "The remaining issues to be addressed relate to the management of all past, present and future cases that would meet the threshold for an SAI review, as well as establishing why this happened and whether action could have been taken by the Southern Trust to identify and address the apparent deficiencies in the consultant's clinical practice. Given the large number of cases already identified as meeting the threshold for an SAI review and my concerns that there may be more to come, a different and specific approach is required. The fourth action, therefore, that I intend to take is to establish a statutory public inquiry under the Inquiries Act 2005. I believe that that is the best way to ensure that the full extent of the concerns is identified and for the patients and

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[12] WIT-53896

[13] The Trust maintain that Mr O'Brien retired, however Mr O'Brien disputes this as he sought to rescind his notice of retirement. See WIT-82628, paragraph 675 to WIT-82629, paragraph 678

[14] TRA-01356, line 1 to TRA-01362, line 21; TRA-11549, line 26 to TRA-11553, line 11

> families affected to see that those and all relevant issues are pursued in a transparent and independent way."[15]

15. The catalyst for the setting up of this Inquiry was the concerns which emerged regarding the work of Mr O'Brien in the Trust. He is named in the Inquiry's Terms of Reference (ToR) and was a core participant before the Inquiry. The Inquiry received 36,410 pages of material from Mr O'Brien, a response to the Inquiry's Section 21 (S21) Notice comprising 1,736 pages plus annexes and three addendum statements totaling 63 pages. We also received 26 audio recordings of meetings and telephone conversations as well as a final written submission.[16] The Inquiry had the benefit of hearing from Mr O'Brien in person over six days of evidence, both in relation to the Trust's handling of the Maintaining High Professional Standards (MHPS) process regarding its investigation into his work and more generally a year later.[17]

16. This was not, however, an Inquiry directed to any detailed assessment of the clinical shortcomings arising out of any particular patient in Mr O'Brien's care, but rather an Inquiry into systems of governance in the Trust which may have affected an individual's treatment.

17. Throughout its work, the Inquiry has sought to pursue all relevant issues independently and transparently. Although the Inquiry was announced by the then Minister for Health,[18] at no point were we in any way influenced by the Department, the Trust or any other body or individual, in how we set about our work.

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[15] See Inquiry website at: Statement by Minister Robin Swann to the NI Assembly 24 November 2020

[16] WIT-82399 to WIT-84134; WIT-98807 to WIT-98808; WIT-107564 to WIT-107623; WIT-107947; SUB-00185 to SUB-00235. **NB:** all witness statements and associated documents can be found on the Inquiry website

[17] 19, 20, and 21 April 2023; and 8, 10 and 12 April 2024

[18] Much of the Inquiry's work was conducted during the time the Northern Ireland Executive was inoperative. Minister Swann resumed his post on 03 February 2024, before stepping down and being replaced by Minister Nesbitt on 29 May 2024.

18. The Inquiry's ToR are set out in Volume 1. In writing this Report the Inquiry has sought to answer all the questions asked by its ToR. It was clear, having considered the evidence, both written and oral, that there was substantial overlap in the themes and issues that we identified. Accordingly, this Report has been set out as follows:

| | |
|---|---|
| **Chapter 1**: | Patients – this chapter addresses ToR (d). |
| **Chapter 2**: | Maintaining High Professional Standards – this chapter addresses ToR (a) and (e). |
| **Chapter 3**: | Clinical Aspects – this chapter addresses ToR (c). |
| **Chapter 4**: | Governance – this chapter address ToR (b). |
| **Chapter 5**: | Medical Management and Leadership – this chapter addresses ToR (b). |

19. Throughout these chapters the Inquiry has identified learning points and recommendations, although we have endeavoured to bring all recommendations together at the end in an overarching way. The matters that we have examined are evident both in this Report and from the evidence and transcripts placed on the Inquiry's website. We consider that this meets the requirements of ToR (f) and (g).

20. Term (c) of the ToR tasked the Inquiry with examining the clinical aspects of a number of cases in order to provide a report of findings related to governance of patient care and safety. It covered those that had been identified by the commencement date of the Inquiry (06 September 2021) as meeting the threshold for an SAI and any other cases the Inquiry considered appropriate. It quickly became clear that there were more cases relevant to our work than the original SAI cases. We discovered there had been a previous SAI which looked at five cases that had not been triaged by Mr O'Brien. Additionally, a number of cases were the subject of a review by the Royal College of Surgeons, and the Trust was engaged in a Structured Clinical Record Review (SCRR).

21. The Inquiry obtained information in respect of these. The dominant purpose in looking at the material was not for the Inquiry to say whether any individual had received incorrect or suboptimal treatment, but rather to determine whether there were identifiable themes and what the information showed about the governance of patient care and safety within the Trust.

22. In general, it is clear that the Inquiry was essentially being tasked to answer the following main questions:

- What were the concerns?
- When did matters come to light?
- What, if anything, was done to address these?
- What, if anything, ought to have been done and could it have been done sooner?
- What were the extant governance processes which were in place that led to the initial lookback review of patients treated by Mr O'Brien between January 2019 and May 2020?
- Were these processes effective, and if not, why not?
- How were issues communicated within the Trust and how were they escalated both internally and externally?

23. This Report sets out the conclusions that the Inquiry drew from the evidence it read and heard in answering these questions.

24. In addressing all the ToR, the Inquiry has had regard to what it considered were failings in the clinical/corporate governance framework of the Trust, its implementation within the Trust and the steps that have been taken to improve matters. We have considered whether those steps go far enough or what more can be done in order to safeguard patient safety in future.

## How the Inquiry carried out its work

25. When the Inquiry started work in September 2021 the team was few in number. Once material started to be disclosed, it rapidly became clear that more staff were needed in order for it to function effectively. Ultimately the team expanded to a total of 21 people, although at the time of writing this Report the team has reduced to a total of 11 people. Lawyers moved on to other work after our hearings concluded and secretariat members left for other posts.

26. This Inquiry was set up in the midst of the covid pandemic and that brought with it many challenges. The need for socially distanced accommodation and a chamber with appropriate ventilation being just two.

27. The Inquiry was not immune to the virus and at various times during our work members of the team contracted it to varying degrees of severity. Despite this we managed to continue with our work and indeed the Panel member and Assessor when they succumbed were able to attend the chamber virtually which enabled us to stick to our hearing timetable.

28. In order to provide for various procedures relating to the operation of the Inquiry the Chair published the following protocols:

- A Procedural Protocol.
- A Redaction, Anonymity and Restriction Orders Protocol.
- An Assessors Protocol.
- A Media Protocol.
- A Cost Protocol.

29. The Chair subsequently made six Restriction Orders. The Protocols, Restriction Orders and other key documents can be found on the Inquiry's website together with updated statements from the Chair as the Inquiry progressed.

## Designation of Core Participants (CPs)

30. At the outset of our work, it was important to determine who required to be CPs before the Inquiry. In deciding to designate the Department of Health, the Southern Health and Social Care Trust and Mr O'Brien as the three CPs before the Inquiry it was considered that each was able to assist the Inquiry in fulfilling its ToR most effectively by being actively involved in the Inquiry proceedings. Further, each could potentially be subject to explicit or significant criticism at the conclusion of our work, and it was therefore appropriate that they be involved throughout.

31. It was determined, following an application by the family of Patient 1 and a consideration of all applicable law, that there was no requirement to designate that family (or indeed other patients/families) as CPs. There were a number of reasons for that decision which are set out in full on the Inquiry's website. Two of those were that the Inquiry had not been devised to make determinations as to treatment in individual cases and further no patient was likely to be the subject of any criticism by the Inquiry, as no patient could be responsible for the care received or the systems that allowed care to be sub-optimal.

## Gathering documents and evidence

32. The Inquiry Rules 2006 do not apply in Northern Ireland. Rule 9 of those rules enable an Inquiry to write asking for evidence whether written or oral. This is the vehicle generally used to obtain evidence in Inquiries in Great Britain. In the absence of that rule and to ensure compliance with the need to obtain evidence speedily and completely, the Inquiry issued Notices in accordance with Section 21 of the Inquiries Act 2005. This is the provision that ensures production of information and evidence.

33. Issuing S21 Notices resulted in the receipt of 579,549 pages of documentation from the three CPs and other witnesses as well as the 26 audio files referred to

above. The Inquiry also received 108,058 pages of witness evidence from 115 witnesses and 65 witnesses gave oral evidence.

34. The handling of such a volume of documentary evidence created enormous work for the small Inquiry team both administratively and analytically. The volume of material meant it was a laborious and time-consuming task for the Inquiry team to collate and index the material and to analyse the documents to decide which witnesses needed to be called and what needed to be examined in the public hearings, as well as what material witnesses needed to see in advance of giving oral evidence.

35. The Inquiry recognises that the provision of evidence to it, whether written, oral or both, has been stressful for many, particularly patients and family members, but equally and in some instances perhaps more so for medical professionals.

36. Central to the work of the Inquiry was the issue of patient safety and the Panel was acutely aware that behind each case that had been the subject of investigation as an SAI or in the lookback review, was a patient or family whose care had fallen short of what might have been expected. The Panel therefore considered that the first people it should hear from were those patients and families. In fulfilment of ToR (d), procedures were devised to enable the Panel to hear from as many of those affected as wished to engage with the Inquiry.

37. A questionnaire was placed on the Inquiry's website[19] and the Chair wrote personally to all those who were identified to the Inquiry as having been adversely affected by their treatment in the Urology Department of the Trust. A total of 23 patients/family members completed questionnaires. The Panel decided to call a selection of those who contacted the Inquiry.

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[19] See Appendix 1a

## Hearings

38. We were tasked at ToR (d) to afford patients and families affected an opportunity to report their experiences to the Inquiry. We heard oral evidence from a total of 10 patients or immediate family members and what they told us is set out in the Patients chapter.

39. The Inquiry sat in private to hear from patients and families, starting in June 2022. The transcripts of what was said during those sittings were transcribed, anonymised and placed on the Inquiry’s website. Patient hearings were held on six days.

40. We recognised that it is difficult for anyone to be asked to give evidence, especially, as was the case for a number of those we heard from, when that entailed speaking about a loved one who had died. Accordingly, the Inquiry tried to make the patient hearings as informal as it could, bearing in mind that every public inquiry will of necessity have a degree of formality. Each patient or family member could be accompanied by other family members if they wished. Questioning by the Inquiry Panel, Assessor and Counsel was in the manner of a conversation rather than formal questioning. Feedback from those who did give evidence was universally positive.

41. In November 2022 the Inquiry sat in public for the first time. The hearing chamber at Bradford Court is small and the public seating area limited. In order to allow access to the greatest number of those interested in our work, all public hearings were live streamed and accessible from the Inquiry’s website. All evidence was transcribed, placed on the website alongside the documents which were referred to during a witness’s evidence, together with any witness statement they had provided. Where necessary the material was appropriately redacted.

42. At the conclusion of our evidence sessions in April 2024, the Inquiry started to prepare the written statements of witnesses and the attachments appended to each, received in response to its S21 Notices, for uploading onto the website. It

had not been possible to do this sooner due to the redaction that was required before they could be put into the public domain. That exercise was an extremely laborious one for the remaining team members, who each carried it out while still dealing with other tasks. It was finally completed in June 2026 when all statements were uploaded.

43. It was not considered necessary to take oral evidence from all those who responded to S21 Notices. The witness statements from those we did not require to hear from were shared with the CPs and placed on the Inquiry website together with those from whom we did take oral evidence.

44. We wish to acknowledge the willingness to answer our requests shown by all the CPs and other persons who were asked to provide responses to the Inquiry's Notices.

45. A public inquiry must ensure that the matters which it is considering are looked at both independently and thoroughly. Inquiry hearings were conducted in an inquisitorial fashion by Inquiry Counsel taking each witness through their evidence. The inquisitorial approach meant that each witness was able to give his or her evidence, and for that evidence to be probed, where appropriate, without the witness being subjected to inappropriate or unnecessary cross examination.

46. Public inquiries are not trials, and it is not part of an Inquiry's task to take a witness by surprise. In striving to get the best evidence from a witness it is important that a witness is prepared as to the issues the Inquiry wishes to be addressed. To that end, each witness was provided in advance with a bundle of relevant material and met with Inquiry Counsel prior to giving evidence, so that they could be advised as to the issues that would be concentrated on. In this way the Inquiry sought to reduce the apprehension faced by witnesses and to allow them time to consider what the Inquiry needed to hear about.

47. This did not mean that a witness's evidence was taken at face value without being tested. On the contrary, Inquiry Counsel and the Inquiry legal team went to great lengths to ensure that all relevant material was drawn to the attention of the Inquiry Panel and put to each witness. This was the case whether the material was supportive of, or undermined to any degree, the account given by the witness. Further, the legal representatives of the CPs and individuals asked Inquiry Counsel to put additional points to many witnesses. Inquiry Counsel then raised those points with the witness when considered appropriate.

## Role of the Inquiry

48. The Inquiry was not a court and was expressly precluded by Section 2 of the Inquiries Act 2005 from (a) ruling upon, or (b) determining, any person's civil or criminal liability. This meant the Inquiry could not make a finding that anyone was guilty of a criminal offence, or subject to civil liability. That is the responsibility of the civil and criminal courts. The Inquiry did hear and receive evidence that was more directly relevant to civil proceedings but makes no determination as to anyone's liability in respect of same.

49. Further, the Inquiry was expressly precluded from encroaching on the work of the General Medical Council (GMC). Mr O'Brien was reported to the GMC by the Trust in April 2019. The Inquiry liaised with the GMC throughout its work in order to be apprised of the stage of proceedings before the GMC and assure them that we were not overstepping our remit. We nonetheless considered that the standards set out by the GMC in Good Medical Practice were relevant to the matters we had to consider. More is said about this in the Clinical Aspects chapter.

## Standard of Proof

50. The standard of proof to be adopted by inquiries under the 2005 Act and other types of inquiry has been considered on several occasions in recent years. We do not consider it necessary to engage in a review of these authorities and have,

like many other inquiries, adopted the civil standard of proof. Where the evidence was sufficient to satisfy us on a balance of probabilities, that was enough. We have applied this test to the evidence before us and in our assessment of the evidence. We have tried to always have regard to the requirement of fairness in reaching any determination of fact.

51. At the conclusion of hearings, the Inquiry invited written submissions on the evidence from the three CPs and allowed short oral submissions. In preparing this Report the Panel had regard to all those submissions before reaching its conclusions.

52. Although as stated previously, the Inquiry Rules 2006 do not apply in Northern Ireland, the Inquiry has nonetheless had regard to them in seeking to be fair to those it heard from. A draft of the Report was prepared and each body or individual who was subject to criticism in the draft Report was sent a warning letter and invited to respond by a certain date.

53. The responses were then considered by the Inquiry Panel and the draft amended as we considered appropriate, having taken the responses to the criticisms into account.

54. The Inquiry Panel has had regard to all the evidence and to the submissions made. Not all of what we read and heard is referenced in the Report, but where the Panel have relied on the evidence to establish a finding or illustrate a point it has been referenced by way of footnotes. Where significant dispute has arisen as to fact, the reasoning for conclusions has been set out. It is important when considering the conclusions reached by the Inquiry that regard be had to the entirety of the Report, to the witness statements and to transcripts of oral evidence. All of this can be found on the Inquiry's website.

55. The Report deals with all those issues raised by the ToR. Given the interconnected nature of the ToR, it has been inevitable that some material and evidence will be referred to in more than one chapter. Whilst the Inquiry has tried

to keep repetition to a minimum, this was not easy to achieve. In the context of the issues looked at by the Inquiry, repetition and overlap has been unavoidable and was necessary to provide clarity in each chapter.

56. Moreover, throughout our work we considered it important to have regard to the context in which the events we looked at occurred. Those being a healthcare system beset with challenges in terms of resource, recruitment and financial constraints. Nonetheless we identified a number of failings both individual and at Department and Trust level.

## Findings and Recommendations

57. The Inquiry found significant weaknesses in governance arrangements in the Trust including a lack of clarity about the role of management. Primarily the failures in governance both corporate and clinical were responsible for what occurred. Inadequate systems of information gathering, coupled with a lack of leadership from both operational and medical management allowed poor performance from one individual and compromised the safety of patients.

58. With the complexity and success of modern medicine comes the responsibility to measure, demonstrate compliance and justify one treatment over another. Trust managers need to understand all of this and assist in the multidisciplinary role of demonstrating excellence in results. The Inquiry saw too much evidence of staff and managers sticking to silos, as well as undue deference to hierarchy within the Trust. There was too little clear emphasis on the overarching importance of patient safety.

59. Identification of relevant lessons for the future is necessarily dependent upon an understanding of the systems as they are today. The Inquiry sought relevant up-to-date information and noted the changes which have occurred. The Inquiry was encouraged that both the Department and the Trust did not wait until the conclusion of the Inquiry's work and the delivery of this Report before taking action to improve systems and prioritise patient safety. Where we believe that

further work is needed, we have set this out in the body of the Report and in the recommendations.

### The cost of the Inquiry

60. The costs of the Inquiry are set out in Appendix 2. There will be some further expenditure by the Inquiry after the delivery of the Inquiry Report, and its publication. These costs are associated with winding up the Inquiry and placing the Inquiry Record with the Public Record Office of Northern Ireland. Including the estimated costs for 2026/27, the final cost of the Inquiry is expected to be £9,573,717.

61. This represents the costs incurred by the Inquiry and does not include the costs of the CPs, which were not the responsibility of the Inquiry.

## Conclusion

62. All the Inquiry's recommendations have at their core the desire to improve systems that prioritise patient safety. We recognise that there are different methods of achieving this, and accordingly, we have sought not to be unduly prescriptive in how improvements can be made. This is true regarding recommendations that are relevant purely to the Department and those relevant purely to the Trust. We, like the Infected Blood Inquiry and the East Kent Inquiry, have sought not to make too many recommendations prescribing how change should be achieved. We have identified three areas where change is needed and directed attention to specific sections for action within those areas. Nonetheless we are anxious to see all recommendations acted upon. We are strengthened in this view by the words of Patient 10's husband who, when asked by Dr Swart what message he would like to get across to the Chair and Chief Executive of the Trust, reflected that recommendations from Inquiries were often neglected and had to be accompanied by a commitment to act from those who received

them.[20] We ask both the Department and the Trust to commit to act on the recommendations from this Inquiry.

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[20] See paragraph 50 of the Patients chapter

## Contents – Chapter 1 - Patients

# Volume 1 - Chapter 1 – Patients

## Introduction

1. This Inquiry was instigated because patients in the Trust's urology service had suffered harm and from its inception the Inquiry was concerned with matters of patient safety. The Inquiry's Terms of Reference (ToR)[1] relate primarily to the systems in operation in the Trust that had an impact on that issue. The Inquiry considered that although its primary focus had to be on systems of governance, any recommendations that bore on patient safety needed to reflect the impact that the failure of those systems had on real people. Moreover, the Inquiry was tasked by ToR (d):

> "To afford those patients affected, and/or their immediate families, an opportunity to report their experiences to the Inquiry."

2. As was made clear in opening remarks by Mr Wolfe KC,[2] and repeatedly by the Chair in her public remarks,[3] it was not the function of this Inquiry to make findings about the clinical outcomes in individual cases. The Inquiry was not tasked so to do, and it was not equipped to determine whether any individual had received inappropriate or inadequate treatment. In fulfilling ToR (c), the focus for the examination of the clinical aspects of cases was to identify any failings in the systems of governance within and relating to the Trust's urology specialty which may have affected patient care and safety. This was a key aspect of the Inquiry's work.

3. The Inquiry did not, therefore, consider the clinical aspects of cases as a goal in itself, but as a means to identify the existence of deficits in patient care in order for it to properly investigate and assess clinical governance arrangements within the Trust's urology service. Failures in clinical governance which may have

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[1] The ToR can be found on the Inquiry website at: www.urologyservicesinquiry.org.uk

[2] TRA-00009 to TRA-00022

[3] Chair's statement 31/08/2021; Letter to patients of 29/11/2021; Decision of 17/02/2022 on Patient 1's application for Core Participant status; Statement of 13/06/2022 (these documents can be found on the Inquiry's website); TRA-00003 to TRA-00008 opening of patient hearings on 21/06/2022; TRA-00275 to TRA-00293 opening of public hearings on 08/11/2022

permitted clinical shortcomings to occur or recur are referenced throughout this Report.

4. In deciding that the first evidence to be heard in oral hearings should come from patients and their families, the Inquiry sought to demonstrate that the patient voice was at the heart of its work. Failures in governance systems have an impact on patient safety, that is self-evident, but hearing from patients regarding that impact ensured that we gave a face and voice to the actual effects of poor governance.

5. At an early stage the Inquiry received one application, dated 20 January 2022, for core participant status from Patient 1. The Chair determined that it was not appropriate to grant core participant status to Patient 1 or any other patient or family asked to speak to the Inquiry. This was in no way to diminish the patient experience or its consideration by the Inquiry. One consideration for refusing the application was the fact that no patient was likely to face significant, or indeed any criticism from the Inquiry. As the Independent Neurology Inquiry (INI) report stated:

> “Patients are not, and cannot be, responsible for the safety of the health system. That sits with those responsible for governing the system.”[4]

6. Another consideration was that, as stated above, it was not part of the Inquiry’s ToR and the Inquiry was not equipped to answer the most important question regarding Patient 1’s treatment that the family would wish to have answered – *would the outcome for Patient 1 have been different if his treatment pathway had been different?* Questions of causation are the realm of the courts and the General Medical Council (GMC).

7. It was important nonetheless in order to fulfil Term (d) of our ToR, to hear from a number of patients or families who had been impacted by their experiences in the Trust.

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[4] INQ-10781, paragraph 1.13

8. When the Inquiry started it was anticipated that the number of cases it would look at would not extend far beyond the original nine Serious Adverse Incidents (SAIs) that led to it being set up. Unfortunately, the number of individuals affected by what the Trust considered were shortcomings in their care extended beyond the nine SAIs. The material provided by the Trust disclosed previous SAIs dating from 2016, the Royal College of Surgeons invited review and material relating to the Trust's lookback Structured Clinical Record Review (SCRR)[5] together with patient names.

9. Accordingly, the Chair personally wrote to 75 patients inviting them to engage with the work of the Inquiry. She frequently, through statements on the website and in press releases, encouraged anyone who wished to do so to come forward to the Inquiry.

10. Despite these actions, relatively few patients engaged directly with the work of the Inquiry. We considered possible explanations for why this was the case. We noted that many of the patients requiring urological care were elderly men with prostate cancer. This group of patients may have multiple comorbidities and hence be more vulnerable. They may be of the generation which is reluctant to seek medical help or to challenge the medical establishment and more likely to accept paternalistic care.[6] The Inquiry considers that this is one possible reason for non-engagement with the Inquiry, but accepts there could be other reasons, such as a reluctance to give evidence to a public inquiry.

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[5] The Inquiry considers the governance issues highlighted by the conduct of both these processes later in the Governance chapter

[6] The British Medical Journal published an article entitled "A decade after Francis: is the NHS safer and more open?" on 09 March 2023 wherein it is stated that "*most dispiriting of all, is the disproportionate representation of vulnerable groups in these [healthcare] disasters, … Failure to listen to the voices of patients and carers is a recurrent theme of investigations into avoidable harm*". BMJ 2023;380:p513. At: INQ-20440 to INQ-20444. See too: Bailoor, Kunal et al. "How acceptable is paternalism? A survey-based study of clinician and nonclinician opinions on paternalistic decision making." *AJOB empirical bioethics* vol. 9,2 (2018): 91-98. doi:10.1080/23294515.2018.1462273

11. Moreover, given that the Inquiry could not make any determination regarding an individual's treatment, it was not considered necessary to hear from every patient/family member who contacted the Inquiry but rather to hear from a representative number whose experiences reflected the issues that the Inquiry was finding on its consideration of the documentation it received.

12. The Inquiry devised a questionnaire and guide for patients or family members to fill in to make their engagement easier.[7] Former patients or family members contacted the Inquiry by various means (i.e., completion of USI questionnaire/telephone call/letter/letter from solicitor/email etc.). Of those who followed up with accounts to the Inquiry, a number were favourable to Mr O'Brien.

13. In June 2023 the Chair through an update statement on the Inquiry's website and by way of press release indicated that anyone still wishing to contact the Inquiry to speak about their experiences should do so before 31 October 2023.

14. In order to try to be as sensitive as possible the Inquiry decided that it would be inappropriate to compel any patient or family member to speak to the Panel. Conscious that the subject matter was emotional and personal to the individual or his or her family, hearings at which the patients spoke were held in private.

15. The Inquiry considered whether to call any of those who had contacted it in order to express support for Mr O'Brien and to praise his treatment of them. It was concluded however, that as the focus of our ToR is on governance arrangements within the Trust where complaints were received, or where the Trust has had to conduct a lookback review of Mr O'Brien's patients, or where the circumstances for an SAI were met, those patients most likely to be able to assist the Inquiry's work had been identified. The Inquiry has no remit to consider evidence or issues which fall outside the ToR.

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[7] See Appendix 1a and 1b

16. Nevertheless, the Inquiry recognises and acknowledges that many of Mr O'Brien's patients held him in high regard and their experiences of treatment by him were entirely positive. We heard how his colleague would be "more than happy to be his patient" if they needed urological care,[8] we heard that there was a perception that if you got to see Mr O'Brien you received "Rolls Royce" treatment.[9]

17. Indeed, some of those patients we did hear from also commented on how highly they thought of Mr O'Brien.[10] Mr O'Brien was a skilled, experienced surgeon, however the evidence the Inquiry has seen highlighted that his approach to his practice adversely affected a number of patients. This is discussed elsewhere in this Report.[11]

18. In order to ensure privacy, a protocol and restriction orders were drafted to provide patients with anonymity. Patient details were anonymised whenever the transcripts of what the Inquiry was told went onto the website, and at all times when it was necessary to refer to details about a particular patient's treatment, witnesses were required to refer to them solely by the cipher used by the Inquiry. This is continued in this Report and where patients or their family members have been referred to by name in documents, or by other ciphers, for example: the questionnaires that the Inquiry received or the SAI report, this Report has changed any quotations from those documents to the appropriate Inquiry ciphers.

19. The hearing sessions with patients and families were slightly less formal than the public hearings. Patients or family members were simply asked to tell us what they wanted the Inquiry to know. Each patient or family member received a bundle of evidence from the Inquiry to assist them.[12] For some this was the first

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[8] TRA-09180, lines16-17

[9] WIT-34189 to WIT-34190

[10] TRA-00158; TRA-00245

[11] See Clinical Aspects chapter

[12] When a patient/patient's family agreed to give oral evidence, the Inquiry sought relevant material from the Trust which was then shared with the patient and the CPs in Patient Bundles.

time that they learned details about their or their loved one's treatment, and the Inquiry recognises that this in itself had an impact on them.

20. The Inquiry was interested in hearing about the entirety of a patient's experience of care and the impact of what has been described as shortcomings in their care. They were, therefore, inevitably asked questions about alleged clinical shortcomings in order to obtain a full picture of the patient's treatment and experience in the urology service in the Trust. It was, however, made clear to all those who spoke with us, it is not the role of this Inquiry to make findings about clinical outcomes in individual cases.

21. We wanted to learn how patients were communicated with, what their experience was in relation to decision making as to their treatment, what information they were given regarding the choices of treatment and what support they had received from the Trust.

22. The Inquiry found listening to the patient and family accounts highly important. It was both informative and moving. This evidence on occasions opened a further line of enquiry for us and in all cases helped to provide context to the questions of governance we were tasked with answering.

23. Universally, we were impressed by the dignity of those we heard from and the balanced way in which they gave their evidence. This was particularly true of family members who had lost their father, mother, wife or husband. We were struck by how each recognised the hard work carried out by the health care professionals in the Trust.

24. Their testimony was invaluable in that it served to remind, were reminder needed, that behind each SAI investigation or lookback case was a real person who had suffered harm or potential harm or possibly received incorrect or sub-optimal treatment.

25. A number of themes emerge from the patient evidence. The Inquiry saw little evidence of the Trust valuing the patient experience in relation to their treatment when they sought advice or complained. Patients themselves seemed to have accepted this poor treatment, whether due to deference to those in positions of authority, a lack of knowledge or an inability to know what needed questioning.

26. What follows is a summary of the evidence that the Inquiry heard relating to and from 10 patients about their experiences of the Trust's urology services and the impact those experiences had on them. The accounts have been set out in accordance with the order in which the evidence was heard.

27. In this chapter the Inquiry makes no apology for the heavy reliance on quotations from patients, whether from documentary evidence submitted to us or from the transcripts of their evidence. It would have been easy to simply state what we learned from the patients, but the Inquiry is grateful to those who did engage with our work and considers that the effect of the failings in their care is best expressed in their words rather than ours. Where appropriate, we comment on what we heard.

### Patient 10

28. The Inquiry heard first from the husband of Patient 10. Patient 10 was never a patient of Mr O'Brien and neither she nor her husband ever met him. This lady had a complex medical history in the 10 years prior to her death having suffered colon cancer and breast cancer. She was referred routinely to the urology service in September 2014. The referral was not triaged by Mr O'Brien who was the consultant urologist on call when the referral came into the urology service and whose duties as consultant urologist on call included the triage of referrals. Mr O'Brien's colleague Mr Young had agreed to do Mr O'Brien's triage for a period in 2014. The Inquiry was told, however, by September 2014 Mr O'Brien had asked to take his triage duties back and has seen an email dated

19 September that indicated Mr Young was no longer performing triage.[13] By November 2014 a Urologist of the Week (UoW) system was in operation and by agreement the triage duty was included as part of the duties of that role.[14] As a result of the failure to triage, the patient was placed on a routine waiting list and not seen by the urology service until 16 months later.

29. There is a dispute as to whether triaging would have actually resulted in an upgrade to red flag. The SAI investigation into her case, which was chaired by Mr Anthony Glackin, found that the MRI report of the 29 September 2014 failed to reference the main clinical focus, which was the anterior cyst on the right kidney, meaning that those reading the report (including the GP as well as the breast surgeon) did not appreciate that there was growth in the size of the right kidney cyst.[15]

30. The SAI Review Team found that:

> "This error was the primary contributing factor to the delayed recognition of a potential renal cancer".[16]

It is not necessary for the Inquiry to determine whether triaging would have resulted in an upgrade in the case of Patient 10. The case was relevant to the Inquiry as it was this case that led to the exclusion from work of Mr O'Brien at the start of the Maintaining High Professional Standards (MHPS) investigation into what were described as his 'administrative practices'.[17] Moreover, it led to a lookback review that resulted in the discovery of further cases that had not been triaged by Mr O'Brien that same week, which resulted in the SAI investigation that reported in 2020.[18]

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[13] WIT-26283 paragraph 58.1 and WIT-30993 to WIT--30994

[14] TRU-00685; WIT-82431, paragraph 82

[15] Mr O'Brien trenchantly defends this position in his response to the SAI at AOB-01394, 25 January 2017

[16] PAT-000006, Findings, paragraph 1

[17] The MHPS process and investigation of Mr O'Brien is discussed in detail in the MHPS chapter

[18] TRU-161175 to TRU-161199

31. Nevertheless, the fact that her case had not been triaged was very important to Patient 10. In both the questionnaire that he had completed for the Inquiry and in his oral evidence the patient's husband described the effect that learning about the issue of non-triage had on his wife:

> "She was shocked, angry and disappointed that not only had her appointment not been triaged but 7 other patients in the same week had also not been triaged. … The extent of this error certainly undermined her confidence in the entire system for her care."[19]

32. In describing the mistakes made by the radiologist and breast surgeon as "one-off mistakes", Patient 10's husband compared that to the lack of triage:

> "But the serious aspect to us was that, not only was hers not triaged in that week, that there were seven others not triaged. And that was just a week in time that was pulled out of nowhere. … So we thought that that was not human error. That was a systemic failure of the system".[20]

33. In response to the Chair, regarding the effect of learning that there had been other cases untriaged in the same week:

> "And there were eight mistakes made in that week which, as I said, was pulled out of nowhere. And that had a major effect on [Patient 10] because, while the report said that in a lookback at the other seven, that there didn't appear to be any serious consequences as a result of the delay, that was pure good fortune that that happened. And you don't go into a hospital and rely on good fortune, you have to rely on each individual.
> And while each department, in a way, is separate in the hospital, Urology is separate from the breast end of it, Oncology, the heart end of it. They really are, and if you see [Patient 10]'s history, they really are all linked because you get a scan in relation to the bowel and it shows up something somewhere else

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[19] PAT-000034

[20] TRA-00033, lines 7 and 14-23

> or whatever. So there is interaction between all of the departments and that's the way it should be.
> It really frightened [Patient 10] that this had not been dealt with."[21]

34. From Patient 10's husband's evidence the Inquiry also learned something about how the Trust failed to adequately involve patients in the SAI process.

35. The first that the patient knew about the SAI process was at the initial meeting with Mr Mark Haynes on 06 January 2016, when she was told about the mistake that had been made regarding her scan and that he had reported that as an SAI:

> "Now that meant nothing to us at the time."[22]

36. Thereafter there was no communication from the Trust until they received a telephone call advising that the SAI report had been completed:

> "We didn't even know there was a report being carried out."[23]

37. Later in response to the Chair:

> "initially whenever we were contacted to state that the report was available, they asked us did we want a copy of the report, or did we want to go over and see them. And this is not a criticism, at that time I thought, well, that's a bit strange. And I said, well, can we not actually have a copy of the report and then go and [sic] over and see you? … and they did send me a copy".[24]

38. At the meeting to discuss the report on 10 April 2017:

> "they were open, they answered our questions, it was relatively short. That was of our making, not of their making because of the way that we wanted to deal

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[21] TRA-00042, line 28 to TRA-00043, line 19
[22] TRA-00030, lines 8-9
[23] TRA-00031, lines 8-9
[24] TRA-00041, lines 7-16

> with it. So, yes, they were helpful, we didn't find that they were evasive in any shape or form. It was totally open."[25]

39. The first that the patient and her husband knew about the lack of triage was when she read it in the SAI report.

40. The Inquiry considers that the failure to triage and the other failings in this case ought to have been explained to the patient at the outset. Currently there is no duty of candour in Northern Ireland, unlike the rest of the United Kingdom,[26] although the Inquiry understands that the Department is engaged on work related to the implementation of a duty of candour which has yet to conclude.[27]

41. No further communication was received from the Trust. The couple were content to leave the matter and to draw a line under it. Subsequently, Patient 10 received a telephone call:

> "from a lady to say that she was putting her on notice that in the Press the next day the issue about Mr. O'Brien was going to break in the Press and on television.
> And the purpose of the call was to assure [Patient 10] that, whatever problems were being reported in the Press in relation to the Urology Department, that they didn't affect her treatment. And what they were getting at was not the issue in relation to Urology and the triaging, but in relation to her treatment by Mr. Haynes, and we accepted that, and we were pleased that she had been put on notice of that, that it didn't affect her."[28]

42. Despite the relief she felt in relation to her own treatment, Patient 10 also considered other patients and their care. In the aftermath of the announcement of the Inquiry, Patient 10's husband reported:

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[25] TRA-00042, lines 5-10

[26] The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

[27] The Inquiry into Hyponatraemia related Deaths recommended in 2018 that a statutory Duty of Candour should be enacted in Northern Ireland applying to all Healthcare organisations and those working for them. See: https://www.ihrdni.org/Vol3-09-Recommendations.pdf

[28] TRA-00035, lines 9-22

> "We then both felt guilty that we had maybe taken too narrow and relaxed a view in dealing with the SAI report and we felt that, to put it bluntly, we should have maybe created more of a stink. … [Patient 10] especially felt guilty that we hadn't done that."[29]

43. As a result, the patient's husband contacted the Trust and arranged to meet with Mr Haynes when he received assurance that a new triage system (which he was shown) had been put in place.

44. The Inquiry considers elsewhere in this Report the communication between Trust and patients generally,[30] but this is an example of poor communication – patients need to be properly updated as to progress regarding any investigations about their care and any steps taken as result of such investigations.

45. In 2023 the Parliamentary and Health Service Ombudsman in England produced a report entitled "Broken trust: making patient safety more than just a promise".[31] The report, inter alia, highlights the fact that patients and families can suffer compounded harm from the failures of Trusts to investigate promptly, failure to involve them in the investigation and failure to improve systems. This desire to improve systems is well illustrated by this family.

46. Patient 10's husband wanted to ensure that the Inquiry was aware of the excellent care that his wife had received at Craigavon Area Hospital (CAH) during her years being treated there:

> "But I certainly want to make sure that the Panel, who may not be really as familiar with the workings of Craigavon Hospital as I am, I now know nearly every nurse and surgeon in it, that the work that was being done outside of these mistakes was absolutely first class and [Patient 10] appreciated that right

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[29] TRA-00036, lines 9-17

[30] See Clinical Aspects chapter

[31] The report dated 26 June 2023 can be found at INQ-20218 to INQ-20258

> up to her death and I think it's important that that's set in context in this Inquiry in relation to it.”[32]

47. The evidence given by Patient 10’s husband highlighted the lack of involvement of the patient when there was a serious incident involving that patient in the subsequent SAI investigation. More is said about the SAI process later in this chapter and elsewhere in this Report.[33]

48. Failure to triage self-evidently presents a risk to patient safety. The fact that the discovery of the non-triage of Patient 10’s referral led to a lookback of other patients whose referrals had not been upgraded and whose diagnosis and care had been delayed, clearly showed this.

49. Mr O’Brien’s explanation to this Inquiry was that he triaged red flag referrals and any urgent referrals or routine that he had time to do when he was UoW, but that his priority during that time was the inpatients, telling us that:

> “the most important patients that you have as urologist of the week are the inpatients. They are the critically ill. You should not be sending a junior registrar to deal with those people whilst you triage. There’s something fundamentally wrong about that.”[34]

The Inquiry is of the view that failing to triage the urgent and routine cases before the red flags was the wrong way to approach the task. Red flag cases were always going to be seen more quickly, but the risk to those who languished on an urgent or routine list of not being upgraded was an unacceptable risk to patient safety that Mr O’Brien took. Moreover, Mr O’Brien took this risk without any discussion or agreement with the wider clinical team or, as became clear in the MHPS investigation, without explicitly saying that he was doing so, although he

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[32] TRA-00045, lines 7-14
[33] Patients chapter paragraphs 126, 128, 132, 268, 335, 359 to 361 and the Governance chapter
[34] TRA-04657, lines 10-14

said that he made it clear that he found it impossible to complete his triage. More is said about this later in this Report.

50. When asked by Dr Swart what message he would like to get across to the Chair and Chief Executive of the hospital, Patient 10's husband said:

> "A. So if, in dealing with all of the evidence and witnesses, that I'm quite certain you will, in dealing with people like me and other witnesses, will find out what is wrong, and you will be making recommendations to the Minister, well then I think it probably would be incumbent upon people like myself and other people to make sure that the politicians accurately, not only read the recommendations, but will act on foot of them. Because, again, just from ordinary reading of news and that, that certainly not all recommendations from Tribunals are implemented. But, and if they are not well then the whole procedure is a total waste of time and nonsense. I'm not suggesting in any shape or form, if the recommendations are not implemented.
>
> So in answer to your question there really is not one thing. I would like that there was so whenever the report is there it would be at the top of the list and I would say, that's me. But, no –
>
> Q. DR. SWART: I think you have given it to me, the one thing is a commitment to act.
>
> A. Yeah, yeah.
>
> Q. DR. SWART: If that reflects what you have just said.
>
> A. Absolutely."[35]

### Patient 18

51. Patient 18 was admitted as an emergency patient with bladder retention in 2006 and was operated on by Mr O'Brien for enlarged prostate. He was told then he did not have cancer. He had follow-up appointments between 2006 and 2008.

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[35] TRA-00046, line 23 to TRA-00047, line 17

There was no further contact until 2011 when he received a letter from the Trust telling him to come in. His prostate-specific antigen (PSA) level had risen. Biopsies were taken and he was diagnosed with prostate cancer. In July 2011 the Multidisciplinary Meeting (MDM) recommended external beam radiation therapy (EBRT). Mr O'Brien prescribed Bicalutamide 50mgs and Tamoxifen. Patient 18 was not referred for radiotherapy until July 2012.

52. Patient 18 complained to the Inquiry that he was provided with inaccurate information regarding his condition and treatment options so that he was unable to make an informed choice as to his treatment.[36] He said that Mr O'Brien did not discuss Multidisciplinary Team (MDT) decision or outcomes with him.[37] Rather it was the patient who, having researched radiotherapy, raised it as a treatment option with Mr O'Brien.

53. Moreover, he was clear that Mr O'Brien tried to dissuade him from radiotherapy:

> "he tried to put across to me, I'm a man of 73, I'm not running the man down, he is a lovely man, but how I was treated. He was trying to put across, it was going to be a very tiring thing because I had said I would like to get radiotherapy because I had read it up and got help from my family. It had a good 80% success rate. And you had to go to the City Hospital Cancer Unit to get it. So Mr. O'Brien was saying, it's very tiring and you'll have to travel for seven weeks, five days-a-week."[38]

54. Patient 18 said that instead of radiotherapy he was prescribed Bicalutamide but not told about the side effects.[39] He said that he was told by Mr O'Brien that he was being selected for a "system" for Bicalutamide patients which was being put into operation.[40]

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[36] PAT-000545 to PAT-000546; TRA-00059; TRA-00068

[37] TRA-00064

[38] TRA-00061, lines 2-11; TRA-00062, lines 8-9; TRA-00069, lines 1-4

[39] TRA-00063; TRA-00071; TRA-00072

[40] TRA-00061; TRA-00075

55. Eventually Patient 18 wrote to Mr O'Brien telling him what his wishes for treatment were. That letter is set out in full here:

> "I am aware that you are processing a letter regarding my treatment. However, although this has not yet been received, I feel I have to state my wishes.
> Until the 27th April 2012 I have been on Bicalutamide. The side effects I experienced were: fatigue, headache, dizziness, depression, loss of strength, forgetfulness, lack of appetite (resulting in unhealthy eating), weight gain.
> As a result of this treatment I was only able to walk slowly for a short distance and could not do much more than sit in an arm chair. I persevered with the treatment for 7 ½ months as I was informed at my first consultation that I would be treated with radiotherapy when my PSA count came down.
> At my consultation on the 27th April 2012 I was told that the referral for radiotherapy would mean travelling to Belfast City Hospital every day of the week for 7 weeks and that this was very tiring. However, it was also pointed out that that this would mean getting the tiredness over and done with. It was then suggested that I should go on to what I believe is Intermittent Hormone Therapy and quality of life was also mentioned.
> Apart from the side effects mentioned above, I could potentially develop muscle loss, bone thinning, risk of heart disease and insulin - dependent diabetes. I understand that this treatment could continue but only as long as it continues to work. It can take 6-9 months or sometimes longer for the side effects to wear off. The longer you are on the treatment, the shorter the interval between treatments becomes. In these circumstances I cannot foresee quality of life with this treatment. There is also no cure.
> I understand that radiotherapy is used for treating men with prostate cancer that is localised or worse and is as effective at treating this as surgery to remove the prostate. The only disadvantage mentioned on the 27th April was the tiredness. We have an available alternative to avoid travel. I understand that there are other side effects but the percentage risk is low.
> When younger I was involved in athletics and long distance running. I never smoked nor drank and prior to diagnosis I could go for a four hour hike. This agrees with [Patient 18's Dr's] recent tests; so I consider myself a healthy

73 year old and feel that I could cope with radiotherapy. In this case I understand that there is a long term cure rate of 80%. I would like to have radiotherapy. [sic]"[41]

56. The Chair quoted from Patient 18's letter to the Inquiry:

"Q. So I think, if I can just quote what you said in your letter to me, you sum it up there, that although you were aware of the possible side effects of radiotherapy treatment, you believe that due to inaccurate and disingenuous information?

A. That's it.

Q. That was provided to you regarding your condition, and your treatment options earlier in your treatment, you were unable to make an informed choice about your treatment?

A. Well they weren't put to me correct.

Q. You don't feel you were given options?

A. I wasn't given options.

Q. Can I -- I mean, you go on to say that you believe that that led to delayed treatment, thus restricting your further options, and that that resulted in a poorer treatment outcome for you in general?

A. Yes.

Q. Which you have described to us the effects, the physical effects you are still having today?

A. Yes.

Q. Can I ask you, what do you feel ought to have happened?

A. At the beginning? Well, when they realised that I had cancer, I should have been sent for radiotherapy I believe. I should have been. And I'm not a Doctor, I'm an [redacted], but I know you deal with it immediately and they didn't.

Q. Were you given any reason as to why it wasn't being dealt with immediately?

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[41] PAT-000537 to PAT-000538

> A. No reason at all, other than Mr. O'Brien trying to put me off in his explanation, how tiring it would be, I've already quoted that. But there was no reason why I shouldn't medically have my radiotherapy."[42]

57. Patient 18 describes the difficulty he had getting an appointment with Mr O'Brien:

> "I mentioned the length of time that I had been, last been to see him. And my wife can't, when she rings, can't get an appointment. His secretary would say, he's a very busy man, he's dealing the people who are dying of cancer, things like that. And I can remember saying to [my wife], well, how does he know I'm not dying of cancer. But we told him that and he produced his private card. Now we accepted it out of politeness but I didn't do anything about that."[43]

58. Despite his cancer diagnosis no key worker was assigned to him, nor was he referred to oncology until after he wrote to Mr O'Brien.[44]

59. Patient 18 stated that he received no communication from the Trust between 2008 and 2011 and the first time he knew about the outcome of the SCRR was when the Inquiry provided him with the information.[45]

60. When asked by Dr Swart what he wanted the Trust to know it was clear he wanted the lesson to be as Dr Swart put it:

> "please make sure you listen very carefully to the voice of the patient in those discussions? [regarding treatment options]."[46]

61. The Inquiry is of the view that what it was told by Patient 18 suggested that the patient did not feel that he was fully involved in the treatment decision. This could reflect an old school approach to patient treatment that was patriarchal and not

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[42] TRA-00068, line 1 to TRA-00069, line 4

[43] TRA-00062, lines 18-26. See also Clinical Aspects, Private Patient section

[44] TRA-00065

[45] TRA-00058 to TRA-00059; TRA-00075 to TRA-00076.

[46] TRA-00070, lines 18-20

consistent with the modern approach of involving patients in all aspects of their care. Patients must be properly informed about their condition and treatment options. The patient's views should be listened to, and all options must be clearly presented to the patient and recorded with the patient's wishes clearly articulated and, ideally, also communicated in writing back to the patient. Doing so not only protects the patient and ensures real patient focus but also provides protection for a clinician where there is any dispute as to determinations regarding treatment.

62. The Inquiry considers that part of properly informing a patient is to set out the treatment plan in writing for the patient. Currently there is no requirement for clinicians in Northern Ireland to write to a patient directly or to copy a patient into a letter sent to his GP post consultation. Practice differs among clinicians. The evidence we heard showed that some did write a letter to the GP and either copied that to the patient or sent a version of it to the patient,[47] others did not copy in the patient.[48] The Inquiry considers that this requires to be changed and that post consultation all clinicians must write to the patient and send a copy to the GP. This ought to be mandated by the Department.

63. Doing so would be consistent with the approach in England following the Report of the Independent Inquiry into issues raised by Paterson[49] which recommended:

> "that it should be standard practice that consultants in both the NHS and the independent sector should write to patients, outlining their condition and treatment, in simple language, and copy this letter to the patient's GP, rather than writing to the GP and sending a copy to the patient."[50]

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[47] For example: Mr Haynes: TRA-01306 to TRA-01307, line 17 et seq

[48] For example: Mr O'Donoghue at TRA-09832 to TRA-09833; Mr O'Brien at TRA-12182 to TRA-12183 expressed scepticism about the practice of copying in patients as they often did not understand the content and that could lead to confusion or distress

[49] Paterson Independent Inquiry Report dated February 2020. At: https://assets.publishing.service.gov.uk/media/5e3947ed40f0b6090e0b446b/issues-raised-by-paterson-independent-inquiry-report-web-accessible.pdf

[50] Paterson Independent Inquiry Report dated February 2020, Recommendation 2, page 218

64. This recommendation was accepted in full by the UK Government in its response of December 2021 when it issued a directive[51] requiring Trusts to implement a mandate to all clinicians to write post-consultation letters directly to patients, a position that is supported by the Academy of Medical Royal Colleges (AoMRC).

65. The Inquiry notes that once the new operating system 'encompass' is fully operational in Northern Ireland patients will have the ability to access their health records directly. Nonetheless, many will not choose to do so or may be unable to do so. It is therefore important that clinicians comply with the GMC's Good Medical Practice (GMP)[52] core duty of communicating effectively with patients by writing such letters.

66. The Inquiry recognises that this will mean that many practitioners may need to learn to adapt their language to ensure that such communication is accessible to the lay person, however that is to be welcomed, as being able to explain to patients complex medical issues in plain English will enhance a clinician's practice. In September 2018 the Academy of Royal Medical Colleges in England issued a guidance document entitled "Please Write to Me" about writing outpatient clinic letters to patients to be included in undergraduate and postgraduate teaching materials and to be used when assessing written communication skills. This has been supplemented by guidance from the Professional Record Standards body in setting an Outpatients letters standard, the current version was updated in April 2023.[53]

67. The Inquiry considers that medical students, both undergraduate and, more particularly postgraduates, would benefit from greater emphasis in training in communication skills and with writing letters to patients. The Inquiry considers that the Department should ensure that this guidance material is used for training doctors and other clinicians in Northern Ireland. It would also be beneficial to

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[51] See Government response to the Paterson Report published 16 December 2021 at: https://questions-statements.parliament.uk/written-statements/detail/2021-12-16/hcws499

[52] See GMC Good Medical Practice Guidance, March 2013 Domain 3 at INQ-30881 to INQ-30885; also updated Good Medical Practice Guidance, January 2024 Domain 2 at INQ-30919 to INQ-30924

[53] See Outpatients letter standard - PRSB at www.theprsb.org/standards/outpatientletterstandard/

issue reminders to those who have practiced for some time, especially those who do not currently write to patients directly.

### Patient 84

68. Patient 84's evidence demonstrated further significant communication issues on the part of the Trust. The narrative of his complaint can be found in his letter of complaint about his treatment to the Trust,[54] the Questionnaire he completed for the Inquiry[55] and from the Trust's responses,[56] as well as in his evidence to the Inquiry.

69. This man had developed a kidney stone that required him to be admitted to hospital for stent insertion in March 2016.

70. He described slight difficulty in the admission process. He was contacted and told to come into the hospital on Sunday but when he arrived, he was not expected, he had to go home and return the following morning:

> 'it was just a wee bit of communication there, issues, no big deal really, but Sunday coming in, but nobody was expecting me and that kind of thing. And then I did go home and then re-admitted then on the Monday morning … so, yeah, communications."[57]

He was operated on by Mr O'Brien on 28 March 2016, he was told that there were a lot of stones in both kidneys and that the stent would be removed in six weeks[58] and therefore expected his stent to be removed by mid-May at the latest.

71. Patient 84 was not given an appointed date for the removal of the stent and subsequent to its insertion he began to have problems which he tried to self-manage. He tried to contact Mr O'Brien as he became increasingly unwell but

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[54] PAT-000200 to PAT-000202 letter to the Trust dated 19/09/2016

[55] PAT-000212 to PAT-000223

[56] PAT-000206; PAT-000211

[57] TRA-00085, lines 24-29

[58] PAT-000200; PAT-000217

only got as far as his secretary, Mrs Noleen Elliott. He told the Inquiry that he tried:

> “Ten times at least maybe, phone calls and stuff like that. … I phoned quite regularly, particular with the pain, it was just the pain of it all.”[59]

72. This was part of his later complaint to the Trust:

> “In desperation from knowing I was unwell I had to continue making calls to the secretary but I was made to feel like a nuisance and never actually got to speak to a medical professional or get an appointment for surgery. I was informed that the waiting list was over 200, this however is not acceptable and I do feel like I was severely neglected.”[60]

73. He felt that he was ‘fobbed off’ by Mrs Elliott. When speaking to the Chair he told the Inquiry:

> “Q. I think you said there that you were trying to contact Mr. O'Brien's secretary to see if what was happening to you was normal?
> A. Yeah.
> Q. And what response were you getting?
> A. Nothing. Just getting the fobbed-off. Go back to the GP, that kind of thing. And the GP was very good like, just trying to be supportive and that kind of stuff, but they can only do so much. They're not specialists and that. They just really were prescribing me more antibiotics, Amoxicillin, and that kind of thing, and painkillers and that kind of stuff like.
> But yeah, she was just telling about the waiting lists and that kind of stuff, but I was just looking for some kind of commitment, some kind of a date, you know, at least then something I could aim for and know that it was happening then and then I could just manage it, grin and bear it kind of thing. But there is no plan, they just didn't seem to have a plan for me. ….

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[59] TRA-00104, lines 11-19

[60] PAT-000201, paragraph 6

So that's the way I felt and I was just getting fobbed-off and I just wasn't getting listened to kind of thing.

I just wanted to speak to somebody medical, just somebody that just sort of says, this is normal, don't worry, I'm trying my best, I'm trying to get this waiting list down, I've got all this X, Y and Z going on, you know, and there was just some kind of commitment to get me sorted kind of thing and just to hear someone, this is normal, that's fine, just do this and do that, or whatever. I don't know like. But I don't think there was much I could do really.

Q. You didn't get to speak to any of the medical?

A. No, that was one of my complaints in the letter, like you know. That's one of my suggestions, don't be leaving it to the Admin Staff. Obviously they were the barrier to, I suppose, get rid of people and not get near the consultants. But surely it could have been delegated to a Junior Doctor or somebody, a nurse, anybody, just to sort of say anything, I don't know.

Q. How did you feel? You described you thought you were being fobbed-off, how did that make you feel?

A. It was just a bit helpless. You're just kind of like, what do you do? You're speaking to your GP and stuff and obviously they are supportive and things, …

But then that's when I got worrying about the whole infection and stuff, because is it because of the overuse of antibiotics then this is going to lead to some kind of superbugs and stuff? ... So it was kind of like, these better work. Like what happens if they don't, sort of thing."[61]

74. Clearly the inability to speak to someone medically qualified other than his GP, or to have Mr O'Brien respond to his phone calls caused Patient 84 distress and worry.

75. Ultimately, he was admitted to hospital via A&E as an emergency on 06 August 2016 with severe infection. Due to the infection, he was unable to have the stent

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[61] TRA-00088, line 5 to TRA-00090, line 16

removed until 11 August when the operation was successfully carried out by Mr John Paul O'Donoghue. He was discharged on 14 August but required to be readmitted with suspected sepsis on 17 August and was not discharged until 24 August.

76. Patient 84 wrote a letter of complaint to the Corporate Complaints Officer of the Trust on 19 September 2016. Having set out the difficulties he experienced, and the treatment received, much of which he considered to have been avoidable, he stated:

> "I want to make it clear that the staff during my stays were excellent but the duty of care potentially with serious implications between March and August was incredibly poor. If I had been dealt with in the correct manner after the insertion of the stent with it being removed after a 5-6 week period, not only could I have avoided enduring all that pain for 5 months but I wouldn't have to stay in the hospital for 2 full weeks to clear up a serious infection and the procedure could obviously have been much more straightforward.
>
> I suggest you vastly improve consultant and patient communication when the patient is not in the hospital, particularly knowing they are required to return to finish a procedure. Medical concerns should be addressed by the consultant or a member of his/her medical team, not by administrative staff. I understand there is a risk that the consultant could find all his time taken up with external patient concerns, but maybe this is where his/her administrative team and a member of his medical team work together to screen non-urgent/ less important issues, then a window in the day is left for the consultant to phone patients with real urgent concerns. If Mr O'Brien hadn't ignored my many calls and failed to return any of them, I wouldn't have been in this situation and the tax payer's money would be better spent. I can't understand in this cost conscious NHS system why it seemed a better plan to ignore my issues for so long and wait until I needed to be admitted to hospital for a 2 week period;

> taking up a bed, using up time, resources and antibiotics in addition to the impact on my health.” [62]

77. Patient 84 received an acknowledgement on 20 September 2016 and two further holding letters on 19 October 2016 and 23 November 2016.[63] Following communication from Mr O’Brien to her on 16 October 2016,[64] Mrs Esther Gishkori, then Director of Acute Services sent a substantive response to Patient 84 on 01 December 2016[65] on behalf of Mr Francis Rice, then the Trust’s Interim Chief Executive Officer (CEO). There is no explanation as to this delay of six weeks in responding.

78. The Trust’s letter of 01 December essentially summarises Mr O’Brien’s response to the complaint explaining the miscommunication with the ward and how it led to staff on the ward not expecting his attendance on Easter Sunday; stating that cancer patients must take priority and this is why his stent was not removed by the target date; the letter advised that Mr O’Brien was sorry that he did not respond to Patient 84’s many calls but due to clinical commitments and the number of patient queries he received daily he was too busy to respond to people individually. The letter stated that:

> “The Urology Department are currently working at improving the pathway for patients experiencing similar symptoms such as yours. This will involve having a 7 day week stone service with detailed information leaflets for patients with more access to health care professionals if advice is needed. It is hoped through the development of this service it will mean that patients will have their treatment and follow-up done in a timelier manner and hopefully avoid the poor experience that you had endured.”[66]

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[62] PAT-000202, paragraphs 4-5, see PAT-000200 to PAT-000202 for full letter

[63] PAT-000203 to PAT-000205

[64] PAT-000236 to PAT-000238

[65] PAT-000206 to PAT-000208

[66] PAT-000207, paragraph 5

79. The Trust apologised on behalf of the urology service. Patient 84 felt that this response was inadequate and failed to actually address his complaint. He wrote again on 28 February 2017 stating that he appreciated the apology on behalf of the urology service "but an apology direct from Mr O'Brien would have been more acceptable."[67]

80. In the letter he criticises Mr O'Brien for failing to come to see him in August 2016 (when he was in for stent removal) to explain the delay in treating him; he challenges the Trust suggestion that there was ever a plan to remove the stent in four to six weeks; he critiques the logic of delaying stent removal in favour of caring for cancer patients by pointing out that failing to address his needs caused him to get very ill and have to be admitted, thereby directing valuable resources away from cancer patients; claims that as he was so ill, requiring round after round of antibiotics, his case should have been treated on its own merits; suggests that Mr O'Brien dealt with him incompetently in March by failing to remove the stone:

> "Overall, the response I have received is unsatisfactory. After my surgery I was informed that the stent should be removed in six weeks' time. If that is the clinical target then it should be met. If that target is unrealistic then it should not be communicated to patients. The Trust has a duty of care to me; I feel there was a breach of that duty due to the evident negligence and the loss I suffered to my quality of life and earnings over this time."[68]

81. Mrs Gishkori wrote again on behalf of the Trust on 14 March 2017, acknowledging Patient 84's further letter and adding:

> "The contents of your letter has [sic] been shared with the Urology Team in order that they can consider how best to meet the needs of patients who require stents to be removed after surgery." [69]

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[67] PAT-000209, paragraph 1

[68] PAT-000210, paragraph 3

[69] PAT-000211, paragraph 2

82. When speaking to the Inquiry he expressed his dissatisfaction with how his complaint was handled by the Trust and how his main concerns were not addressed:

> “I just sort of felt, they focused on the wee smaller parts and really didn't really deal with the main issue of the communication and the plan and stuff.
> They sort of focused on wee things that I did, in fairness mention in the letter about admission times and communication and that kind of stuff, but for me that's fine, that's not the end of the world you know like. Things get misplaced and whatever like. But it was the over, yeah, they just didn't address the main concerns.
> Obviously then they brought in the cancer patient stuff and, you know, while obviously I have sympathy with them, life-threatening conditions and things, but that wasn't, I suppose you shouldn't be made [sic] feel guilty. All the more reason for me to, get me dealt with and then you can focus your time and efforts and energy on those people that need it and stuff like. But yeah, it just seemed a bit of a sort of a weak argument.”[70]

83. A patient being ‘fobbed off’, ‘made to feel guilty’ or being ‘made to feel I was a nuisance’ are all worrying phrases. They sit alongside evidence of patients being told about work pressures and workloads and are indicative of a failure to properly listen to patient concerns.

84. Patient 84 set out the substance of what he wished the Inquiry to know by completing a questionnaire. He outlined the thrust of his complaint, he stated:

> “The operation was undertaken on Monday 28th March 2016 and I had a stent inserted, this is where my main complaint lies. As admitted by the hospital later on 1st December 2016, in a response to my complaint letter, a stent inserted should have this removed and have an ureteroscopic lithotripsy

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[70] TRA-00094, lines 7-27

> performed four to six weeks later. I didn't get this stent removed until 10th August, nearly 5 months later. During these 5 months I was in excruciating pain throughout, right from the start, particularly when passing urine. I was passing fresh blood post exercise and had severe urgency and severe frequency. It was very disruptive to my home and work life. I had to bear the pain for so long and take painkillers all the time, likely putting more strain on my kidneys. …
>
> I feel there was a definite breach of duty of care to me. The staff including the different consultants during my unnecessary stays were excellent but Mr O'Brien and his admin staff provided a poor quality of care and very little communication, and this all could have been avoidable." [71]

85. His view of the Trust's response to his complaint was:

> "I just got an unsatisfactory response from them, blaming the demand on Urology Service. While I can appreciate the demand on the staff, and prioritising confirmed cancer diagnoses, I think it was illogical to keep my stent in as this later put a strain on resources elsewhere throughout the hospital like in 3 South when I was admitted twice with bad infections and for the riskier stent removal."[72]

86. In his questionnaire Patient 84 also described the key effects that delay in treatment had on him, both physical and on his mental health.[73]

87. It was clear that for Patient 84 the most significant issue was a lack of effective communication with the Trust, despite being worried and seeking medical advice he never got to speak to anyone beyond Mr O'Brien's secretary. Furthermore, his stent was only removed because he was so ill, rather than as part of a planned and organised process.

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[71] PAT-000217 to PAT-000218

[72] PAT-000220, answer to question 7

[73] PAT-000222

88. When he spoke to the Inquiry, he responded to a question from the Chair about what his major complaint was by saying:

> "It was that communication again, just back to that communication, just to be able to speak to a medical professional and stuff and just being some kind of plan, just a commitment, this is going to get sorted."[74]

> "but I was just looking for some kind of commitment, some kind of a date, you know, at least then something I could aim for and know that it was happening then and then I could just manage it, grin and bear it kind of thing. But there is no plan, they just didn't seem to have a plan for me. …
> So that's the way I felt and I was just getting fobbed-off and I just wasn't getting listened to kind of thing.
> I just wanted to speak to somebody medical, just somebody that just sort of says, this is normal, don't worry, … and there was just some kind of commitment to get me sorted".[75]

89. In response to a question from Mr Hanbury, Patient 84 explained clearly why he had wanted to speak with medical staff:

> "Q. you have mentioned that you would have liked to have spoken to either Mr. O'Brien or one of his junior staff, or one of the middle grades. How do you think that might have changed things, how did you envisage?
>
> A. Just to give me the reassurance that I was being looked at and that they had a plan and that it was imminent or whatever, or just some, just a personal touch. Just to say, look, you know, I'm under pressure, I'm trying to do this here, my hands are tied. You know, just that there [sic] something planned really and that I was being sort of acknowledged. I just felt like a bit of a nuisance and stuff phoning up all the time and whatever, you know.
>
> Q. By 'plan' you mean?

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[74] TRA-00091, lines 20-23

[75] TRA-00088, line 19 to TRA-00089, line 10

A. A plan as to how I was going to get, how I was going to get the removal, the stent removal essentially.

Q. Okay.

A. And maybe just a medical person to just reassure me that it's fine, do this, you know. I kind of knew to keep up the water uptake and that kind of stuff. But yeah, I suppose a bit of a reassurance at that time in the earlier days and then just to have an idea of when I was going to be seen."[76]

90. Patient 84 confirmed that he would have been content with having his stent removed by another surgeon:

> "Yeah. Totally. Yeah. No issues at all who does it like. … it didn't matter. That was something I remember at the time I remember I was phoning the secretary and they said they only do surgeries on a Wednesday or something. … And then they were saying there is a big backlog of so many hundred patients."[77]

91. Patient 84's incredulity that there is not some kind of plan to deal with the stent issue is clear. Problems related to infections and pain from stents being left too long are a recognised problem in urology and have been reported extensively in the literature and discussed at urology forums for many years leading to recommendations for developing protocols and registers of stent patients. Most Trusts have an agreed system or protocol for managing this. Most recently the Health Service Safety Investigations Body (HSSIB) has looked into this issue at a national level in England and issued a report with recommendations.[78] These include a recommendation for a national standard for logging and tracking stents which should include guidance on monitoring and human oversight.[79]

92. Further work in this area involving professional bodies is underway, but in the meantime Trusts should have an agreed system to manage stents to avoid the

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[76] TRA-00101, line 16 to TRA-00102, line 10

[77] TRA-00102, lines 22-28

[78] "Unplanned delayed removal of ureteric stents" published 22 October 2020, www.hssib.org.uk.

[79] www.hssib.org.uk, Safety recommendation R/2020/091

issue of delayed stent removal. The issue was raised on a number of occasions in the Trust from as far back as 2015,[80] but despite there being general agreement that all patients who had a stent fitted needed to be added to a waiting list with a planned date to come in for removal, no formal system was put in place to ensure timely removal. Therefore, when Patient 84 rang there was no means of telling him when his stent would be removed. We heard from clinicians that the matter was discussed between them but no agreement on a system to ensure removal was reached.[81] This demonstrates a failure to learn and improve from past issues and a somewhat chaotic management of waiting lists that is unacceptable and unfair to those patients who had urgent problems that were not cancer related. More will be said about this elsewhere in this Report in relation to governance which will include a section on learning from and acting on the recommendations from the SAIs.[82]

93. This evidence clearly shows the impact on an individual of being unable to access appropriate advice from a clinician. The Inquiry knows that for cancer patients the key worker,[83] usually a specialist cancer nurse, provides an immediate point of contact, reassurance for patients and alleviates pressure on consultants and their secretaries when advice is needed. No such designated point of contact exists for non-cancer patients who may also need a medical point of contact. Urology services did have specialist nurses involved in the non-cancer issues who did deal with some things but from the evidence we heard there was no coordinated or unified clinical offer to patients.

94. Each clinical specialty has patients who run into trouble between appointments or have an urgent worry and many departments have specialist nursing staff to bridge the clinical problems. It is, however, necessary for the whole team to work together to ensure that patients and families are not left in limbo.

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[80] See: WIT-50465 IR2 for Patient 136 in 2015; WIT-33314, SEA for Patient 91 in 2018

[81] TRU-387332, paragraph 1 – minutes of a meeting in July 2019

[82] See Governance chapter

[83] The issue of cancer patients not being assigned a key worker is the subject of discussion elsewhere in this Report: see Clinical Aspects chapter, section on CNS liaison and referral

95. The Inquiry is of the view that departments should have a system whereby patients can ring a secretary or a nurse (not necessarily a cancer nurse) to indicate they have a problem and who will ensure that someone will get back to them. A department should be able to identify whatever staff are appropriate and the system could be managed by the complaints department. A failsafe troubleshooter type service, managed under the auspices of the Complaints Department, which actually listens to patient concerns and solves problems before a formal complaint is raised, could save time and resource and allow matters to be resolved quickly.

96. In response to being asked by Dr Swart what would have made the complaints process better for him, Patient 84 indicated that he had seen an improvement in the manner of the Trust's engagement:

> "A. I think they have improved since because I have had discussions, you know, they have been very responsive and they have been sort of telling me every step of the way and phone calls. So they have obviously reacted to some of these things.
> Q. So who has been ringing you then more recently?
> A. Well part of Mr. Young's Stone Clinic, so that's all the people with kidney stones and things go there. So the likes of Mr. Young, or delegated part of the staff, or whatever, a medical person, there is a nurse phoned me as well. And so obviously they're...
> Q. So you think they have learned from that?
> A. I think they have, yeah. It sounds like they have reacted to that because I never would have had that before. So, yeah, that's what was missing that time, just letting me know that there was a plan in place and you're going to be dealt with, and being able to speak to a medical professional and stuff."[84]

97. In conclusion Patient 84, when asked if he wished to add anything said:

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[84] TRA-00098, line 18 to TRA-00099, line 6

> “they seem to be doing things better and I think they need to do that. They just need to dedicate more time to the patients and things and have that medical staff to sort of chat to the patients and set time aside.
>
> I know Mr. O'Brien says, oh, that's nice in an ideal world and that, but that should be an important part of his job and find the time for that or whatever. ...
>
> I just think the patient communication could be better and sort of give plans.
>
> He says there about his 25 years, he has never committed,[85] maybe he should have, you know, and had those dates and stuff so that the patient feels that they are being listened to and dealt with and looked after, and basically just get on with their day-to-day life and that kind of stuff. So, yeah, there's definitely things there to be learned. I am sure that will come out of your Inquiry and whatever. But, no, that's about it really as far as myself.”[86]

### Patient 16

98. The Inquiry heard from the daughter of Patient 16, he had sadly died five years previously. This too was a case concerning the Trust’s failure to arrange for timely removal of a stent, attendant communication failures and serious medical complications that followed.

99. Patient 16 was a wheelchair user having suffered a spinal injury in 1976. In July 2012 he was diagnosed with colon cancer. At that time he underwent an operation but opted not to have chemotherapy. In 2014 following a recurrence of his tumour he was referred back to oncology when it was agreed that he would be kept under review and treatment considered in the event of disease progression. In March 2015 he was experiencing pain and his review was expedited. On 12 March 2015 the Cancer MDT discussed his case, and his consultant oncologist wrote to urology for consideration of a ureteric stent to

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[85] This was a reference to what Mr O’Brien had said in response to Patient 84’s complaint: “I have never, ever committed myself to perform a procedure within a particular time unless I have actually fixed a date. However, during those 25 years, such commitments have been given to patients on numerous occasions by junior staff who have never once seen a waiting list.” See: PAT-000237, paragraph 2

[86] TRA-00110, lines 2-10 and 15-26

relieve a kidney blockage. A stent was inserted on 31 March. The stent required removal or replacement after six to nine months. Patient 16 underwent chemotherapy which finished on 08 October 2015. Following that the oncology consultant wrote to Mr O'Brien on 26 November 2015 asking him to consider changing the stent.[87]

100. Thereafter there were a series of communications between oncologists, not always copied to urology and Patient 16's daughter phoned urology to try to get a date for the stent removal. Eventually Mr O'Brien removed the stent on 29 June 2016. Mr O'Brien and the other consultant urologists were aware of the problems with stents and did make individual representations about urgency for specific patients, including Patient 16.[88] More is said about this governance issue later in the report.

101. Patient 16's daughter sent a letter of complaint to the Trust dated 05 December 2016, shortly before her father died. In that letter she indicated that the complaint was with his knowledge and consent. In the letter she set out the background: she explained that the stent was inserted in March 2015 prior to the commencement of Patient 16's chemotherapy treatment. The family were advised that the stent would be due for removal immediately after the treatment ended as its life span is six to nine months. Chemotherapy finished in November 2015 and Patient 16 was advised that arrangements would be made with urology to have the stent removed.

102. Patient 16's daughter describes the impact on her father over the six months that followed:

> "my father suffered from a range of complications synonymous with a stent in place too long including; significant pain and persistent urinary tract infections."[89]

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[87] PAT-000105
[88] AOB-77568
[89] PAT-000129, paragraph 2

103. Patient 16's stent was finally removed on 28 June 2016 – 15 months after insertion and seven months after removal was requested by the oncologist. Post-operatively, he became unwell due to septicemia and spent 12 days in hospital.

104. Three weeks later, an oncologist advised Patient 16 that he would make arrangements for him to attend the Radiology Department at Belfast City Hospital (BCH) to have initial measurements taken. His daughter understands this was delayed for a short period following intervention by the urologist as a new stent would need to be inserted. This was done in August 2016. Following insertion of the new stent, a further scan was required in September 2016. At the next meeting on 01 December 2016 (13 weeks later), Patient 16 was advised that radiotherapy was no longer an option as the disease had progressed.

105. Patient 16's daughter considered that the delay in the removal of the initial stent was linked to the removal of cancer treatment options for her father. In her letter, she distinguished the care her father received in the Trust from the care her mother received in the South Eastern Health and Social Care Trust (SEHSCT).[90] Her letter listed a number of expected outcomes from her complaint.

106. As a direct consequence of this complaint an SAI investigation was carried out. On 19 April 2017 the family were advised that this course was being taken by a letter from Mrs Gishkori, then Director of Acute Services.[91]

107. Patient 16's daughter then phoned on 04 October 2017 seeking an update on progress and received a letter dated 26 October 2017 from the Acute Governance Co-ordinator saying that the investigation was ongoing.[92]

108. The family heard nothing for a year and on 30 October 2018 Patient 16's daughter emailed the Trust seeking an update on her complaint letter of

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[90] PAT-000130

[91] PAT-000133

[92] PAT-000134

December 2016. Ms Roisin Farrell, on behalf of Mrs Trudy Reid,[93] replied advising the draft report was with the Chair for review and apologising for not keeping the family updated.[94]

109. Four months later in April 2019 Patient 16's daughter sent the following email:

> "To whom it may concern,
> I am requesting an update on the above referenced complaint lodged in December 2016 regarding my father, [Patient 16]. It is with utter disbelief that I am still having to initiate contact with your department to request information regarding this matter. It is incredulous that the investigation has not yet reached a conclusion. I feel that we have been very patient but our desire to get answers to our questions has not diminished over time. We are now extremely anxious to get closure on this issue as my mother has a [personal information redacted by USI] and so time is now of the essence. Therefore please do not provide me with the usual non-committal response that you are unable to provide me with a timeframe for the completion of the investigation.
> Regards,
> [Patient 16's daughter]."[95]

110. She received a holding email on 09 May 2019 and a substantive response on 16 May 2019 advising that the report had been completed and would be shared with the Acute Governance Meeting in June.[96]

111. The Review Team did not report until January 2020.[97]

112. The Review Team found that the crucial period regarding any unnecessary delay in treatment and care in this case appears to be from the time Patient 16 was deemed ready to have his stent removed or replaced (i.e. 26 November 2015)

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[93] Acute Clinical & Social Care Governance Coordinator
[94] PAT-000135
[95] PAT-000138
[96] PAT-000137
[97] PAT-000100

and when he was finally admitted for his surgery (i.e. 29 June 2016), a period of 217 days or 31 weeks.[98]

113. In preparation for palliative radiotherapy, further surgery was required on 10 August 2016 to insert another stent but in December 2016, due to disease progression, Patient 16 was no longer fit for the planned radiotherapy. As his daughter had set out in her letter of complaint referred to above, it was the family's belief that the delay in treating him impacted on the treatment options available to him. According to the SAI report oncology commented that:

> "with the benefit of hindsight, it is clear that palliative radiotherapy would not have affected the clinical outcome and could have been detrimental."[99]

114. Nonetheless the SAI team did consider that the delay was:

> "probably significant in terms of,
>
> - an easier progression through the process of having the stents removed and replaced;
> - reduction in the level of pain and discomfort reported towards the end of life."[100]

The SAI team concluded:

> "There was a <u>treatment and care delay</u> – specifically, to the changing of ureteric stents, due to,
>
> 1. Lack of effective communication systems and processes; and
> 2. Long Waiting Lists leading to delay."[101]

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[98] PAT-000109 to PAT-000111

[99] PAT-000101, paragraph 4

[100] PAT-000101

[101] PAT-000113

115. In relation to the lack of effective communication systems and processes the Review Team stated that there were two aspects to this:

   (a) communication between oncology and urology; and
   (b) failure to action correspondence within urology.[102]

116. The Review Team noted that oncology letters were not on the Northern Ireland Electronic Care Record (NIECR) and thus not accessible outside of patients' clinical notes for other clinical teams to access and use when planning treatment. There were also many occasions when letters from oncology which contained urological issues were not copied to urology. On some occasions, when they were copied to urology they were copied to another consultant urologist and not the Urologist in charge of Patient 16's care, Mr O'Brien.[103]

117. The Review Team also noted that communication opportunities involving Mr O'Brien appeared to have been missed a number of times, resulting in Patient 16's stent not being removed and/or replaced in a timely manner:

> "Throughout this case, there were letters not received or acknowledged, emails not actioned and phone messages from the patient and family that also did not result in action."[104]

118. Another factor leading to delay was the long waiting times for routine and urgent urology inpatient and day case treatment.[105] The increase in waiting times was discussed many times during the Inquiry and reasons for same are covered elsewhere in this Report.[106]

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[102] PAT-000114
[103] PAT-000114
[104] PAT-000114, paragraph 5
[105] PAT-000114
[106] See Clinical Aspects and Governance chapters

119. The Review Team noted that the Trust did not have formal guidance on managing letters in terms of both tracking and what is expected of clinicians when dealing with clinical matters using paper correspondence/email.

120. Following finalisation of the report a copy was sent to Patient 16's daughter in early February. She then emailed the Trust on 05 May 2020 as follows:

> "To whom it may concern,
>
> The above referenced document was received on 3rd February 2020. I would now like to meet with the Chair and Acute Governance Facilitator to discuss the report. I am cognisant of the significant pressures all personnel within the HSC are under at the moment on account of the COVID-19 crisis and I fully understand that it is likely to be some time before this meeting can take place. I would also like to advise that I plan to request that a member of the Patient and Client Council be in attendance.
>
> Yours sincerely,
> [Patient 16's daughter]."[107]

121. The next written communication was another email from Patient 16's daughter to the Trust on 29 December 2021 as follows:

> "To whom it may concern,
>
> I received the SAI report referenced above in February 2020 and I subsequently requested a meeting with relevant personnel. I received a phone call later that year from a Mr David Carson, who advised me a potential date for the meeting but as I explained to Mr Carson, I was unable to attend on the given date as I was caring for my mother who was at end of life stage, at that time. I indicated that I would be most grateful if another date could be

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[107] PAT-000139

> arranged. Since then I have received one phone call from the Governance team to advise me that there was going to be negative publicity about a Urology consultant, involved in my dad's care, in the the [sic] Southern Trust. I have had no further contact from the department despite reiterating to the lady who called that I wanted to proceed with the meeting. I understand that COVID has severely impacted on your service and the availability of meetings however I would be most grateful if you could make arrangements to set up a meeting at your earliest convenience, to review this report.
>
> Kind Regards,
> [Patient 16's daughter]."[108]

122. When she spoke to the Inquiry Patient 16's daughter explained why she wanted to have a meeting, telling us:

> "So there were issues I felt that weren't explored and there were other issues that, as a lay person, I really struggled to understand and felt I could have done with clarification."[109]

123. Further, it was only when she came to complete the questionnaire for the Inquiry in December 2021 that she realised that the Trust had not offered her an alternate date and that no meeting had taken place with her to discuss the report.[110] She contacted the Trust again and found a conversation she had in February 2022 helpful, but it appears that at no point did she meet with the SAI Team.

124. The SAI review team comprised: Dr Johnston (Consultant Medical Adviser and Chair), Mr Haynes (Consultant Urologist), Mrs Katherine Robinson (Booking & Contact Centre Manager) and Mrs Reid (Acute Clinical & Social Care Governance Coordinator) and while their investigation arrived at reasonable

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[108] PAT-000140
[109] TRA-00134, lines 21-24
[110] TRA-00128 to TRA-00129

conclusions regarding the delay in the case, the efficiency of inter trust and inter departmental communications and the effect of waiting lists on the delay, this case highlights a number of deficiencies in the Trust's systems.

125. The above account of how the family's complaint was treated also highlights a number of issues:

- There was no patient or family involvement with regard to settling the ToR for the SAI.
- No-one from the SAI team spoke to or otherwise engaged with the family or explained what an SAI was, or what it was designed to achieve.
- The family were not kept updated throughout the investigation and instead had to repeatedly pursue the Trust for updates.
- The SAI took too long to investigate and report.
- Even after the report was issued the family had to push for it to be discussed with them.
- That discussion never took place.

126. In relation to the SAI process Patient 16's daughter clearly considered that proper involvement of families was important and that there was a need for transparency:

> "So I feel that system, while the process is really good and very thorough, that the lack of communication, the lack of the families actually having an opportunity to see the response of the people involved to the initial complaint. So, you know, I have obviously been able to view Dr. O'Brien's response and that has been very useful. But obviously there's a response from Oncology as well that we are not privy to. So there are certainly a few things in relation to that process that possibly could be improved as well."[111]

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[111] TRA-00129, lines 2-13

127. She also, when questioned by Dr Swart, indicated that it would be very useful for families to have input into the SAI ToR.[112]

128. The Inquiry considers that SAI investigations require to be more patient focused as there is a clear link between the patient experience and clinical safety and effectiveness.[113] Transparency and honesty when things go wrong is important and that transparency should extend to the SAI process as well as the outcome and post report discussion.

129. Mr O'Brien made a number of comments in his response to the SAI report.[114] It seems that Mr O'Brien was advised on 30 December 2016 of the possibility of an SAI in this case. On 28 October 2019 he was sent the Root Cause Analysis (RCA) report asking that he check it for accuracy and respond within two days, by 30 October. He requested and received an extension to 13 November 2019 but did not in fact respond until 19 November 2019.[115]

130. Mr O'Brien makes a number of points regarding this SAI report:

- He claimed that Patient 16 was not admitted to hospital on 31 March 2015 under his care. He enclosed a copy of his operating list as entered on the Theatre Management System in support of this, albeit he proceeds to concede that he may have supervised Patient 16's procedure in another theatre that morning and agreed to him being added to his list for stent removal.
- He noted that the letter of 26 November 2015 was not copied to him. He explains that the handwritten note of the CAH unit number on the letter was written by his secretary who, he states, confirmed to him that she did not appreciate it was addressed to Mr O'Brien as it was addressed to someone else and had filed it in Patient 16's chart without showing it to Mr O'Brien.

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[112] TRA-00132, lines 15-22

[113] See: Doyle C. et al (2012). "A systematic review of evidence on the links between patient experience and clinical safety and effectiveness". At: INQ-20450 to INQ-20467

[114] PAT-000124 to PAT-000127

[115] TRU-169362 to TRU-169365

- He pointed out that the Review Team did not include any reference to a series of emails in early December 2016, in relation to Patient 16's admission. He also highlighted that he was, himself, recovering from surgery at the time.
- He complained about the time allowed for his response.
- He concluded by stating that the SAI had been investigated without due diligence and that the report was "compiled with a prejudice and bias betrayed in its writing."[116]

131. This response shows that the Review Team did not engage with one of the consultants involved in its investigation until the report was complete. The Inquiry's view is that he ought to have been spoken to, if not at the outset, then certainly at some point before concluding the report.

132. Following the report of the Hyponatraemia Inquiry,[117] the Department commissioned the Regulation and Quality Improvement Authority (RQIA) to review the Systems and Processes for Learning from SAIs in Northern Ireland. The RQIA report was published in June 2022.[118] That report concluded that the current SAI process was not achieving the intended purpose of the SAI procedure and that to improve the situation a redesign was needed not just of the procedure but the system in which it operates. More is said about the SAI procedure elsewhere in this Report,[119] however the RQIA Report recognised that any redesign needed to ensure the involvement of patients and families. It made the following recommendations:

    1. "The Department of Health should work collaboratively with patient and carer representatives, senior representatives of Trusts, the Strategic Performance and Planning Group, Public Health Agency and Regulation and Quality Improvement Authority to co-design a new regional procedure

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[116] PAT-000124 to PAT-000127

[117] The Report of the Inquiry into Hyponatraemia Related Deaths, published January 2018.

[118] WIT-85795 to WIT-85862

[119] See Governance chapter, section on management at the Trust

based on the concept of critical success factors. Central to this must be a focus on the involvement of patients and families in the review process.

2. Health and Social Care organisations should be required to evidence they are achieving these critical success factors to the Department of Health.
3. The Department of Health should implement an evidence-based approach for determining which adverse events require a structured, in-depth review. This should clearly outline that the level of SAI review is determined by significance of the incident and the level of potential deficit in care.
4. The Department of Health should ensure the new Regional procedure and its system of implementation is underpinned by 'just culture' principles and a clear evidence-based framework that delivers measurable and sustainable improvements.
5. The Department of Health should develop and implement a regional training curriculum and certification process for those participating in and leading SAI reviews."[120]

133. The Inquiry notes and agrees that improvements are needed in the SAI review process and more is said about this elsewhere in this Report.[121] The Inquiry would endorse in particular the increasing focus on the involvement of patients and families, the open exchange of information between patients and staff and the imperative to make any rapid changes needed to ensure patient safety.

134. In her completed questionnaire for the Inquiry dated 29 December 2021, Patient 16's daughter has described her main concern on behalf of her father as the lack of response by Mr O'Brien to the numerous attempts to communicate with him to address the stenting issue. She also stated in that questionnaire that her father found Mr O'Brien to be arrogant and dismissive in his dealings with him.[122]

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[120] WIT-85807 to WIT-85808

[121] See Governance chapter

[122] PAT-000144 and PAT-000147

135. Patient 16’s daughter when speaking to the Inquiry raised concerns about communication in respect of the communication between specialties within the Trust (i.e. urology and oncology) and between the Trust and patient.[123]

136. Patient 16’s daughter described the confusion that existed when he arrived at CAH on 31 March 2015 for stent insertion to find that he was not in fact listed for surgery that day:

> “I can see from the submission from Mr. O'Brien that there was some level of confusion about surgery lists et cetera. But this was a gentleman with a spinal injury in a wheelchair who, you know, was in for a procedure and we sat around in a corridor. We clearly could see that there was great confusion as to where he was to be placed, on whose list he was et cetera, et cetera.
> And absolutely, the staff in these Departments are absolutely incredible. Like I have the utmost respect for all people in the world of medicine, and the mismatch between demand and capacity in all of these departments is something that we all acknowledge, but it's just a little bit of respect for the person in question. And he should never have been privy to that information that he wasn't on a list and that there were issues with that. [sic]”[124]

137. In response to the Chair asking she described the effect of lack of response to both her and her father’s attempts to find out when his stent was scheduled for removal:

> “Q. What did you feel about the level of communication from the Urology Department to your father about the removal of the stent?
>
> A. I have concerns on two levels. I have concerns, as I say, the fact that there was no reciprocation of communication. So all we would have asked for was someone to get back and say we've spoken with one of the consultants or whatever and, you know, we can assure you he is on

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[123] TRA-00118 to TRA-00119; TRA-00124 to TRA-00125

[124] TRA-00121, line 28 to TRA-00122, line 16

> a waiting list, we can assure you that it will be carried out, obviously we're under severe pressure at the moment or whatever.
>
> But there was never anything like that. It was almost like you were speaking, you would give your message but there was never anyone to come back to you. So as I say, that communication I felt just wasn't reciprocal. There was nothing coming back. It was very much I'm making this phone call.
>
> Now, again, looking through the documentation, the GP would have told us and Macmillan nurse would have said that they would have made contact, but there is no reference to that in the documentation so I don't know if that ever happened. But certainly it felt like it was coming from various quarters and no one was getting a response to it. So that communication, but I also could never understand why there wasn't a more robust mechanism for recording people who needed intervention, you know."[125]

138. Patient 16's daughter described the effect that the inability to get anyone to answer her father's attempts to get information had on him:

> "And I suppose he was very taken aback at the fact that all through his life, I mean those 30 years, all he had to do was to make a phone call to that particular department. And that consultant, I mean that message would be relayed and the consultant would then come back to him and say look we'll bring your review forward, or try this medication, or whatever. So whenever that wasn't happening in response to the communication from both Oncology and the surgeons in relation to this particular, the stent being in place, he was quite dismayed because it was a very different experience to the one he had had all his life.
>
> And that, as a family, to watch him suffer unnecessarily, you know, given the fact that he had already come through all of the, you know, [personal information redacted by USI], the intensive rehabilitation that that required and

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[125] TRA-00124, line 22 to TRA 00125, line 21

> his resilience was always incredible and to find then that he wasn't being listened to, that was very, very difficult to watch and he was suffering, and he knew why he was suffering and he could relay that very clearly and he was a very articulate and intelligent man and that was why we found it so difficult to accept that no one was coming back.
>
> And the communication, certainly from ourselves, both dad would have rang and I rang and whatever, and you never got a response to that. You know, the message was relayed obviously but no one, the secretary didn't come back to say, well, the consultant, you know, he's on a waiting list, he will be seen in a couple of months, in the meantime maybe you should try this or... So it was that lack of reciprocation of communication which was particularly upsetting."[126]

139. In answer to Inquiry Counsel about the number of times she had contacted Mr O'Brien's secretary on behalf of her father to try to find out when he would be seen she said:

> "A. From recollection it would have been asking if there was kind of a timeframe, could we have any idea when it was likely that the procedure would happen. And as time progressed I can certainly remember it would have been trying to explain some of the symptoms that he was having that appeared to be in relation to the stent being in place for too long. So it would have been dad advising her of his symptoms.
>
> And as I say, we would clearly have been told that that would have been passed on and it clearly was, but it was the fact that no one ever got back to say that information has been passed to the correct source and this will be the action that we will take as a result of that.
>
> Q. Did anyone on, you say no one got back to you. No one, literally no one. Literally. Not a secretary and not a medic?
>
> A. No. I have no recollection of anyone ever returning a phone call or advising. As I say, then we would have been waiting on our next

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[126] TRA-00117, line 15 to TRA-00118, line 19

> appointment with another discipline, be that Oncology or the surgeon just to kind of see if there had been any further movement."[127]

140. She did not accept as an excuse that the letter sent to the Urology Department being incorrectly addressed and therefore not brought to Mr O'Brien's attention:

> "So it doesn't matter, to me it's irrelevant who the letter is addressed to, what the salutation is, whether it is filed or it is not filed. Surely there is a system that can go in place which shows this person is about to breach the timeline for this intervention happening, you know. And a good IT system surely would be able to do that.
>
> Now obviously then the pressures of operations and availability of that facility, a lot of that is out of control of the consultant or whatever. But it's just, we always felt, and you know reading the documentation, something was filed away, the letter was filed away. Well to me that's not good enough. You know, that should have been put on a system that red-flagged that this person is now, the stent is in place, it needs to be removed within a particular timeframe. And to think that that wasn't in place in that department, I mean I don't know enough about it, but certainly from a layperson I feel that there must be a more effective and efficient way of recording those."[128]

141. In response to Mr Hanbury she made the point about the fact that there did not appear to be a waiting list specific to those awaiting stent change:

> "And, again, that doesn't surprise me because there didn't seem to be a robust mechanism for flagging these patients up again for procedures which were required. It's not – I understand, as I say, there's a waiting list and all of the demands that go with that. But if someone requires a procedure as part of their journey for cancer treatment, you can't wait. It's not something that you can postpone. One was very much dependent on the other."[129]

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[127] TRA-00141, line 21 to TRA-00142, line 13
[128] TRA-00125, line 23 to TRA-00126, line 13
[129] TRA-00140, lines 13-21

142. This is the same point made by Patient 84. In order for there to be some form of plan or system for the removal of stents, the clinical team should have agreed some kind of system and operated it in an organised way. This did not happen, the time to stent change or procedure after stent was not audited or measured regularly. Complaints and SAIs involving the failure to change/remove stents did not, until recently, result in a robust plan for improvement. The patient found it difficult to understand why there is not a system.

143. As stated previously, this is a governance issue considered elsewhere in this Report. It is more complex than just waiting list management and involves understanding of the ongoing clinical risks to patients on waiting lists, whether of stents or otherwise.[130]

144. In her final comments she compared what had happened with her father to her mother's experience of care:

> "You know, we saw disciplines working very much together where she had joint appointments with consultants from both Belfast and South Eastern Trust who came together and that worked really well, and there was that advocacy as well service where, again, where there were issues we were automatically able to make a phone call and someone would look into that issue for us.
> Whereas with this, with dad's experience, you felt you were very much as a family working alone."[131]

145. She told us that making a complaint was not something that either she or her father did lightly, particularly as her father held the medical profession in high regard:

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[130] This is mentioned in the Clinical Aspects chapter and more fully discussed in the Governance chapter

[131] TRA-00145, lines 7-17

> “Just for the record, making a complaint was not something that either myself or my father did easily. In fact after the first, after the operation where the stent was taken away, I talked to dad at that point because I was just so frustrated with the way things were going. And I said, look, do you want me to put this on a more formal basis? And he said no, I do not. He said, you know, these people have saved my life over the years, I relish and respect the patient relationship with consultants and he said, I don't want to engage in that.
> But I suppose as time progressed and, as I say, that particular, I suppose the crux of that was that day that we were informed that treatment options were no longer available. He just was so dismayed that he said, yes, go ahead.”[132]

146. She explained the family’s intention regarding the complaint:

> “It wasn't that in any way you were trying to apportion blame or anything like that, it was just a case of, look, something has to be done here, this patient's experience cannot be replicated, somebody has to intervene.”[133]

147. She described the fact that when she was told about the SAI no one explained to her what that meant and that she had to research that herself.

148. In relation to the lengthy time it took for the delivery of the SAI report she told the Inquiry that she had to involve the Patient Ombudsman and believes that it was due to her doing so that things started to move.[134] No one ever offered an explanation as to why it took so long.

149. Whatever the reason or reasons that this SAI did take a long time to progress, the fact that a grieving family felt that they needed to bring the matter to the attention of the Ombudsman in order to achieve some momentum is completely unsatisfactory.

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[132] TRA-00126, line 18 to TRA-00127, line 5
[133] TRA-00127, lines 19-24
[134] TRA-00128

150. In terms of the outcome of the report she stated:

> "I respect the recommendations and if they were put in place I would be extremely content. But there was never an opportunity to discuss the findings."[135]

151. This witness praised the Patient and Client Council (PCC):

> "I suppose I found the Patient Client Council were very good at explaining what exactly the SAI entailed et cetera. So I think that sort of advocacy service should be available to people who have to go through the process."[136]

152. In response to questioning from Dr Swart, asking Patient 16's daughter what key messages she would like to get to senior people from the Trust, she said:

> "So it is when you make the decision, as I said, it's with a heavy heart that you feel that you have to put your concerns in writing. It's having someone then to, it's navigating that system, it should be clear I think to begin with. So you're having to research how the Trust, how you do that as a lay person. Then I suppose it is that initial response to that, if someone could lift the phone and say, we have received that, this is how it will be looked at and this will be the possibility, there are a number of possibilities.
>
> And as I say with the SAIs, it seemed such a serious kind of course of events to take that it was not something that I had anticipated. So it's having someone there to explain that and to advise of what that would entail. And it's just in relation to the timeframe of that as well, just to be kept updated. You know, all it takes is someone to have on file, you know, it is three months that have passed, we'll just get back to that person who made the first complaint and advise that, you know, we are still working on this, you are still in our thoughts, but this is possibly, this has maybe held things up a little bit. It's all of that."[137]

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[135] TRA-00128, lines 11-14

[136] TRA-00130, lines 17-21. The role of the PCC is discussed elsewhere in this chapter at paragraphs 353 to 366.

[137] TRA-00131, line 12 to TRA-00132, line 7

153. She stressed the importance of keeping people informed:

> “As you know, once you're kept in the picture people will accept and are much more understanding. It is when you're not informed and you feel that you're kept out of that loop.”[138]

154. In her questionnaire to the Inquiry Patient 16’s daughter stated that her father had found Mr O’Brien to be “arrogant and dismissive”.[139] In her evidence to the Inquiry she explained that this was in relation to:

> “dad's concerns over the stent being in too long and the experience that he had as a result of that. So it was that period of time when he was extremely ill and he just - he found, there was a sense of non-acceptance of there being any issue in terms of delay and how that would...
> While certainly it was acknowledged that the issues that dad was encountering or was encountering as a result, that they were in relation to that, I suppose there was a dismissiveness about that.”[140]

155. She also described a phone call from Mr O’Brien on the evening of 01 December 2016 when he apologised for the way things had occurred but stated that a lot of it was outside his control.

> “I can certainly recall being extremely upset and annoyed during that conversation, both with Oncology and Mr. O'Brien. It all occurred on the same day. He advised me that he was actually making the phone call and he wasn't at work at the time because he was recovering from a procedure himself. And I do remember saying to him that I am sure that his experience was very different from that of my father's. But as I say, he certainly acted within -

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[138] TRA-00132, lines 9-12
[139] PAT-000147
[140] TRA-00143, lines 8-18

> following that there was an appointment sent out immediately and I think dad was then admitted on, shortly after that for the stent to be removed."[141]

156. In closing her evidence to the Inquiry Patient 16's daughter summed up what she wished the Inquiry to know in the following remarks:

> "I think from a family's perspective, as I say, in an ideal world there are so many financial implications and I think Urology is a Department that could well-benefit from an injection of budget that would oversee some of these issues. As I say, we certainly respect the difficulties that Mr. O'Brien would have had as Head of that Department and trying to deal with that mismatch between demand and capacity.
>
> But just I suppose in terms of code of conduct, it is just having respect for the people involved. It's having a more robust means of communication. And probably maybe just even overlooking a review of how patients with cancer who have involvement with a number of disciplines, I think there is an easier way, there has to be a more joined-up approach in terms of multidisciplinary work.
>
> And I think from [personal information redacted by USI] experience we saw that. You know, we saw disciplines working very much together where she had joint appointments with consultants from both Belfast and South Eastern Trust who came together and that worked really well, and there was that advocacy as well service where, again, where there were issues we were automatically able to make a phone call and someone would look into that issue for us.
>
> Whereas with this, with dad's experience, you felt you were very much as a family working alone. So I think, I certainly still feel very strongly about the recommendations that I would have made as part of the initial complaint and I think they are very much embedded in your Terms of Reference. ... I just hope that there will be recommendations that can be actioned that will make

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[141] TRA-00142, line 21 to TRA-00143, line 3

> the journey for people and the safety of practice will very much be addressed."[142]

157. The Inquiry repeats that it considers that the Patients should be involved in any investigation into their care from the outset, whether that is an SAI or a procedure that replaces that. They ought to be updated throughout the process and any delays should be fully explained. Their views should be sought on findings and they should be able to contribute to any recommendations.

158. The Inquiry recognises that some patients will not wish to engage in any process but consider that given the opportunity to do so in order to improve patient safety, this is an option that the majority would wish to have. We also appreciate that all patients are not as articulate as Patient 16's daughter and consider that there should be a properly resourced patient advocacy service that could act for patients.

159. The current body carrying out this function is the PCC. The Inquiry heard from its Chief Executive Ms Meadhbha Monaghan on 21 February 2024. Her evidence is discussed at the end of this chapter.

### Patient 13

160. Patient 13 had been referred to the Trust's Urology Department as Routine by his GP on 28 July 2016. This letter was not triaged and he was added to the routine waiting list on 30 September 2016. In January 2017, he attended his GP again and indicated that he had not received any communication from the hospital. The GP wrote again this time making a red flag referral and he then received an outpatient appointment for 31 January 2017.

161. His referral was upgraded to Red Flag and he was reviewed at an outpatient clinic on 31January 2017 where he underwent investigations. He was found to have invasive bladder cancer and had to have surgery for same. In oral evidence

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[142] TRA-00144, line 18 to TRA-00145, line 21; TRA-00145, line 28 to TRA-00146, line 2

to the Inquiry Patient 13 described his experience at the urology service's Thorndale Unit and suggests he was not given much information on his condition: "Nobody said there was a possibility of cancer."[143] He is later very complimentary about Mr John Keane's (consultant uro-oncologist at Belfast Cancer Center) care at the time of his cancer but found Mr Glackin to be cold when discussing his prognosis in March 2017:

> "Also on March 2017 my wife and I attended C.A.H Thorndale unit to discuss and find out what my prognosis was, Mr Glackin, Urologist, CAH told us the terrible news, I was speechless I then asked Mr Glackin how long it had been in my body (the cancer) he replied – "2 weeks, 2 months, 2 years I don't know" and shrugged his shoulders, we both broke down in tears at his coldness. I asked him had cyclophosphamide been a reason for my cancer and he turned and faced his computer and didn't reply."[144]

In his oral evidence he confirmed that the meeting was "traumatic".[145]

162. Patient 13 had been a patient of Dr Michael Watt neurologist[146] in the Belfast Trust and had been prescribed a drug which carried an increased risk of bladder cancer. Patient 13 claims that he was not told of the attendant risk when the drug, Cyclophosphamide (a chemotherapy drug) was prescribed to him in 1995/1996.[147]

163. Mr Glackin was not asked in oral evidence about this meeting but has since told the Inquiry that he disputes the above account, stating that it is both unfair and inaccurate. He recognises that hearing bad news is traumatic for patient and family but says that he answered all questions fully and truthfully and Patient 13's account was not reflective of how he speaks to patients. He specifically recalls advising Patient 13 that cyclophosphamide was the likely cause of his cancer.

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[143] TRA-00162 to TRA-00163

[144] PAT-000481

[145] TRA-00166 to TRA-00167

[146] Dr Watt's practice led to the establishment of the INI which reported on 22 June 2022

[147] PAT-000434

He also says that it was necessary to wear a face mask at the time which will not have helped communication. The Inquiry makes no finding regarding the accuracy of Patient 13's memory of this meeting, but it is clear from the evidence he provided to the Inquiry he and his wife were deeply unhappy with the encounter.

164. Following the SAI into Patient 10's treatment the Trust carried out an internal review and identified 30 patients whose referrals had not been triaged. Patient 13's case was one of five considered by an SAI team led by Dr Johnston and Mr Haynes. That SAI commenced in 2017 and did not report until 22 May 2020.[148] The review team established there were factors in the service delivery to the five patients that resulted in unnecessary delay in treatment and care. With four patients the delay was thought not to be "clinically significant" but in the case of Patient 13 "there probably was a significant delay."[149]

165. In the SAI report the Review Team stated that 11% of GP referrals are changed, therefore it is essential that consultant urologists should triage these GP referrals.[150] The Inquiry considers that non-triaging of routine or urgent referrals is much more serious than the non-triaging of red flag referrals. By their nature patients who are red flagged will be seen sooner than the others and it is imperative that the opportunity to upgrade a routine or urgent referral is not missed.

166. The SAI report made comment on Mr O'Brien's failure to triage which is considered elsewhere in this Report.[151]

167. Due to the non-triaging of the referral Patient 13 suffered a six-month delay in diagnosis. The SAI Review Team considered that this delay in diagnosis and treatment was probably 'clinically significant' but that time would tell. This was based on expert advice that stated:

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[148] PAT-000400 to PAT-000424

[149] PAT-000413

[150] PAT-000413

[151] See MHPS and Clinical Aspects chapters

> “Delay in definitive surgical treatment beyond 12 weeks conferred an increased risk of disease-specific and all-cause mortality among subjects with stage II bladder cancer. He remains disease free as of September 2018.”[152]

168. In terms of communication with the patient, his SAI investigation was handled very differently to that of Patient 16. Patient 13 was written to by the Trust and given the opportunity to participate in the investigation and encouraged to do so. Mrs Gishkori’s letter dated 19 February 2018 advised there was delay in processing his GP referral and that an SAI had been commissioned to investigate. The letter explained what an SAI was designed to do and requested his participation, stating:

> “An integral part of this SAI review is to engage and inform those patients included in the review. To this end the Trust would encourage your participation in the SAI review whilst fully understanding and respecting if you choose not to participate.”[153]

169. Patient 13 confirmed to the Inquiry that he did not contact the Trust when he received this letter as he was more “concerned about trying to get better” and that he was letting the SAI “take its course.”[154]

170. Nor did he question the length of time taken to complete the report:

> “Q. But you didn't get a report until two years after that, did you ever question the delay?
>
> A. I was just more worried in living and trying to cope with the condition I was left with. And scans, and hoping scans, hoping the phone doesn't ring after you get a scan and things like that.”[155]

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[152] PAT-000411

[153] PAT-000431

[154] TRA-00154, lines 18 and 22

[155] TRA-00160, lines 15-20

171. On 26 November 2018 Mrs Gishkori sent another letter to Patient 13 apologising for delay to date and advising the report would be provided as soon as possible.[156]

172. An undated letter that was presumably sent after 22 May 2020, when the Review Team reported, was sent by Mrs Melanie McClements, then Interim Director of Acute Services, to Patient 13 advising him that the review had been completed and stating:

> "The panel assessed medical evidence regarding the potential impact of delays in treatment for your condition and found that there is evidence that the delay you experienced placed you at a higher risk of that treatment being unsuccessful. However, having undergone your treatment you have subsequently been followed up for almost 3 years and have been free of bladder cancer and therefore in your case this delay has not affected your outcome from treatment."[157]

173. Patient 13 came into contact with the Inquiry when we were contacted by his solicitor who represents him in a medical negligence suit against the Trust.[158] He subsequently completed an Inquiry questionnaire.[159] He described the impact that having a stoma bag had had on his life and told us that at times he had been anxious and suicidal. He went on to state:

> "I started receiving telephone calls from people from admin at Southern Health Trust, one was a lady called Patricia Kingsnorth, … she told me there was a SAI ongoing, I received possibly 2 more fone calls from SHT, usually different ladies, one told me on a Friday possibly in 2019/2020, that I shouldn't be concerned by what I would be reading in the papers that next Monday about Urology at C.A.H as it didn't apply to me, confused and anxious after this the

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[156] PAT-000432
[157] PAT-000433
[158] Faloon & Company
[159] PAT-000469 to PAT-000483

> next call from S.H.T the lady said that the team examining Mr O'Briens conduct had concluded that I was not involved in this and I should have no worries and enjoy life. I was so incensed I just said to her you know nothing about what I have went through and still going through in my life and that I will never be able to enjoy life again. She realised how upset I was and asked would I like to see one of the Doctors who had wrote up the report on me, I said I would so she said she would get this set up for me. [sic]"[160]

174. In his questionnaire Patient 13 complained about the location of his stoma bag saying it was too near his belly button producing leaks that cause him anxiety.

175. On 25 November 2020 Patient 13 met with Mr Haynes and Mrs Carly Connolly, from the Trust's Acute Governance Team. At this meeting Patient 13 was able to ask any questions about his treatment and the delay in diagnosis. It is clear from the minutes of that meeting that Mr Haynes took time to explain matters to him in detail.[161]

176. In his questionnaire Patient 13 told us that Mr Haynes "listened to my concerns and answered all my questions." Although he felt that Mr Haynes blamed his GP and he was dissatisfied that in his discussion with Mr Haynes regarding Cyclophosphamide he found his response "inadequate" given the high toxicity of this drug.[162]

177. In his oral evidence when being questioned about the meeting, Patient 13 expressed his concerns regarding whether the drug had caused his cancer:

> "Q But certainly in regards to the communication with Mr. Haynes, you felt that he was able to answer the questions that you were asking and that you wanted answers to?

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[160] PAT-000478
[161] PAT-000434 to PAT-000439
[162] PAT-000478 to PAT-000480

A. Well, he answered the questions. But if they were satisfactory for me, I don't think they were, because I would have looked at some of them a different way but...

Q. I think one of the things that you were concerned about was whether or not the drug that you had been on had actually caused the cancer?

A. That's correct.

Q. Wasn't that the big worry?

A. Yeah, it was Mr. John Keane actually said it to me in the City Hospital that he done the -- he was the surgeon and it was him said to me about the Cyclophosphamide, he mentioned. Anybody that I've went to, even the glaucoma in my eyes from 2000, Mr. Sharkey, the Ophthalmologist, whatever you call them, he highlights the Cyclophosphamide. Every doctor or anything I've went to, this Cyclophosphamide keeps hitting me, you know, and nobody seemed to follow anything up, you know, I'm on such a high dose of it. 150 milligrams-a-day, 50 in the morning, 100 at night or whatever it was.

Q Just in relation to Mr. Haynes, there was one question, according to what you told us in your questionnaire and that's at PAT-000479, you had asked him if you hadn't gone back to your GP in early January 2017 to find out what was the delay in Urology contacting you, when did he think you would have been called and he didn't answer?

A. That's correct.

Q. But he seemed to give you reassurance that the delay hadn't adversely affected your bladder cancer?

A. That's correct.

Q. And that your treatment path would have been the same?

A. Would have been the same, yeah. But he did mention it could be something to do about the invasive, something to do with the muscle, possibly could be one or the other I think in that letter too, type of a bladder cancer. Non-invasive or invasive, I'm not sure. I don't know if it's in the thing, maybe you have it in the letter there. But he answered the questions that I asked him anyway.

> I mentioned to him about this Cyclophosphamide again and he said that it was, smoking is the biggest cause of bladder cancer, and he said, do you smoke? And I says, well I did smoke until I got my diagnosis and I smoked about 10-a-day. So he seemed to be blaming more on the smoking end of it than being on that drug."[163]

178. When he spoke to the Inquiry Patient 13 said that he mentioned to his GP that he had not heard from urology and that, shortly thereafter, he received an appointment letter. He was firmly of the view that had he not been attending his GP who pursued the matter he may not have been seen for a longer period and his outcome could have been worse.

> "A. So I think if I hadn't have highlighted it, when was it going to be highlighted.
> Q. Yes.
> A. Until it was all spread through me?"[164]

179. When asked by the Chair about the meeting with Mr Haynes Patient 13 said:

> "Q And he was able to answer all the questions that you asked about your treatment, about your bladder cancer, about the drugs --
> A. Oh yes, he was very informed so he was, and he is a very good doctor too because he saved my [personal information redacted by USI] a few years ago and [personal information redacted by USI]. I have good regards for Aidan as well and Michael Watt, they done [sic] their best for me I thought at the time, you know. Obviously they were snowed in with work too maybe."[165]

180. Clearly there is understanding on the part of patients about the pressures on clinicians. However, the experiences described by Patient 13 show the

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[163] TRA-00158, line 15 to TRA-00160, line 8
[164] TRA-00155, lines 13-17
[165] TRA-00158, lines 5-14

importance of proper communication and ensuring that a patient’s concerns and anxieties are properly addressed. This necessitates listening appropriately and ensuring that those concerns are properly understood. The Inquiry recognised that for Patient 13 his major concerns were the difficulties he experienced over the location of his stoma and the worry that his cancer had been caused by cyclophosphamide and whether it might have been caught earlier with monitoring. This was particularly evident when he was asked questions by Dr Swart:

> “A. I would highlight, I don't know if they're still using that drug, but if there's anybody still using it please keep an eye on them patients because it can lead to a lot of trouble.
> Q. And what do you think you would have liked to have known as a patient?
> A. Well, I would like to have even a yearly check-up.”[166]

181. Mr O’Brien responded to the SAI report on 11 December 2019. His comments about the failure to triage generally are discussed elsewhere in this Report.[167] Essentially his view was that as UoW he did not have sufficient time to triage all cases and that this was known to the Trust. Moreover, he felt that the Trust ought to develop “a clear, agreed, written policy of the Trust concerning the conduction of triage.”[168] He stated:

> “the singular and significant flaw of the Review has been to investigate the failure to triage urgent and routine referrals in isolation of other pressures and clinical priorities which I believe are evidently more important. As a clinician and a clinical department, I believe that these greater clinical priorities cannot be compromised for the sake of triage, as they have been and continue to be.”[169]

182. He elaborated on this in his oral evidence to the Inquiry:

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[166] TRA-00163, line 26 to TRA-00164, line 3
[167] See MHPS, Clinical Aspects and Medical Management and Leadership chapters
[168] AOB-02289, paragraph 4
[169] AOB-02284, paragraph 2

> “I'm not dismissing the significance of triage. I contributed greatly to, at a regional level, emphasising at that point in time back then, let's say 10 to 13 years ago, that perhaps consultant urologists were those people best able to undertake triage rather than considering others like junior staff, staff grades or clinical nurse specialists. I do appreciate everything that you are saying in that regard, but what I'm also saying is I found the situation whereby, as urologist of the week, if you started a ward round at nine o'clock, if you had 32 patients in a ward, if you actually had to go and see 10 outliers during the course of which you had to deal with referrals of an acute nature from two other hospitals in your geographical area, and take five cases to theatre and leave at two o'clock in the morning in order to get some sleep. Now, the alternative is that you defer the surgeries in order to do that meaningful triage. I appreciate everything you're saying. Or you don't do the ward round, or you don't go to theatre. And that's how it was done and I didn't believe to be right. I wasn't the only one who felt that was not the *raison d'être*, the whole purpose of being urologist of the week. The whole purpose of being urologist was to try to ameliorate, to try to mitigate the risks that Catherine Hunter described. It was not -- it was unfortunate. I agreed to it actively to include triage as urologist of the week in order to get urologist of the week across the line, because at least it was a better option than doing a clinic because the clinic is at a fixed time whereas, whereas at least you could triage at two o'clock in the morning. So, I do appreciate the perspective that has been formed. As an individual I have worked very, very hard and I have always had patient care at the centre, but the most important patients that you have as urologist of the week are the inpatients. They are the critically ill. You should not be sending a junior registrar to deal with those people whilst you triage. There's something fundamentally wrong about that.”[170]

The Inquiry’s view is that the above answer demonstrates that Mr O’Brien is still of the opinion that his method of working was the ‘right’ one. The Inquiry

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[170] TRA-04656, line 2 to TRA-04657, line 14

considers that doctors should be supported to meet the expectations of good professional standards.[171] These include the mandate to work collaboratively, which entails working to agree how to resolve any important difference in approach between clinicians, where this impacts on patient care. This is particularly important when operational pressures are significant and there is a need to balance risk. Clinicians cannot unilaterally deviate from Trust working policies. This will be considered further in this Report in terms of the governance issues we identified.[172]

### Patient 15

183. Patient 15 is another example of a referral not being triaged by Mr O'Brien. He was referred to the urology services by his GP in August 2015 because of an elevated PSA for assessment and advice. The referral was marked routine. He heard nothing and so spoke to his GP again who referred him a second time in January 2016, this time it was a red flag referral and marked 'Suspect Cancer Red Flag'.

184. Following the second referral Patient 15 was seen in clinic by Mr O'Donoghue on 08 February and investigations were carried out. On 26 February he received a diagnosis of prostate cancer.

185. The failure to triage meant that Patient 15 had a 6-month delay in receiving his diagnosis and commencing treatment. Patient 15 was treated in accordance with the MDM recommendation, assigned a cancer nurse specialist (CNS) and made a good recovery.

186. His case was considered as part of the same SAI as Patient 13's.[173] In Patient 15's case the Review Team concluded that the six-month delay in

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[171] See GMC Good Medical Practice Guidance March 2013 at INQ-30867 to INQ-30906; GMC Good Medical Practice Guidance January 2024 at INQ-30907 to INQ-30938 and GMC Leadership and Management Guidance at INQ-30846 to INQ-30866

[172] See Clinical Aspects and Governance chapters

[173] TRU-161175 to TRU-161199

obtaining a diagnosis is “unlikely to be clinically significant”.[174] Patient 15 had sadly died from causes unrelated to his cancer diagnosis.

187. As a result of the Chair writing to Patient 15’s widow, the Inquiry heard from Patient 15’s son, who completed a questionnaire on 14 June 2022. In the questionnaire he described the family’s concern as follows:

> “Any delay in treatment relating to cancer is obviously concerning and my father was extremely worried during this period of silence as there was no communication or guidance on what action would be taken.
> When the diagnosis of prostate cancer came in February of 2016 with a Gleason grade 4+5, the concern was the cancer was more severe than would have been the case without the six month delay.”[175]

188. He indicated that his father did not raise a concern at the time simply because he assumed the timeline post referral was normal, but eloquently described the effect of this six-month delay:

> “My father was understandably upset when told that he had a raised PSA count and was being referred to Urology and the longer the silence lasted after the referral the more worried he became. Having been told that you need specialist attention for what could become a potentially life-threatening problem was stressful for my father and my mother. As a result of Urology ignoring the referral for 6 months, our family saw a very pronounced change for the worse in my father’s personality and demeanour; he was much quieter and more withdrawn than we ever knew him to be. We only attribute this to him worrying about his condition.
> When prostate cancer was eventually confirmed my father was acutely aware that the length of time which had passed could only have made things worse and he feared that he would not survive. He spoke to me about preparing for

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[174] PAT-001112

[175] PAT-001154

> the worst possible outcome and he genuinely believed that he was not going to survive.
>
> This was an immensely stressful time for my father as he dealt with these fears and it was also an extremely anxious time for my mother.
>
> Treatment for the prostate cancer was ultimately successful in June of 2017, almost two years after being referred but we question why the process took so long and if the cancer and treatment would have been as severe if my father's case had been reviewed sooner. When he did eventually get the all clear, he was a changed man. He returned to being the happy man we knew before this all started. We believe there were an additional six months of unnecessary stress due to Urology's inaction."[176]

189. Patient 15's son in speaking to the Chair gave more details as to the impact of the 6-month delay on his father and the family:

> "A. So there was the initial referral because of the elevated PSA levels and then, in a way, my father was one of those people who didn't complain, so whenever there was a delay it was just this is the way things were. But eventually the worry of it brought him back to the GP and it was a worry for him, for my mother, for myself and my sister, and that's at the point that things started to move, I suppose. But that initial six-month delay was the main thing, you know.
>
> Q. Would I be right in thinking that that is the main thing that you and the family are concerned about?
>
> A. Concerned about not only the delay but the impact. I know you say that this isn't looking at, you know, outcomes and things from a medical point of view, but we believe it impacted his health. We certainly know that the PSA levels were increased six months down the line, things like that. So we do believe it had an impact on his life. And I notice one of the phrases used, not only for my father but for other patients, was things weren't clinically significant. But I believe I noted "clinical significance" defined

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[176] PAT-001155

> as a real genuine, palpable effect on daily life. So it was certainly was clinically significant from a mental health point of view, from stress levels and the impact on my mother and sister, so
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> Q So there really was -- that six-month delay did have an impact on you and your father and your family?
>
> A. It really did. Again, as I said in my submission in the questionnaire, I mean, it seems to be a very unnecessary additional six months of worry and stress but it didn't need to be. It shouldn't have been. [sic]"[177]

190. The cancer diagnosis itself brought fear for Patient 15:

> "A. I believe, just the silence of that first six months was very difficult for him, for everybody, waiting, what's going to happen? And I know that he spoke to me whenever the diagnosis came through in January, or February, that he spoke to me basically going, we need to make arrangements now for what happens next, because this is it.
>
> Q. He was expecting the worst?
>
> A. He absolutely expected the worst. As I said in submissions, whenever the all clear eventually did come through, back to normal, it was like years being lifted off people, that's exactly what it was."[178]

191. Patient 15's death was not related to his cancer but the family considered that stress had played a part and cannot have helped.

192. Papers disclosed to the Inquiry by the Trust show that there is a letter dated 19 February 2018 and signed by Mrs Gishkori. The letter advises Patient 15 that his case formed part of an SAI review and invites him to participate with the investigation. The letter promises further correspondence sharing the draft report once available.[179] There is then an identical letter, dated 01 November 2018 which is unsigned. Two further letters appear in the Trust's papers; an unsigned

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[177] TRA-00183, line 22 to TRA-00184, line 24

[178] TRA-00186, lines 15-26

[179] PAT-001136

letter from Mrs McClements dated 07 October 2020 stating that there had been a delay in diagnosis but that it did not have any impact on treatment or outcome,[180] and an undated and unsigned letter from Mr O'Donoghue that was clearly drafted after Patient 15 had died.[181]

193. There is a Trust document entitled "Incident Screening Checklist" with an entry dated 21 October 2020 which suggests that letters have issued to all patients by that stage. However, internal email correspondence on 02 November 2018, attaching an unsigned letter of 19 February 2018, indicates that Patient 15 is the only urology patient who has not been informed of the SAI.[182]

194. The family confirmed to the Inquiry that they did not receive any written communication from the Trust. Patient 15's son told us how his father was fastidious in filing documents. When asked about the first letter from Mrs Gishkori he said that:

> "not only that but my mother and my father worked as a team. There was nothing hidden. It would have been incredibly out of character if my father had received a letter and not shared it and not filed it. And on top of that, my sister, after my father died, my sister was going through various things like this and this is the sort of thing that stands out and she doesn't recall ever seeing it. So we're not aware of it, is the way I'd phrase it."[183]

195. In respect of the Mrs McClements' letter, he said:

> "Now that letter was dated the day before my father died. So whether something arrived and it was missed in the few weeks after my father's death, I don't know."[184]

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[180] PAT-001138
[181] PAT-001139
[182] PAT-001216 to PAT-001217
[183] TRA-00192, lines 4-12
[184] TRA-00193, lines 22-25

196. Clearly there appears to have been an intention on the part of the Trust to communicate with Patient 15 and his family in writing, but according to the Trust's own internal email that does not appear to have happened and one can only speculate as to why. Nonetheless it suggests a less than optimal system of written communication and tracking thereof.[185]

197. The first the family learned about any investigation regarding Patient 15's care and that Mr O'Brien had been in any way involved was by way of a telephone call. In the questionnaire Patient 15's son described contact that the family had from the Trust:

> "My father passed away in October of 2020. On the 19th of May 2021 my mother received a call (which I witnessed) from Mr Mark Haines on behalf of the Trust to advise that an article would be running in the Irish News about Mr Aiden O'Brien and that my mother should basically disregard anything in the article. He framed the piece as a witch hunt and there was nothing relevant to my father's case and despite the delay in diagnosis this that would not have affected his treatment. As a family we were unaware that Mr O'Brien was involved in any stage of my father's treatment or diagnosis and so accepted this at face value but noted with Mr Haines that the additional months of unnecessary stress took its toll on both my father and my family. This call is to date the singular contact from the Trust. We read the Irish News article with interest along with the media reports which followed. There were reportedly five cases which were undiagnosed which turned out to be positive for cancer and therefore assume that my father was one of those five. We also assume that Mr Haines did not call round hundreds of people to put the Trusts 'spin' on the Irish News article.
>
> In hindsight, this phone call appears to have been an appalling attempt to obscure the truth of what was going on and the patronising manner which was used with my mother was unacceptable. His attitude came across as

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[185] The RQIA was critical of the content of letters sent to patients in the lookback exercise. The RQIA report can be found at TRU-157737 to TRU-157782

> treatment was successful therefore you can ignore what has happened. [sic]"[186]

198. When asked about this communication from the Trust by the Chair, Patient 15's son told the Inquiry:

> "The only thing we, as a family, knew about any of this, we never heard of SAI or we had never heard of any review, we never heard of any details, was in May of last year whenever my mother received a phone call from the Trust, I presume the hospital, Craigavon, saying: "I believe you have made a complaint about the treatment of your husband", and this was confusing. No complaint was made. We didn't know that there was a reason at this time for a complaint to be raised. And then a phone call was arranged for Mr. Haynes to call back to my mother to speak to her. So that happened later in the week, and during that phone call was the first time any indication that there was any sort of delay, any sort of abnormality or reason for concern in the treatment or triage or anything like that, but for the fact that it was going to -- it seems to us but for the fact it was going to be in the media, we wouldn't have received that phone call".[187]

199. Patient 15's son listened to the call from Mr Haynes with his mother. The Trust's Screening Template contains a brief record of the telephone call. It is noted that Mr Haynes phoned Patient 15's wife and advised her that her husband was part of the original SAI into urology services. He firstly apologised and then advised her about the original review into the triage of GP referral letters. He advised her that the review looked at two aspects: 1. What can be done about the process and the consultant? 2. What impact the delay in referral letters had on the patients' overall care? He advised that "we would follow up with the learning to the family."[188]

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[186] PAT-001155

[187] TRA-00187, line 20 to TRA-00188, line 8

[188] PAT-001132

200. In evidence Patient 15’s son said that they do not recall being told about the SAI:

> “We discussed this and neither of us recall SAI or Serious Adverse Incident or anything like that, we don't recall the term but it may have been mentioned but it wasn't what the call started for. The call started to let us know that there is going to be a report in the Irish News that there was some attempt by whoever going to be made to block it but that this was shining a light on somebody and practices within the Trust. And again, for us not to worry, it didn't affect the treatment or the outcome for my father. I queried that point again, what was said there, any delay did have an impact, both for my father and the family. But the impression we were left, after the call, was this was purely a spin exercise. This seemed to be going -- 'There is going to be media attention, just ignore it, don't worry about that, everything is fine. Patient 15 survived.' That seemed to be the thing.
> If SAI was mentioned, it may have been, I don't honestly remember, neither of us can remember those terms being used. There was mention of a delay and this was the first time we'd had any indication that there'd been any sort of delay or problem with the treatment. It was the very first instance and the only instance until the Inquiry. So there was mention -- he did offer to meet, in fairness, but at the time, Covid was rampant and nobody wanted to go to a hospital in the middle of that, but he said he would follow up and that never happened. That is the only information we had and it seems to be purely the only reason we got it was because there was going to be something in the press.”[189]

201. The family became further confused by the unsigned letter from Mr O’Donoghue when it was provided to them by the Inquiry:

> “A. And from Mr. O'Donoghue. It seems to be a very well intentioned letter but what has got us baffled is:

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[189] TRA-00189, line 9 to TRA-00190, line 12

> "*Firstly, I want to apologise if the phone call you received from the Trust caused you some distress or confusion. That was not my intention.*"
> How did he know? Where did he get this information from? We were only spoke to by Mr. Haynes once. We didn't speak to anybody else to let them know that it had caused distress. Mainly, whenever the Irish News published the article, my mother wasn't in great shape for a couple of weeks after that but.....
>
> Q. But you hadn't actually contacted the Trust after that Irish News?
>
> A. No. We were, between ourselves, debating what should we do next and then we found out Mr. Swann had announced that there'd be an Inquiry. … But this letter, why it's confusing, we don't understand the background to it, where the information that Mr. O'Donoghue is working from there is coming from and an offer to discuss. As my mother said to me, if for a second she thought at this stage, you know, she could have talked to somebody or we could have talked to somebody, the offer would have been accepted, definitely."[190]

202. Patient 15's son in response to Dr Swart indicated that had the family been approached as part of the SAI "absolutely we would have engaged with them."[191]

203. He described the family's frustration and suspicion at the lack of communication:

> "It's that sort of frustration of why, you know? Is it somebody trying to hide something? Is somebody trying to avoid culpability? Why were we excluded? Why was the information not shared? It's frustrating and it makes you worry about if this has happened to us, what else is happening? You know, you lose faith in the systems which are there, which shouldn't be the case."[192]

204. In terms of what he would like to see occur as a result of the family's experience:

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[190] TRA-00194, line 7 to TRA-00195, line 7

[191] TRA-00197, lines 21-22

[192] TRA-00197, line 29 to TRA-00198, line 6

> “It seems that there is no auditing in the past of these procedures to catch any sort of failure or anything or anybody that would be missed and there is no escalation process. So that is the thing I guess I would say to the Trust; improve your procedures to make it so that this can't happen, you know.”[193]

205. When asked if there was anything else he wished us to know about his father or his care Patient 15’s son emphasised the impact of the delay on his father and made general comments. He stated:

> “Again, just I'm not very good at conveying just how big an impact it did have on him but what is very frustrating for the family, I think, and I don't know if "anger" is the right word because you're at a stage where you are frustrated and everybody, I think, when it comes to this sort of thing, initially you go; 'Well, maybe it was a mistake', but then when you see the evidence and you read the media articles, which seem to be reasonably accurate, you're going; 'It's not a mistake and we can't ignore it.' The fact that, you know, we don't see any one individual, there is certainly plenty of individuals who have caused problems but we don't -- we see it as a collective, if there's a failure to triage and then there's a failure to address the failure to triage and it goes back 25 years, I mean, if you or I, we were talking about, anybody in a normal profession was in that position where they were challenged multiple times, something would be done. But even excluding individuals, the Trust has a duty of care, everyone knows that, the Trust has a duty of care and the Trust needs to be grown up and deal with its problems and it hasn't done that. … if a thousand patients are successfully cured and then a handful are missed because of any sort of action or whatever way you want to describe it, it's not acceptable. I understand there's pressures on every part of the NHS at the minute, financially and all that, but we still need to find ways to do the important things, unfortunately.”[194]

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[193] TRA-00198, line 15-21

[194] TRA-00195, line 23 to TRA-00197, line 1

206. These general comments reflect much of what the Inquiry learned about the fact that the Trust failed to measure or audit matters that impact on clinical care. Regular measurement appears to have been confined to performance against ministerial targets, whereas there was a lack of regular reliable information on a number of functions that impact on clinical care. This is a significant issue.

207. There was a general lack of data on triage times; times for letters to go out; time to stent replacement or removal; time to definitive procedure after emergency admission; day case rate and waiting times for different procedures, to list just some of the matters that impact patient safety. The Trust did not measure these things, and this must change.

208. The Inquiry understands that the Trust has now set up a task and finish group following the SAIs in urology and commenced to implement the various recommendations and to improve the urology service.[195] Mr Haynes told us about some of the improvements in measurement of standards, for example, times for looking at reports, but it was clear that some of the efforts to collect information were very labour intensive for an already busy medical practitioner. The Inquiry was interested to have his perspective on the benefits of regular information as a tool to drive improvement but considers that it should be incumbent on the Trust to develop these systems in a way that supports improvement in all departments and, as far as possible, information should be visible to all staff and patients:

> “we do have monitoring that is ongoing of the entire team on a number of issues directly related to some of the failings that have been identified. I've mentioned there that private practice is -- as I say, I know that this is monitored but I haven't had to escalate it. If we look at management of results, we have a monitoring process, we have an escalation process within that, but I haven't had to go beyond the first step of that escalation at any point. That first step of the escalation is me contacting the clinician. Typically that is that they've

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[195] TRA-11463

> fallen behind because they've had a period of leave and they are just over two weeks in terms of actioning their results.
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> If we look at triage, we have a monitoring process in place, we have an escalation process in place. I haven't had to trigger the higher steps of that escalation process because they haven't happened. So I'm confident that we have processes surrounding a number of the failings that have procedures linked to when there is a failing identified that escalate it through the system and the medical management structure that will identify the problem and enable it to be tackled.
>
> The very first point, though, is that actually lots of it is self-policing, certainly I found with many things. If you are telling your team of consultants this is how well you are doing at this particular thing and you've effectively got a league table, although you may not portray it as a league table, they make sure that they are not the outlier. So it is self-policing. So before anyone needs to escalate, someone will spot that I'm a bit behind, I better pick myself up."[196]

209. The Inquiry notes that the urology service has taken steps to ensure that it meets its targets for triage. Mr Haynes gave evidence that the team now receives a dashboard, produced on a monthly basis, which gives them information on a number of matters, including triage and timescales for triage, which is monitored and escalated if required.[197] Triage and other administrative functions can clearly have an impact on patient safety. These could and should be routinely and automatically measured across all Trust specialties in a suite of metrics. The Inquiry notes from the evidence of Mr Haynes that he has been passing on learning to other Divisional Medical Directors, for example, the weekly audit devised by urology to ensure that results are actioned.[198] The Inquiry was surprised to learn that a monitoring system had to be devised and implemented by a consultant in one specialist department to ensure an important aspect of patient safety was being complied with. This is an unacceptable use of resource

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[196] TRA-11380, line 10 to TRA-11381, line 15

[197] TRA-11484, line 28 to TRA-11485, line 10

[198] TRA-00955

and ought to be addressed as a matter of urgency at Board level within the Trust and if need be, regionally by the Department.

210. While it is incumbent on everyone working in healthcare to assure themselves that they practice safe care, it ought not to be for any specialism to self-monitor in the way described by Mr Haynes. The specialist teams ought to be able to rely on their employer to provide them with the information needed to give them the assurance that their practices are indeed safe.

211. More is said elsewhere in this Report about the emphasis on meeting performance targets at the expense of good governance.[199]

## Patient 35

212. Patient 35 was a patient of Mr O'Brien. He was referred to him in September 2008 and was diagnosed with prostate cancer in December 2009. He was reviewed a number of times by Mr O'Brien, and his case was discussed at MDMs on 11 November 2010 and 20 December 2012. There was no discussion at the time of diagnosis as the MDM only became operational in the Trust in April 2010. His treatment throughout was that of active surveillance.

213. His treatment was considered in the lookback review[200] carried out by the Trust into all patients under the care of Mr O'Brien for the period 01 January 2019 to 31 May 2020.

214. The SCRR[201] which reported on 23 November 2021 made a number of criticisms regarding Patient 35's care. Essentially, the view of the reviewer was that there were shortcomings in the MDM discussion in that there was a failure to discuss treatment options, he was inappropriately prescribed Bicalutamide and while he had radical radiotherapy in 2014 he ought to have been referred in 2009 for

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[199] See Governance chapter

[200] This initial lookback was the subject of an Early Alert to the Department dated 07 June 2020

[201] PAT-000804 to PAT-000823

improved prognosis but the reviewer could not quantify the extent to which his overall survival was compromised by the five year delay.

215. Patient 35 ultimately died in 2019 from metastatic prostate cancer. In accordance with the recommendation in the SCRR report:

> "The family should be informed that the patient did not receive standard care for localised prostate cancer".[202]

Patient 35's widow was written to by the then Chief Executive for the Trust, Mr Shane Devlin on 31 December 2021 indicating that Patient 35's care would be considered as part of the SCRR process:

> "The external independent Consultant has determined that the treatment plan your Husband was given in 2009 was potentially not appropriate. This treatment plan will be reviewed in the SCRR. Once this is complete we will write to you to inform you of the outcome."[203]

216. A further letter of 23 June 2022 was then sent by Dr Maria O'Kane, Mr Devlin's successor as Chief Executive, indicating that the SCRR had been completed and a report received. The letter did not enclose a copy of the SCRR outcome but stated:

> "I would like for the detail of this report to be shared with you in person so that it can be explained in depth and any questions that you may have can be answered directly. We will follow up that meeting with a written summary of the report for your records."[204]

217. On 27 June 2022, Patient 35's son contacted the Information Line to request that the detail of the SCRR be shared in writing prior to any face-to-face meeting.[205]

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[202] PAT-000818

[203] PAT-000824 to PAT-000825

[204] PAT-000826 to PAT-000827

[205] PAT-000828

218. The detail of the SCRR was subsequently shared in writing via a further letter from Dr O'Kane on 27 July 2022. The letter acknowledged that Patient 35 did not receive the correct treatment in 2009, that his case should have been discussed at MDT meeting,[206] that he should have been offered active radical treatment, that 'active surveillance' was inappropriate, that the prescription of Bicalutamide was further inappropriate, that he was denied potentially curative treatment for his cancer as a result of a failure to follow cancer guidelines, and that he experienced a:

> "five year delay in receiving the appropriate treatment for his condition which may have had a bearing on how his disease progressed."[207]

219. Patient 35's son contacted the Information Line again on 01 August 2022 to arrange a virtual meeting to discuss the SCRR report.[208] A virtual meeting then took place on 10 August 2022 with Patient 35's widow and son, Mr Haynes, Mrs Margaret O'Hagan (Director of the Lookback Review) and Ms Sarah Ward (Head of Service for the Urology Lookback Review Team). The minutes of the meeting reflect that an apology was issued on behalf of the Trust.[209] Mr Haynes indicated that there was no record of any discussion of 2008 National Institute for Clinical Excellence (NICE) treatment recommendations being discussed with Patient 35.[210]

220. The minute of the meeting records that:

> "[Patient 35's wife] advised in 2009 following this diagnosis they were advised that this was "non-aggressive cancer" and "doing nothing for a year will make no difference" and he will be reviewed in a year."[211]

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[206] The Inquiry accepts that no MDT existed in the urology services until April 2010 and therefore there could not have been an MDM discussion in 2009.

[207] PAT-000829 to PAT-000830

[208] PAT-000831

[209] PAT-000966 to PAT-000968

[210] PAT-000966. The Inquiry heard that Mr O'Brien did not record discussions he had with patients in the notes, see: TRA-00904 to TRA-00905 and TRA-12587 to TRA-12590

[211] PAT-000967

221. Throughout the meeting Mr Haynes explained in what respect his treatment had not been in accordance with standard practice and answered questions from the family.

222. When it was discovered in 2019 that the disease had spread, Patient 35's wife said that her husband had not been advised of the seriousness of his condition, the treatment options available and that his disease could not be cured, and any treatment would be considered palliative. She stated that:

> "she was under the impression that the addition of a hormone injection was all that was required at that time."[212]

Both she and her son described:

> "their shock and devastation when they were informed within minutes of being reviewed by an oncologist in Daisy Hill Hospital in October 2009 that [Patient 35] was "palliative" as his condition was never described like this before."[213]

223. Patient 35's wife was devastated to learn after losing her husband that there were issues with his care.

224. Patient 35's widow was written to by the Inquiry Chair and she completed a questionnaire with her son's help. She described the treatment, pain and suffering:

> "In 2009 Mr O'Brien performed an operation on [Patient 35], where he removed a lesion from his left kidney. [Patient 35] was informed that he had Prostate Cancer and Mr O'Brien advised that as the cancer was not aggressive, he did not need any procedure at that time other than medication

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[212] PAT-000967

[213] PAT-000967

> in the form of a tablet. [Patient 35] suffered severe abdominal pain in his left side from the time of this operation in 2009 and was in constant pain with this until he passed away in 2019. …
>
> As a result of this pain he was prescribed ever stronger pain killers which impaired his quality of life and, in our opinion, prevented his recognising the subsequent return of his cancer.
>
> In 2010, [Patient 35] received a letter informing that a CT scan had revealed that a lesion, similar to the one removed the year previously, had been identified. However, we have no recollection of any further treatment until 2014 when [Patient 35] had Radiotherapy in Belfast City Hospital. He received daily treatments of radiotherapy from 4 November until 24 December.
>
> In 2019 after having a series of tests and scans [Patient 35] was told that his cancer had come back and spread into his bones. In Craigavon Hospital at end of August 2019, Mr O'Brien told [Patient 35] and myself that the cancer had spread but he was optimistic with the treatment he had prescribed a few months prior which had reduced his PSA levels and with new medication in the form of a monthly injection he would be fine. … this injection had an adverse effect on my husband, his PSA levels went up and his movement was restricted from the second month."[214]

225. Patient 35's wife described in the questionnaire how the loss of her husband and having to witness him suffer had a detrimental effect on her health. She added:

> "[Patient 35], or the family, never made a formal complaint to the Trust as at the time we had total faith in the system. It has therefore been very distressing to learn about the Inquiry into Mr O'Brien who was overseeing [Patient 35]'s care for over 10 years. Furthermore, it came as a huge shock to learn in the recent letter that the Independent Consultant found that the treatment plan [Patient 35] received in 2009 may have been inappropriate."[215]

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[214] PAT-000838

[215] PAT-000838

226. The Inquiry heard from Patient 35’s son who gave evidence remotely. He spoke of the after effects of the operation in 2009 and the resultant pain. He also told us about the diagnosis of cancer and how the family now wish they could go back in time to ask more about that:

> “it was sort of explained at the time that this is non-aggressive and that we have, we don't really need to do anything immediate here with this, this cancer. And so, you know, "we'll keep an eye on it", basically and, sort of like, you know, once you're reading all this back now, maybe it's like a moment where I wish that you could go back in time and sort of, like, you know, sort of -- but I suppose throughout this entire process like, you know, there was no reason for us -- there was complete trust on the part of my Dad and the rest of us that, do you know everything, the advice, everything he was getting was -- well, there was no reason to doubt it. And actually at that time as well, you know, really, the pain that he was now experiencing in his side was actually the thing that was most prominent and the thing then, it was almost taking his primary focus, if you know what I mean, you know. He was told that the cancer piece, "you don't need to worry about that, we'll keep an eye on things, it's fine." But it was the pain that was causing him such trouble day in day day out that, you know, that kind of distracted, I suppose, as well, him and my Mum's attention away from that other piece.”[216]

227. He spoke about his father and the fact that when his PSA observations prompted action, the dosage of hormone prescribed was incorrect according to the lookback review and it was sometime later that he received radiotherapy treatment five years after his original diagnosis, finishing that in 2014.

228. He then spoke about what happened next:

> “So after 2014 he was then, you know, he was again monitored every maybe -- he got a PSA test taken every three months or so and for the most part there

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[216] TRA-00210, lines 6-28

was -- at least if you were to look at that as a metric of whether he was healthy or sick, those scores were good until 2019 when, you know, it shot up quite significantly then and it was sort of springtime of 2019. So he had to go and get various sort of tests and scans and whatever done then and I think it was like around about August 2019, him and my Mum went to Craigavon to meet Mr. O'Brien and it was then when he told them that, you know, he sort of put it like: "There's good news and bad news. The bad news is that the cancer has returned and it's spread to the bone and the lung, but the good news is that the tablet, the treatment that we've been putting you on for the last two months or so has significantly reduced the PSA values down." And so whilst my Mum, or as soon as she heard, like, you know, that it was in the bone, you know, she kind of almost had a breakdown there and then in the hospital room or whatever but it wasn't, you know -- I don't believe they left that meeting with -- well, they didn't leave that meeting with the understanding that it was like this was a terminal condition, that it was now just a matter of how long. It was explained that had it not have been for this PSA coming down, he would have needed chemotherapy immediately and we could be looking at one-and-a-half years of life expectancy. However, because of this positive reaction that we don't need to look at chemo immediately and there's nothing really to be that worried about in terms of immediate, you know, urgency and they were advised to go on holiday, they were booked to go for a month on holiday. He received another hormone, analogue treatment there and then in the hospital, it was delivered, like, through an injection, and that didn't really react very well with him and by the time they came home from hospital, he was in pretty bad shape, actually, because I went back to visit them then and I was very shocked by kind of what I was walking into because, like, I had seen him maybe two or three months previous to that, and the change in that space of time was really quite significant. So, like, do you know it wasn't really -- I know there's a balance to be had between optimism and sort of doom and gloom, you know, you can't just tell somebody that game's over here, but I don't think that the full severity of the situation was properly explained there and, you know, not that it would have changed anything but it might have -- it would have changed how those last few months were spent, you know, and they didn't really talk about the fact that he wasn't going to be here, he was trying to stay positive and saying "I can beat this", but, like, in hindsight, even reading all the material that's there, it was fairly obvious he had no chance of beating this. It was like, it was very sort of ominous, as the text put it in some of those letters."[217]

229. He described learning that his father's condition was terminal:

> "A. Well, I kind of pieced it together when -- he was checked into Daisy Hill Hospital one time I was at home and the night before I went back, he just was in really bad shape and we got an ambulance and so he went to Daisy Hill that night and was taken into a ward and the next day, a Consultant Oncologist was there and was able to see him and look at the same data, I presume, that was available, you know, from the previous meetings and it was kind of his tone, the language he was using and, you know, "we just got to get your Dad comfortable." He used the word "palliative", which was the first time I heard that. I actually had to Google it to make sure my interpretation of what it meant was correct, and even he didn't -- it was almost like he kind of assumed that we knew. You know, it wasn't like he said, you know, your Dad, I am sure, is only -- he never talked about a timeline or "terminal" or anything but it was almost like he would have assumed that this was known to me and my Mum, that this is just something we have to manage now; it's not something that you're going to win, to beat.
>
> Q. How did you and your Mum and your father feel when you discovered this?
>
> A. Well, I mean, to be honest I didn't -- like, I kind of figured it out a little bit but it was almost like because my Dad was still so... I kind of knew in my heart, let's say, but he was still -- because no-one had actually told him that, I didn't want to -- I wasn't going to be the person to sort of say, do you know -- like, he was still being as positive as he could. So it wasn't really spoken about, to be honest. And, you know, it was kind of like

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[217] TRA-00211, line 24 to TRA-00213, line 23

> always this: "Well, we're seeing this consultant in a week, we're seeing this person then." You know, it was kind of like a week by week sort of a process and, like, in the end it all happened very quickly. But there wasn't really ever a conversation about, like, this is now, this is kind of, you know, that "terminal" thing, which is strange when you sort of say it out loud now but it wasn't. Like I said, it was kind of like, maybe it's something that -- like, I mean, I didn't feel comfortable in bringing that up to him just based on this sort of inference that I had heard from this, if you know what I mean, from this particular doctor."[218]

230. With regard to learning that there were issues regarding his father's treatment he told us:

> "with the exception of that moment in the Daisy Hill Hospital where I was like why, you know, why is this guy saying one thing and Mr. O'Brien hadn't really spelled this out? There wasn't really any moment along this entire, like, that ten-year span that there was any reason for us to have anything other than complete trust in the care that he was receiving, you know, everything surrounding that. And even after he died, you know, it was -- you kind of just were: 'Well, he was unlucky, you know, and there was nothing that could be done', and whatever, and it was only really when this process came through and in the last few moments when there was, you know, the findings of the investigation that these issues had been presented where, you know, it sort of appears that had different things been done at different times then, you know, we could have had a very different outcome and that's really just in the last few months we've become aware of that."[219]

231. He told us about receiving the letters from the Trust about the lookback review and about the meeting that took place after the SCRR report was received:

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[218] TRA-00213, line 28 to TRA-00215, line 13

[219] TRA-00215, line 18 to TRA-00216, line 7

> "it was a very informative meeting, I suppose, to ask a lot of questions and to hear I suppose more on the medical side. Margaret did apologise upfront, you know, on behalf of the Trust in terms of, like, you know, for the below standard of care that my Dad received and we didn't, I suppose, dive into too much of, like, the governance around, like, why these decisions, like who was making the decisions, why were they not again these MDM meetings going on and checks and measures and stuff like that. It was more the sort of looking at the lookback review and the findings and giving us a chance to ask some questions around that."[220]

232. In response to a question from Dr Swart he talked about the manner the meeting was conducted:

> "And in fairness, in the meeting, I got the feeling that, you know, that the individuals there were not trying to hide or, like, offer any excuses or anything. They were being brutally honest. They gave their own opinion on matters where we asked it. They were critical and, you know, agreed with the findings that were found. They weren't trying to sort of, like, wriggle out of anything, or anything like that. So I don't really have any major issues with how that whole communication side of things has been managed here."[221]

233. At the meeting the Trust had said that they would come back to him on a number of matters: giving a copy of the summary of the meeting, advising when MDMs had commenced in the Trust, and including a copy of what changes the Trust had made to improve the effectiveness of the MDMs.[222] Patient 35's son confirmed to the Inquiry that as of the date he spoke to us, September 2022, he had not had any update from the Trust.

234. The Chair asked him about the impact of learning that there was an issue with the care received by his father. He responded:

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[220] TRA-00218, lines 10-22

[221] TRA-00225, lines 15-25

[222] PAT-000968

“well, obviously it's difficult to lose someone. You know, for me and my Mum it was a hard time back in 2019. They were very, very close and so it was very tough for her, you know, even more so. So you're starting to just come to terms with this loss and then it is quite distressing, very distressing whenever this news comes out again and I suppose there's all this information is starting to get dug up and, you know, memories are evoked again and wounds that maybe are starting to heal are opened. So it has been a very emotional and distressing time, for my Mum in particular. And then whenever you find out that, like, you know, whenever you read what the findings are and you sort of hear how critical they have been and I suppose there's, like, a sense of it could have been avoided and, like, all the pain, especially at the end, the pain that he was in and endured, like, you know, to feel that that could have been prevented, maybe he could still be with us today had, you know, just the right checks and measures been in place. That's heart breaking and it's really tough to come to terms with that and, you know, if you dwell too much on it, you would sort of like, you know -- well, you can't dwell too much on it because it is, it's so sort of sad. And, you know, I suppose, like, on the back of that, at times you maybe feel angry. You want to sort of maybe -- like, I'm keen to know what went wrong, how did these things happen, what's been done to make sure it doesn't happen again? Was it like a cultural thing or what? Because, like, I mean, even for me, like reading that, you know, last week, one night last week I sat and read all of the pack that you sent, you know, from start to finish and there was a lot of letters in it back and forth and, like, that was, you know, quite emotional, it's almost like reading a book where you, you know, your Dad is like the main character in it and you kind of -- you know how it ends and you sort of just put yourself in his shoes as you go through that. And, like, you know, so that's difficult and it sort of just brings it all back. To me, you know, I didn't know the half of it, I suppose, of what he was going through because he kept so much of it to himself. But, like, you sort of -- yeah, so it's tough like that. I mean, at times you kind of feel like a little bit -- like I say, there was so much trust put in it. You sort of read, like, you know, he had this prostate cancer diagnosis and, like, we sort of just took it at face value

> that yeah, well, you don't need to do anything. So you kind of feel a little bit almost like a little bit of guilt and regret as well that you didn't sort of poke him and, you know, sort of question my Dad and sort of, you know, give him a harder time about: “Are you sure, like? Should we not research this ourselves or go and ask somebody for another opinion or whatever?" We kind of went along with it. So there's an element of guilt in there as well. And, yeah, I suppose it's just not nice, obviously, I'm sure, for anyone in this position. But I think one other thing when I read through that was, like, for me, I would like to know why because, you know, on each of these letters back and forth to various consultants along the way, it was almost like a summary at the top of each of these letters of what his history was, the key points, and when the cancer returned, it was almost like this amazement of how could this -- shock, how could this clever cancer have come back? You know. And there was some conversations my Mum and Dad had with various consultants that they would have talked to, with this sort of language that made them feel quite, I don't know, sort of belittling almost that, you know, these clever consultants have done everything they possibly could and yet this thing had outwitted them and it's unlucky, sort of thing. When in fact surely they all knew that by looking, you know, that they themselves were partly culpable here and had they -- you know, there was never a mention of, like, maybe we could have done something different or, you know, self-reflection or anything. It was, you know, there was one or two moments towards the end where I would say the lowest points were coming, having met some consultants who kind of spoke to them with that sort of language which kind of to this day my Mum still talks about having, you know, left a very sort of negative impression.
>
> So, yeah. So, I don't know, it's almost like, you know, there wasn't any sort of culture of looking at what had been done and what they can learn from it and instead it was like, you know, this must be the cleverest cancer ever if it has outwitted us.”[223]

235. Dr Swart then thanked Patient 35’s son for reminding the Inquiry about:

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[223] TRA-00219, line 27 to TRA-00222, line 29

> “the need for humility on the part of the medical profession. Patients usually teach us that and it's very, very important because without it, we don't learn.”[224]

236. It is clear from the evidence relating to Patient 35 that when the Trust explained that their expert reviewer had found fault with the care provided, the family, who had always had faith in the medical system, did not feel all treatment options had been sufficiently explained to the patient. This suggests that an old-fashioned approach to patients and their families still exists. In situations where this ‘doctor knows best’ attitude does persist, it can be accompanied by a failure to properly inform patients and family members about their care. This is particularly the case when options are not fully explained in writing, allowing patients and their families to properly reflect and do research of their own, if they so wish. The Inquiry considers that there is no place in the modern health service for such a paternalistic approach. All care ought to be delivered in a multi-disciplinary way. Patients must be partners in their care and doctors must be prepared to learn from their patients. Doctors must also be prepared to listen to the views of colleagues and other health care professionals in order to deliver optimal care.

237. Patient 35’s son expressed his disappointment about learning of the lack of multi-disciplinary decision-making in his father’s care:

> “it is disappointing now to hear that, like, well, you know, was it the Wild West or was it just like, you know, when the most senior person in the room just gets to make a decision and no-one... There isn't like a culture where people can challenge or have a debate or whatever and I know that's what those meetings were there for; to drive that sort of quality and make sure the right decisions were being made. Obviously, like, they weren't happening for whatever reason -- or either they weren't happening or didn't happen in the case of my Dad at that time. And, you know, I don't think that's a healthy environment where just

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[224] TRA-00223, lines 12-16

> there's too much responsibility if it's just on one person to make these decisions, it should be experts from different viewpoints are considered.”[225]

238. Further, from the meeting with Mr Haynes he learned that there are now MDMs:

> ”it sounded as if measures had been taken but it's certainly a learning there. Even if the meetings are happening, you know, are all the right people there and do they have -- is there an environment where they feel its safe for them to speak their opinion and, you know, challenge a decision or an opinion even if it's that of -- it all boils down to culture, ultimately, and I guess so many people inside of that environment would be able to answer that. [sic]”[226]

239. In response to questions from Mr Hanbury, Patient 35’s son said that if his father had been given options as to his treatment at the time of his diagnosis he would have acted on that information:

> “it wasn't like he came home and spoke about having radiotherapy or having the prostate taken out and, like, I don't think he would have, like, not mentioned that. I mean when it was then mentioned later, five years later, he took it. It wasn't that, you know, if somebody was to tell him there's no need to worry about this or whatever, you know, he would have totally believed them and taken that easy way out, in a sense. But if they had have told him, well, we need to do something and there's these two options, then I believe he would have acted on those. So not to my knowledge was there any talk of any other treatment options at that time.”[227]

240. Patient 35’s son believes that had his father been offered the assistance of a CNS on diagnosis he would have engaged with that person:

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[225] TRA-00226, lines 2-17

[226] TRA-00226, line 28 to TRA-00227, line 7

[227] TRA-00228, lines 3-15

> "I think he would have. I mean, yeah, I think if it had have been offered, he would have because, like, he was seeing lots of different doctors and nurses. So, yeah, I mean, if there had have been a person available, I'm sure he would have availed of that. [sic]"[228]

241. The importance of cancer patients having access to a CNS is discussed elsewhere in this Report.[229] Another cancer patient who was not assigned a CNS at diagnosis was Patient 1.

### Patient 1

242. Patient 1's care was one of the nine cases investigated in the SAI review that precipitated this Inquiry. We received a detailed completed questionnaire from his wife and daughter in January 2022. This had been compiled with the aid of a diary kept by Patient 1 and that too was provided to the Inquiry.

243. As a result of a high PSA reading Patient 1 was referred to urology services in June 2019 as a red flag referral. Following an MRI scan requested by Mr O'Brien, Patient 1 met with Mr O'Brien in July 2019 at South Western Acute Hospital (SWAH)[230] and was told that he had suspected prostate cancer. His case was considered at MDM on 29 August 2019 and a CT scan and biopsy were recommended. Patient 1 met with Mr O'Brien again on 23 September 2019 and was informed that cancer was present in the prostate gland but that it had not 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 pending the results of the scans.

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[228] TRA-00230, lines 5-9

[229] See Clinical Aspects chapter

[230] Although SWAH falls within the jurisdiction of the Western Trust, as part of the remodelling of urology services into three Teams, from 01 January 2013 Team South took on responsibility for the provision of urology services to the population of County Fermanagh. Out Patient Clinics were conducted at SWAH by Mr Young and Mr O'Brien from that time.

244. Due to the unpleasant side effects of the drugs, Patient 1 contacted Mr O'Brien's secretary. Mr O'Brien then spoke to Patient 1 by telephone and was told to stop the two drugs and then take 50mg of Bicalutamide.

245. A second MDM took place on 31 October 2019 and the recommendation was to start Androgen Deprivation Therapy (ADT) and refer for an opinion from a clinical oncologist regarding EBRT. Patient 1 saw Mr O'Brien again on 11 November 2019. He was not referred to oncology and instead according to the letter sent to Patient 1's GP and quoted in the SAI report Mr O'Brien's plan was:

> "that if the PSA level did not decrease further at a subsequent check, "*it may be necessary to take an incremental approach to increased androgen blockade by increasing the dose of bicalutamide to 50mgs twice daily, and hopefully subsequently to taking the higher dose of 150mgs once again…. I suspect that the addition of an LHRH agonist may be more intolerable".*"[231]

246. Over a series of outpatient appointments between this date and 07 March 2020 the dosage of Bicalutamide was increased to 150mgs. Patient 1 was not referred to oncology. The family believe that the Patient was told he would be referred once his PSA level had come down:

> "He understood that he would be getting his PSA level down to a certain level and at that point he would be receiving radiotherapy. I know that there is reference in his diary entries, …That he was being referred to an oncologist in the January and it does state that quite clearly, "refer to oncologist", and I think that's backed up by the clinical notes."[232]

247. On 23 March 2020 Patient 1 attended the emergency department at SWAH. He was assessed and sent home. Then on 07 April 2020 he attended and found to be in urinary retention. He had a catheter fitted. Patient 1's PSA continued to

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[231] PAT-001307, paragraph 4

[232] TRA-00258, line 25 to TRA-00259, line 5

increase and on 01 June 2020 Mr O'Brien advised that Patient 1 start on a Luteinising Hormone-Releasing Hormone (LHRH) analogue drug by monthly injection at his GP surgery. Arrangements were made for him to undergo an operation to resect his prostate and to remove the catheter. Mr O'Brien operated on 17 June 2020.

248. On 22 June 2020 when he was in hospital, he was seen by Mr Haynes who dictated a letter (typed on 26 June 2020) to the GP advising of what had happened and directing further treatment. Mr Haynes also wrote to Patient 1 on 25 June telling him of the treatment plan. That plan, for him to have a CT and a bone scan to update staging and allow appropriate referral to the oncology team in Altnagelvin Hospital, was explained. At that point Mr Haynes referred him to the Oncology Team.

249. At some point after Patient 1 was discharged from hospital Mr O'Brien called him and confirmed that there was concern his cancer had started to travel and accordingly another CT scan was needed.

250. Mr O'Brien also wrote to Patient 1's GP in which he described this conversation with Patient 1 which appears to have taken place between the date of Patient 1's discharge, 22 June 2020 and the date the letter was dictated 26 June 2020. The family later took issue with one paragraph in that letter when it was disclosed to them. Mr O'Brien told Patient 1's GP:

> "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 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. [sic]"[233]

The family refuted that there had been any cognitive decline in Patient 1, that he lacked insight or that he did not particularly wish to have treatment for his cancer.[234]

251. According to the questionnaire completed for the Inquiry:

> "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 [Patient 1 and his family] 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. [Patient 1] was shocked, we simply could not take the news in. A cancer nurse specialist was present who indicated her surprise that [Patient 1] 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. [Patient 1] 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, [Patient 1] was going to die and we had to deal with whether now lay ahead for us. [Patient 1] 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. [Patient 1] 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

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[233] PAT-001503

[234] See post paragraph 270. See also PAT-001361, paragraph xxvi

> tomorrow with Dr Darren Brady, Consultant Urological Oncologist at the Cancer Centre in Altnagelvin. [sic]"[235]

252. On 15 July 2020 Patient 1 was reviewed by Dr Brady in Altnagelvin Area Hospital. The oncologist's opinion was that Patient 1 had become too unfit to consider any treatment option with curative intent. He was commenced on palliative care.

253. Patient 1 had to subsequently be admitted to SWAH suffering from a urinary infection. His health continued to deteriorate and the family found it difficult to access the help they required due to the covid restrictions in place. (A care package was only offered after his death).[236]

254. Patient 1 developed another serious infection and was admitted to hospital by ambulance in August 2020 and died five days later.

255. Following his death the family received an unsolicited telephone call from Mr O'Brien. The call was described in the questionnaire:

> "He expressed his condolences and said that he was very fond of [Patient 1]. [Patient 1]'s daughter said that the feeling had been mutual but that we were so shocked that he had ended up in the position he did. Mr O'Brien said he was happy to ask [sic] any questions that [Patient 1]'s daughter might have had. [Patient 1]'s daughter's first question was why when [Patient 1] began to experience urinary retention had the matter not been red flagged at that stage. Mr O'Brien asked for clarification of that. [Patient 1]'s daughter explained that if that was, as we now know, the first sign that the disease may be progressing then why wasn't [Patient 1]'s treatment re-assessed at that stage. [Patient 1]'s daughter also asked why a scan wasn't taken out prior to the TURP procedure being carried out and if it had shown disease progression would the procedure have still been carried out? [Patient 1]'s daughter also asked was there any chance whatsoever that the medication prescribed might have by any chance

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[235] PAT-001353

[236] PAT-001354

caused the tumour to flare and therefore accelerated the disease. Mr O'Brien answered all these questions thoroughly explaining that the spread of cancer had been "phenomenal" and that nothing, beyond the treatment he received, would have made any difference. Lastly [Patient 1]'s daughter asked would [Patient 1] therefore have been a candidate for surgery – using the rationale that if the cancer could not be treated but had been contained would a radical prostatectomy have been an alternative option. Mr O'Brien replied no.
[Patient 1]'s daughter accepted what Mr O'Brien had said. It was much easier for [Patient 1's daughter and wife] to believe that the best care had been given to [Patient 1], that he had been given every opportunity to have the disease cured than to entertain any other narrative. We wanted to believe that this had been a natural progression of the disease and that the end result of [Patient 1] dying, had been inevitable. Entertaining any alternative was simply too painful to bear."[237]

256. Having been reassured by Mr O'Brien, the family did not complain to the Trust. They were then contacted in late September 2020 by Mrs Patricia Kingsnorth, then acting Acute Clinical Governance Co-ordinator. They were informed both about that day's Irish News article and also about the SAI Review. She told the family that the Review Team wished to meet with the family.

257. The family first met with the Chair of the Review Team, Dr Dermot Hughes and Mrs Kingsnorth on 09 November 2020, prior to the report being completed and again virtually on 18 February 2021.

258. The SAI report described the engagement with the family as follows:

- "The review panel met with [Patient 1]'s family. They were advised that [Patient 1] did not have a CNS to support him through his cancer diagnosis. [Patient 1]'s daughter was planning to get married next year and brought

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[237] PAT-001355

her wedding forward to November when they learned of [Patient 1]'s disease progression. But [Patient 1] died sooner than they expected.

- The family highlighted the huge impact of the indwelling catheter problems caused to [Patient 1] from March/ April 2020. The family described his difficulties in trying to contact Dr 1 [Mr O'Brien] and his secretary. Had a CNS been introduced to [Patient 1] at his initial diagnosis, he would have been provided with contact details. He would also have been sign posted to other community services to alleviate any potential physical or psychological problems, resulting from this diagnosis and complications.
- The family described how difficult it was to access district nursing and palliative care services during the pandemic, which resulted in [Patient 1]'s admission to hospital and subsequent passing. They had tried to support him at home by recruiting family and friends to assist with the basic caring needs. The challenges the family experienced due to restricted visiting times caused additional stresses to the family.

**<u>Questions from the Family</u>**

The family wished to explore if the initial biopsy of the 20 August 2019 is representative of an aggressive cancer from this date. The review team have scrutinised the report and find that the biopsy sample was adequate and comprised appropriate numbers of biopsy cores of both lobes of the prostate. It concludes the biopsy was conducted properly
The biopsy was signed off by the SHSCT consultant pathologists with specific interest in urological cancer.
The biopsy was deemed representative off [sic] [Patient 1]'s tumour which was graded as Gleason 4+3.
The review team would suggest there is no evidence to support the contention that the biopsy may not have been representative."[238]

259. The conclusions of the SAI Review Team were that:

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[238] PAT-001310 to PAT-001311

> “[Patient 1] was investigated appropriately up to and including the original biopsies. The staging scans (bone and CT) would normally be expected to have been performed with a degree of urgency. These would have demonstrated no metastases and this should have led to a referral to a Clinical Oncologist as it would have been reasonable to consider radical treatment with external beam radiotherapy. Conventionally this would have been preceded by at least 4 months of neo-adjuvant ADT and this could have been started before the results of the scans were available.
>
> [Patient 1] suffered disease progression whilst being inadequately treated for high-risk prostate cancer. The opportunity to offer him radical treatment (with curative intent) was recommended by the MDM, but not actioned by those responsible for his care. The local progression of the disease should have been considered in the light of both the symptomatic deterioration and PSA changes.”[239]

260. The impact on the family of Patient 1’s treatment was set out in the questionnaire in detail:

> “[Patient 1] is gone and we are broken-hearted. His loss in our lives is immeasurable.
>
> His diagnosis was a shock however he had done the “sensible” thing by requesting a PSA test and upon learning that the cancer had not spread, we and more importantly, he, felt that he was in safe hands. We were going to deal with this and come out the other side of it. He was young at heart and had lots of life left to live and was making plans for the future.
>
> The events that overtook those plans commenced, in our view, in March 2020. [Patient 1] lost control of his bladder and never regained it. With no access to (or indeed knowledge that he should’ve been provided access to one) a Cancer Nurse Specialist he was treated exclusively at A&E from March – June 2020. The negative impact that this void in care and the reality of having

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[239] PAT-001311

to live with a urinary catheter had on [Patient 1], cannot be overstated. He suffered considerably in those months. He was prescribed antidepressants (with no previous history of mental illness) anti-anxiety mediation [sic] and sleeping tablets. He was crying out for help but couldn't get it. He thought he was losing in [sic] mind. In reality he was extremely ill unbeknownst to us all. All of this was compounded by the isolation of the ongoing Covid restrictions. After he died, we realised the true extent of his anxieties and suffering throughout those months; We found handwritten notes in his car detailing whom he wanted to carry his coffin at his funeral and what hymns he wanted played. It caused us unbearable pain to think of the distress that he must've been in given that these would've been written prior to him being told that his disease was terminal in the July of 2020.

The weeks that followed after our meeting with Mr Haynes on 14th July 2020 until [Patient 1]'s death [personal information redacted by USI] will remain etched on our memories forever. The lack of support and care from across the board of the medical profession and the ancillary professions meant we were left to care for a terminally ill patient with complex needs, at home, with zero input from anyone outside of our family. Whilst it was our privilege to care for [Patient 1] throughout this period it came at a huge personal cost for both him and us. He was stripped of his dignity and felt entirely abandoned and unsupported to endure the cruel and unrelenting symptoms of his disease. A disease which only one year earlier he believed he had every chance of securing a recovery from.

Upon hearing [Patient 1]'s terminal prognosis [Patient 1]'s daughter brought her wedding forward to the end of October, 2020 in the hope that [Patient 1] would be there to walk her down the aisle or at the very least be present to witness the day. It was not to be as [Patient 1] died within 5 weeks of hearing the bad news. The wedding went ahead at the end of November with 25 guests and no reception (having been postponed for one month after we had been contacted by the Southern Trust and advised of the Investigations into Mr O'Brien/The Southern Trust). Two days before the wedding, immediately prior to being presented with a gift from all her colleagues, [Patient 1]'s daughter learned that there would be a Public Inquiry held in relation to the practices of Mr O'Brien and The Southern Trust. Another major blow and shock in the midst of what was already an incredibly difficult, painful time

The wedding went ahead. The day, whilst a celebration of love, was bittersweet without [Patient 1] present. Now with the knowledge that the Southern Trust believed there had been major failings in [Patient 1]'s care the day was underpinned by a sense of shock and horror at what we had learned. The wedding was held in … His absence was painfully felt by us all, given that [Patient 1]'s funeral had taken place in the same building only 3 months earlier. He was nowhere and yet everywhere at the same time.

His death, having coincided with the Covid restrictions which were in place meant that we lost out on being able to visit [Patient 1] in hospital as often as we would've liked and indeed as often as he needed and we had to deal with [Patient 1]'s obvious upset and distress around that. We lost out on the rituals of mourning that usually sustain and carry grieving people, following a loved one's death. A "normal" wake was not possible. Attendance at the funeral was restricted. His last days in hospital were without the constant security of us by his side.

We have received extensive counselling following [Patient 1]'s untimely death. With the support of those Counsellors, we have tried to find a way to move forward. That has proven to be impossible given the nature of the investigations that are ongoing and indeed the inevitable media coverage that they have attracted. The natural grieving process has been altered and impacted greatly by these circumstances. We have been unable to heal or find a sense of peace in [Patient 1]'s passing and we endure ongoing trauma and pain as a result of what we have learned regarding the apparent failings in his care. Due to the findings of the SAI we feel that we have been robbed of our loved one and him of us. We believe we will have to carry that sense of loss with us for the rest of our lives. …

We endeavour to continue to carry the pain of [Patient 1]'s loss with courage and dignity."[240]

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[240] PAT-001362 to PAT-001364

261. Patient 1's daughter attended the Inquiry with her mother to express these feelings publicly. She described the effect on her father of not being able to have his family with him in hospital:

> "unfortunately there was this element of if I go into hospital I'm not going to be able to see you and I'm going to die and I'm not going to come back out and I'll never get to speak to you again. That was a real fear and that was something that we certainly struggled with."[241]

262. She told the Inquiry that the family had to push to find out the results of the CT scan he had after his TURP operation:

> "A. But we then went to Craigavon to meet with Mr. Haynes, both myself and my Mum and my Dad, on the 14th July.
>
> Q. And that was the first time that you understood that his disease was in fact terminal?
>
> A. It was, absolutely. I mean in retrospect you look back and you think, you know, how could it not have been more obvious? I think my Dad knew there was something seriously wrong with him. I think he thought he was going mad, to be perfectly honest, because he felt terrible, we now know why but he hadn't been told that he was as ill as he indeed was. He had been through surgery so, you know, we'd nothing really outside what he was telling us to believe that he was indeed that ill. And Mr. Haynes had communicated to us that the disease had spread. He said the first sign of that really would have been when he had required the urinary catheter in the March of 2020, that that would have been the first sign that this disease was progressing. He'd had weight loss, so really the signs had been there. At that stage he had explained to Dad that, look, you know, radiotherapy isn't an option, your chance for curative treatment here, it is no longer on the table. We asked for a prognosis. Dad had asked why

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[241] TRA-00238, lines 7-12

> he hadn't been given or received radiotherapy, would that have made a difference? I think he sort of struggled to accept that radiotherapy was no longer on the table. He gave him a prognosis, doing the best he could, of in or around about 18 months. But he said we would be going to Altnagelvin the next day to meet with the urological oncologist and that we could discuss that in further detail. That was a really, really, really difficult day for us and for Dad. He just kept saying 'I don't know how I have ended up in this situation, I thought it was going to get sorted out' and I think he was reasonable in that belief."[242]

263. She described the effects of Bicalutamide on her father, that he told Mr O'Brien about the symptoms and said that Mr O'Brien wrote to him and that the gist of what he said was:

> "that the symptoms that my Dad had been experiencing he had found to be unusual and not what he would have expected and having been practising for quite some time he'd never really heard those particular concerns. I think my father felt his hair was thinning, there was other things, and my Dad was quite annoyed about that because I think he had found it dismissive, but albeit he sort of tried to tolerate it as best as he could and that's what he did. I know he had asked to stop taking it for a short period of time when they were going on holiday at the end of November of 2019, but apart from that he took his medication."[243]

264. With regard to the provision of a CNS she told us:

> "A. I think that was on 14th July when we met with Mr. Haynes. There was a Cancer Nurse Specialist present at that meeting and that was the first I'd heard about a Cancer Nurse Specialist.
>
> Q. Your father had never been assigned a Cancer Nurse Specialist?
>
> A. No.

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[242] TRA-00240, line 9 to TRA-00241, line 15

[243] TRA-00242, lines 17-29

Q. From diagnosis?

A. No. I never heard him mention it. I mean that would have been presumably his first port of call whenever the catheter had gone in and, you know, I never was aware of anybody being assigned to him in that regard.

Q. There was a Urology Nurse Specialist with whom he had some contact?

A. Yes. I'd seen that in his diary entries but, to be honest, throughout that time, I mean I didn't live with my Mum and Dad and the Government advice at the time was to stay away so really through that period of time from April to probably the end of May my contact with my Dad was standing in a garage bringing food a couple of times a week, do you know. So, you know, I know he was very upset through that time. I know every day you would speak to him and it would be 'have you heard from Mr. O'Brien? 'I haven't heard from Mr. O'Brien'. And that, that seemed to go on for a long time. And he was making trips to A&E which we were trying to discourage him to do because of Covid and little did we know that Covid probably didn't pose much of a risk to him as what he was dealing with, you know, but hindsight's a wonderful thing."[244]

265. When asked about the telephone call from Mr O'Brien after her father's death she told us:

> "It was strange, if I can just set the scene for it, because all I had heard from March 2020 to June 2020 was my Dad wanting to hear from Mr. O'Brien and here I was having a conversation with him after all of those months, albeit I appreciate he had seen him in the interim time. My Dad was now dead and I was sitting having that telephone call outside the room that his coffin had lay in only maybe a week or so beforehand. So that was a really strange thing and all I could think of was you need to speak to Dad because he's the person that really needs to have the questions answered. And, whatever about this conversation, we can't reverse time, we are where we are. And I remember

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[244] TRA-00243, line 17 to TRA-00244, line 17

that was sort of my feeling about it. He expressed his condolences and he had said he was particularly fond of my Dad and I had said my Dad had felt the same, maybe not albeit towards the end of his treatment, end of his life, but I think it is important that I do say that, that he, his interactions with him on a personal level had only ever been anything but positive and reassuring and I appreciated him expressing his condolences to us. He told me some personal stories. We talked a bit about loss generally and then he asked me if I had any questions about the care that my father had received. I had asked him, sorry, Mr. O'Brien, if -- we now know that the first sign that the disease was progressing when he required the urinary catheter in March 2020, why did that not then precipitate some sort of action or a restaging? I don't think I necessarily put it like that at the time, but I suppose I was saying why was he not red-flagged, I think that was the terminology I had used. He asked me what I meant by that and I just really repeated the same thing to him again. I would be doing the conversation a disservice to say that I really remember what his answers were in any great detail, albeit that the gist of it was that he had had appropriate care and really little beyond what he had had would have made any difference. I appreciate we're not here to discuss issues of causation, but that's really probably, if I'm honest, what I wanted to hear because any alternative I couldn't have really lived with. We are, as it turns out, but certainly at that time I had -- I'm fairly certain that I had asked him about whether or not, knowing what we know now, that he was almost certainly terminally ill at the time that the procedure was carried out. You know, should that really have happened? Should he have been rescanned before that? And if they had found that he had been terminally ill at that stage, you know, would that still have been recommended treatment because it struck me as being futile and that my Dad had been put through that operation entirely unnecessarily. That was a question that I had, I asked him that as well. I do appreciate that my Dad was particularly keen to have the catheter removed. I mean I think we're all in agreement about that, he was, he just absolutely detested having that. He found it undignified and he really, really struggled with it. But albeit if there wasn't, you know, a really good chance that he could have had a successful removal of it, I still think he would have opted not to have it removed. I asked

> him that and then I asked him as well about maybe had the cancer been more aggressive from the outset because I was starting to wonder whether or not my Dad had tried to protect me on some level by sort of, you know, downplaying, you know, the prognosis and diagnosis that he had been given. He did explain to me that, no, that the biopsy was representative. He went into a lot of detail about how a biopsy is carried out and the samples that are taken, how it is done and that they were satisfied that that was representative. And then I had mentioned to him about we knew that then there was Gleason 10 Grade, I'm not going to pretend to know anything about this, but, you know, later on in the samples that had been taken after the TURP procedure and I think, you know, I had wondered after that conversation, albeit I don't think that Mr. O'Brien was saying that my Dad's disease had been more aggressive at the outset than they originally thought, I think I took that, just being fair, having recollected on that telephone conversation and that's why I had then asked for the initial sample to be retested, but I don't think he was saying that. I don't think he is saying that. And that's something maybe that I should have corrected at a later stage but, you know, I'm saying that now."[245]

266. Asked about how she now felt about that phone call:

> "I don't know if I'm honest. We were vulnerable. We were emotional. We were in shock, to be perfectly honest. I took it for what it was at the time and I did appreciate, I did appreciate it as to why it was made or, whether or not it was genuine, I think that's a matter for Mr. O'Brien."[246]

267. The Inquiry understands that it is unusual for families to be phoned after a death by the doctors caring for the deceased prior to death.[247] It recognises that Mr O'Brien liked to speak to patients personally and was very attentive when they

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[245] TRA-00245, line 8 to TRA-00248, line 6

[246] TRA-00248, lines 13-18

[247] In England in the new medical examiner system all deaths are scrutinised and someone will ring the family to give condolences and offer the chance to discuss matters. However, this system is not in place in Northern Ireland and it is unusual for most clinicians to phone families after a death. Treating doctors sometimes write to offer condolences and the chance to come and discuss any issues.

were in hospital and considers that it is likely he felt it appropriate to offer his condolences in this way. However, by this stage Mr O'Brien was no longer an employee of the Trust and the Inquiry therefore believes that it was inappropriate for him to invite Patient 1's daughter to discuss her father's treatment with him. Moreover, at a time when the patient and family needed communication between March and June 2020 this did not happen and when it was too late, it seems they simply received justification for not communicating.

268. When the family met with Dr Hughes and Mrs Kingsnorth the SAI process was explained to them. Patient 1's daughter described the first meeting as "frustrating" but that both were "transparent" in describing what had happened and "blunt about the failures in the care that my father had received."[248]

269. With regard to the prescription of Bicalutamide she told us:

> "Dr. Hughes had communicated to Mum and I that the Bicalutamide medication can sometimes cause a tumour flare and that that's what they believed could possibly have happened. Now, I didn't expect to see it anywhere written down afterwards, and I haven't, but that's what was said. We were told that there were concerns with the practices for a long time, albeit maybe I played slight devil's advocate with that. I couldn't understand if there had been concerns for so long and they were so serious then, you know, why were they only being highlighted now and why were they continuing to employ somebody if this was their view of their practices? It just didn't make an awful lot of sense to me."[249]

270. She cannot recall much about the second meeting but did recall the effect of receiving the SAI report in Spring 2021:

> "It was horrendous. It's the stuff of nightmares to be perfectly honest. It just had a devastating effect on us both. We were still in lockdowns at that stage.

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[248] TRA-00249, line 27 to TRA-00250, line 2

[249] TRA-00250, lines 4-17

> We were grieving. The loss and then we had this additional layer and the person that we really wanted to speak to about it is no longer here and, you know, it was too little too late is the best way I could put it. We understood why that needed to be communicated to us. We welcomed the transparency and the fact that it was done in that frank manner but really any outcome that didn't result in my Dad being taken back to the summer of 2019 and given a second run at his treatment, you know, just there was nothing good could come of this for us. It's been a very, very difficult thing to have to live with it, albeit we try."[250]

271. With regard to the letter that Mr O'Brien sent to the GP following the TURP she wanted to say a number of things:

> "I don't dispute that he found him vague, that's really for him to make that determination. I don't actually doubt that he was vague because he was in a really poor condition at that stage. I do, however, wish to challenge the suggestion that he was displaying a significant degree of memory loss. I'm not sure you could make that determination in a short conversation in any event, but I really don't think that was the case for my father. I don't accept that there was any sort of cognitive decline. I think we have to appreciate he was speaking, Mr. O'Brien was speaking to somebody there who was extremely ill and their only access to healthcare, apart from the TURP procedure, between March 2020 and June of 2020 was via A&E. So, I was disappointed to read that characterisation and we don't accept that there was a deterioration in cognitive function, no.
>
> The point following on from that where it's stated that 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, I would challenge that as well. I don't think it's clear as to whether or not the treatment Mr. O'Brien is referring to is the Bicalutamide, which he shouldn't have been on in any event, or the commencement of radiotherapy. But I do remember my father speaking to me after that

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[250] TRA-00251, lines 10-24

> appointment and stating that I've asked Mr. O'Brien is it okay for me to go on holiday, they went away for five days at the end of November 2019, and would that interfere with anything. He said no, this is how my Dad put it to me, you'll not be starting your radiotherapy until probably the early spring, because you're on this medication and the idea is we want to get your PSA driven down through the floor before you would commence that. So if he is referencing radiotherapy there, I think that's disingenuous and it wouldn't have prevented him from making the referral to the radiological oncologist anyway. I was disappointed to note that. I haven't seen any contemporaneous note that my father had asked for his treatment to be deferred. I accept it's in the diary entries and I remember him saying that he wanted to stop taking it for a short period of time whilst he was going on holiday. But it's the characterisation of him being in denial or lacking insight. My Dad was diagnosed on foot of him being diligent enough to ask for a PSA test, that's how this diagnosis came about. This wasn't somebody who was flippant with their health or that was in denial or lacking insight. He knew he had prostate cancer and I want to be really clear about that. If he had have been told you are going to see an oncologist the following week he would have been there. If he had been told you're commencing radiotherapy next week, let me tell you he'd have been the first person in that cancer centre.[sic]"[251]

272. The Inquiry considers that this was a situation where deviation from the MDT would have benefitted from a wider team discussion and full discussion with the patient and family earlier in that year. Certainly, trying to justify it to a family after death is against the spirit of MDTs and full patient involvement.

273. When asked by Dr Swart what the family had learned from the SAI team that was most shocking Patient 1's daughter said:

> "The use of the unlicensed medication. That was the most shocking thing. Because that, of course, was the only treatment that my father ever received.

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[251] TRA-00253, line 11 to TRA-00255, line 9

So, to be told that, at best, it wasn't going to do anything for him and, at worst, it had in actual fact made things worse for him, I think that was the most shocking thing."[252]

274. Dr Swart went on to ask about the impact of the SAI report findings:

"Q. And when it came through to the report, and the lessons learnt are fairly clearly set out and stark and there was quite a lot of emphasis on that Multidisciplinary Team meeting, wasn't there, and the recommendations. How did you feel about that, when you read that, the fact that the right things had been recommended but didn't happen, what impact did it have on you?

A. It shocked me. And I wouldn't say I was particularly naive or anything like that. But it did shock me and I remember saying at the time, he's not the first person who has presented with prostate cancer or prostate cancer at this stage. You know, it's not formulaic but also it's not, this isn't unchartered territory either. There should have been a plan in place and you would have expected those fairly basic measures to have been implemented. I was shocked. I knew other people who had came to our home after my Dad had been diagnosed and treated by Mr. O'Brien successfully and had absolutely nothing negative to say about him or their experiences with the Southern Trust, so this was quite a shock."[253]

275. Patient 1's case is an example of failure to follow the MDM recommendation when made. No referral was made to oncology at the time and the Trust had no way to check whether this had been done. The following exchange between Mr Wolfe KC and Patient 1's daughter shows the fact of the non-referral and the Trust not knowing about the non-referral was very important to this family:

"Q. So is it fair to say, [Patient 1]'s daughter, knowing what the multidisciplinary meeting prescribed as the recommended form of

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[252] TRA-00256, lines 5-11

[253] TRA-00256, line 21 to TRA-00257, line 12

treatment for your father, is it your family's fundamental question: Why didn't that happen and how could the Trust have failed to realise until quite late in the day that it hadn't happened?

A. Yes, indeed.

Q. Is that fundamental to you?

A. Very fundamental."[254]

276. The SAI report states that the opportunity to offer Patient 1 treatment with curative intent was lost. Moreover, the prescription of Bicalutamide did not conform to the Northern Ireland Cancer Network (NICaN) guidelines and more is said about this elsewhere in this Report.[255] The Inquiry understands that the treatment received by Patient 1 is the subject of ongoing civil proceedings and we make no comment as to that.

277. This family's account has been repeated at length in order to show the extent of the loss felt by a family who was told that different treatment might have prevented that loss at that time. The complication of covid restrictions also clearly impacted this family, as they did all those other families who were unable to be with loved ones in hospital during that period.

278. The Covid Inquiry, in its Report, considered the impact on, among others, patients and their loved ones, of covid restrictions relating to end of life care. Concluding:

> "Pandemic planning for increased mortality must strive to preserve the dignity of the dying and the deceased and to accommodate the needs of bereaved people with sensitivity and kindness. While safety is the paramount consideration, this must be balanced with a compassionate approach."[256]

This Inquiry completely agrees.

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[254] TRA-00266, line 24 to TRA-00267, line 3

[255] See Clinical Aspects chapter

[256] https://covid19.public-inquiry.uk/reports/module-3-full-report/#section_10_chapter-7-death-and-end-of-life-care, Paragraph 7.50

## Patient 82

279. Patient 82, a man who had cardiac problems, was 73 years old when he was initially referred by his GP to Daisy Hill Hospital with an elevated PSA. Following further investigations, he was subsequently referred onwards to CAH prostate assessment unit on the 13 January 2010. That referral was triaged as routine by Mr O'Brien. As a result, Patient 82 was not seen until 10 May 2010 and, following further investigation, he was ultimately diagnosed with localised intermediate risk prostate cancer.

280. Patient 82's case was discussed at MDM on 05 August 2010 prior to staging scans having taken place. The MDT appears to have recommended watchful waiting. Those scans were then arranged and Mr O'Brien reviewed Patient 82 again on 04 February 2011, by which time his PSA had increased. Mr O'Brien did not refer Patient 82's case back to the MDM to discuss the options. Rather, Mr O'Brien decided himself to commence the patient on low dose Bicalutamide 50mg once daily and Tamoxifen 10mg daily.

281. Due to an overactive bladder, Patient 82 required an intravesical botulinum toxin injection.[257] In September 2012 Patient 82 was treated by 3fivetwo Healthcare at a hospital in Downpatrick on foot of a waiting list initiative. Patient 82 suffered a reaction to the anaesthetic when his blood pressure dropped profoundly, and he suffered a cardiac incident. Patient 82’s family was called to his bedside. Thankfully, Patient 82 recovered and did not appear to suffer any ill effects.

282. In the questionnaire completed for the Inquiry Patient 82’s daughter attached copies of a complaint that she raised with the Trust and with 3fivetwo Healthcare following that incident.

283. The first letter dated 26 October 2012 described in detail the lack of information received from either the Trust or 3fivetwo Healthcare prior to her father’s procedure, how she had to make several calls to ascertain whether he ought to

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[257] This involves an injection of Botox into the muscles of the bladder wall.

stop his medication prior to his treatment and did not get an answer. Patient 82's daughter then described what had happened at the Downpatrick hospital. She listed her concerns as:

> “1. No consultation about transfer to 352 or consent given
> 2. Inadequate information RE: surgery and appointment letter
> 3. Letter from 352 made no reference to stopping medication, even though admission staff is advising patients to stop medication.
> 4. Admission staff advising on medication prescription
> 5. No pre operative assessment at 352
> 6. No sharing of information between CAH and 352
> 7. CAH and 352 failure to recognise my father's complex cardiac history
> 8. Proceeding without notes (surgery/clinics not prepared)
> 9. Communication barriers between professional and patients
> 10. No privacy when discussing information with patient
> 11. And most importantly NO ONE has offered any feedback as to what went wrong at 352 in Downpatrick. [sic]”[258]

284. She concluded the letter of complaint:

> “Further to writing this letter, I attended a follow up appointment for my own medical condition in CAH and when asked was there any family history of a reaction to an anaesthetic, I informed the nurse of my dad's episode. She said that she would not be able to excess my father notes as there is no transfer of notes between the private company and CAH, despite a previous letter informing me that all information would be passed between the two sites.
> Can someone please enlighten me as to what exactly is happening? [sic]”[259]

285. 3fivetwo Healthcare wrote to Patient 82 in January 2013 wherein they apologised for conflicting information provided to him by their staff and the lack of privacy during discussion of his medical history. The letter stated:

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[258] PAT-001622 to PAT-001623

[259] PAT-001623

> “I can advise that your previous medical history was not passed to 3fivetwo Healthcare at the time of your referral and you were booked for your procedure with the information that was provided to us.”[260]

The fact that a Trust patient was sent for treatment in the private sector without the full medical notes raises concerns about patient safety and governance that are discussed elsewhere in this Report.[261]

286. Patient 82’s daughter at a later stage asked Mr O’Brien about the fact that her father was treated without his notes being transferred, she told Mr Hanbury:

> “When we came back to clinic, I said to Mr. O'Brien "Why would you have passed Daddy's file out of Craigavon Hospital; he should have stayed within the acute service because of his heart". Mr. O'Brien says my files were taken, it was nothing to do with me; the list was nothing to do with me. Which, you know, I thought, well, like who decided who was the appropriate person to go forward to 352 and who should stay in the hospital?
> Then 352, they decided -- as I said to them, did you operate just off a list? They had no notes either. They didn't write back to Craigavon Hospital to say we don't know the first thing about this man that you sent on a list. They didn't get the notes. [sic]”[262]

287. The Inquiry is of the view that clinicians should be involved in agreeing suitable patients for treatment in the private sector. The Inquiry is unaware of how this list of patients was compiled. It would seem that more recently clinicians are involved in determining which patients are suitable for transfer to the private sector. The advent of a more integrated digital patient record system will hopefully ameliorate matters, but the transfer without notes was clearly a failure of governance. The Inquiry wrote to 3fivetwo Healthcare, now Kingsbridge Healthcare Group. They

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[260] PAT-001625

[261] See Governance chapter

[262] TRA-01881, line 23 to TRA-01882, line 8

responded in writing conceding some of the points made by Patient 82's daughter.[263]

288. On 10 June 2013, Mrs Deborah Burns, then interim Director of Acute Services replied on behalf of the then Chief Executive, Ms Mairead McAlinden, to Patient 82's daughter's letter of complaint, this was some seven months after the complaint was received in the Trust. She apologised for the "inordinate" length of time taken to deal with Patient 82's daughter's concerns but going on to say:

> "I understand you have been written to directly by 3fivetwo Healthcare about your father's experience and I appreciate that you have further concerns you wish to be addressed. Given the information available to the Trust, I have asked that a full and thorough investigation be carried out into the circumstances of your father's case and we will be appointing a team of persons not directly involved with your father's care to take this forward. We will also be inviting representatives from 3fivetwo Healthcare to participate in this also.
> We would normally aim to have such detailed investigations completed within 12 weeks and it would be normal practice to share the findings and learning from the investigation with the family after that period by inviting them to a meeting to discuss the outcome. I trust you will be happy with this approach."[264]

The Inquiry considers that seven months to reply to a letter of complaint is wholly unacceptable and for the Trust to only then commence to carry out investigations is indicative of a lack of proper attention both to complaints made and of the issues that are raised in those complaints.[265] Regrettably Trust delay in dealing with complaints and SAIs was not unique to this case.

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[263] WIT-108023 to WIT-108027

[264] PAT-001627

[265] The Inquiry wrote regarding Patient 82's daughter's comments to Dr Menown, 3fivetwo Healthcare, and Mr Thwaini. Their responses are at WIT-108008 to WIT-108009; WIT-108023 to WIT-108027 and WIT-108056 to WIT-108058 respectively.

289. When she spoke to the Inquiry, Patient 82's daughter was clearly frustrated by the Trust's failure to take responsibility for her father's care during this period. She explained why she had complained:

> "And as an employee of The Trust as well, as I say, it wasn't to make a complaint really, it was to say, look, you know, people need to be assessed before they go for surgery and there needs to be sharing of information, and if this isn't done, you know, it will be to the detriment of further patients. That was where I was trying to go".[266]

In response to the Chair saying:

> "Q. CHAIR: This was obviously a very upsetting and worrying time for you and your family, and you were concerned to try to ensure that it didn't happen again to anyone else, which is why you wrote then to the Trust?
>
> A. Yes, that was why I wrote to the Trust."[267]

Patient 82's daughter told us that she wrote many letters, made several phone calls but got no answers to her questions and eventually gave up.[268] Despite the letter from Mrs Burns the Trust never advised Patient 82 or his daughter of any outcome to their investigations.

> "Q. CHAIR: Certainly, as far as the Inquiry is concerned, nine and a half years after you received a holding letter saying that the Trust was going to investigate, you received no further communication from them?
>
> A. No. No."[269]

290. Patient 82 was returned to the care of Mr O' Brien who also tried to ascertain what had happened to Patient 82 by writing to the doctor who had tried to carry

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[266] TRA-01858, lines 3-9

[267] TRA-01860, lines 19-24

[268] Any documentation provided to the Inquiry by Patient 82's daughter which is relevant to our work is found at PAT-001857 to PAT-001862

[269] TRA-01862, lines 10-14

out the procedure on behalf of 3fivetwo Healthcare, Mr Thwaini and copied in the Head of the Urology Service, Ms Martina Corrigan:

> "Mr. O'Brien wrote to a lady, Corrigan, copied her into a letter that he had wrote, I think to Mr. Thwani, [sic] asking for information on what had happened. I don't think -- well, I certainly didn't get any reply or I don't think he got a reply from Mr. Thwani [sic] about what had taken place. I thought that it was significant that the head of service and Mr. O'Brien didn't have discussions about what had taken place. He seemed to say in one of the letters, Mr. O'Brien, that he hadn't seen our complaint. In another paragraph, he was proceeding with the spinal because he didn't expect to get an answer. Well, you know, why would you not expect to get an answer?"[270]

291. In her closing remarks to the Inquiry Patient 82's daughter said:

> "I think the Trust is in a very bad light over the 352 [sic] business. I think it is just about clearing a waiting list and they didn't do their assessments properly, and they didn't."[271]

292. When describing the impact of not getting a response to her complaint in the questionnaire she completed for the Inquiry Patient 82's daughter summed up her feelings as:

> "Frustration at the duration of time to resolve the complaint alot of thankyou + sorry for the delay but very little openess and transparency. [sic]" [272]

Further she said:

> "As a working member of the trust at the time my only aim was to improve services ensuring the same would not happen again but lost faith in the

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[270] TRA-01862, line 25 to TRA-01863, line 9

[271] TRA-01888, lines 5-8

[272] PAT-001642

> process I considered it a WHITE WASH. More about self-protection than openess and transparency. [sic]"[273]

293. The Inquiry agrees that this complaint was badly handled by the Trust. It should and could have been handled very differently. The complaint has a number of very important components and should have resulted in a conversation with the complainant. By speaking with the complainant, the Trust could have offered an apology for distress and ensured themselves that all the elements of the complaint were fully understood. Thereafter an agreement could have been reached about the information required to take things forward. Then the complaints team would have been able to coordinate the response from the clinical staff, managerial staff and administrative staff at the Trust, as well as from the private provider. There should have been oversight from a divisional medical director as well as the clinicians involved and if necessary, a face-to-face meeting with the family should have been convened to cover any particularly thorny issues.

294. This case illustrates that there is a need for a better approach to complaints and more is said regarding this elsewhere in this Report.[274]

295. Separately, Patient 82's care was the subject of an SCRR, due to concerns about the prescription of Bicalutamide. This was considered as inappropriate by the SCRR reviewer as the initial referral letter gave a firm indication that this was likely to be a cancer diagnosis and as such the patient had been brought to an urgent prostate cancer diagnosis clinic.[275]

296. The SCRR reviewer indicates that Bicalutamide 50mg once daily is not licensed as a treatment for localised prostate cancer and concluded that Patient 82's overall care was poor and not in keeping with good practice. The reviewer noted that any form of hormone ablation therapy represents additional risk in patients

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[273] PAT-001639

[274] See Governance chapter

[275] PAT-001603

with significant cardiac co-morbidities, as was the case with Patient 82, and remarks that potential harm could have ensued from a long period of inappropriate hormone ablation therapy. In concluding, the reviewer suggested that Patient 82's quality of life may have been affected by the treatment he received.[276]

297. On 02 November 2020, Patient 82 was seen by Mr Haynes, who identified the fact that Patient 82 had, by that stage, been on low dose Bicalutamide for ten years. After discussion, both Bicalutamide and Tamoxifen were discontinued by Mr Haynes, and Patient 82 and his family at that time advised Mr Haynes that they could not recall having any conversation with Mr O'Brien about alternative therapies.

298. Patient 82 died in 2021. His death was unrelated to his urological care as he suffered a deterioration in his health following a fall.

299. The family say that they were not told by the Trust that there was a review taking place into the care of patients in the urology services at this meeting, or that Patient 82’s treatment was looked at in that review. The Inquiry has seen an unsigned letter dated 04 January 2022 from Mr Devlin addressed to Patient 82’s daughter telling her about the Inquiry, that there had been a lookback review of Mr O’Brien’s patients and that:

> “The external independent Consultant has determined that the treatment plan [Patient 82] was given in 2010 was potentially not appropriate. This treatment plan will be reviewed in the SCRR. Once this is complete we will write to you to inform you of the outcome.”[277]

The letter also said that:

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[276] PAT-001614 to PAT-001615

[277] PAT-001628 to PAT-001630

> "The Liaison Team attempted to contact you on the 8th, 9th and 15th December to discuss this letter prior to sending. The leaflet included with this letter outlines the support services available to you. Dedicated Trust Liaison Officers who are trained professional staff are available for any queries, concerns or questions you may have. This is a strictly confidential service for the purpose of this review process."[278]

When asked by Dr Treanor of the Inquiry's Counsel team, Patient 82's daughter said that she had not received the letter dated 04 January, but had received one in similar terms dated 31 January 2022, which the Inquiry has seen.[279]

300. Patient 82's daughter said that she did not receive a letter from Dr O'Kane dated 20 June 2022.[280] It referred to the letter of 04 January and shared the details of the SCRR.

301. It is the Inquiry's view that when letters such as this are sent to patients, they ought to be preceded by telephone calls as was apparently attempted, according to Mr Devlin's unsigned letter. Further, steps should be taken to make sure that they are received. This could be either by sending them by way of recorded delivery, read receipt email or by following them up a few days after posting by a telephone call and retaining a memo of the call.

302. Instead, the family says it learned about the Inquiry from television news. Patient 82's daughter told the Inquiry:

> "I only knew that there even was a review taking place when I heard about it on UTV News, which again aggrieved me because I felt, you know, the Trust had responsibility for our care; there was an investigation taken into it. I know all about confidentiality but it obviously was out there when it was in the news. I think the Trust should have took the opportunity when they had us to have

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[278] PAT-001629

[279] PAT-001860 to PAT-001862

[280] TRA-01885, lines 3-22; PAT-001631 to PAT-001632

> said, look, there is a review also taking place here; we can't go into the ins and outs of it. I could have accepted that but at least I would have been informed, I wouldn't have had to hear it on UTV News.
>
> You know, we talk about openness and transparency and keeping the patients informed. Certainly, I wasn't informed."[281]

303. Patient 82's daughter was dissatisfied with the level of communication from the Trust:

> "Q. CHAIR**:** But if I've heard what you're telling me correctly, you're saying that you were pretty dissatisfied with the level of communication generally from the Trust with patients and families; would that be fair?
>
> A. Yes, yes. I find you write in a complaint and they write back to you what you wrote in. "I wish to complain"; "I see you want to complain", or "You have a complaint; I acknowledge your complaint". But they tell you nothing about the complaint, they don't answer the complaint.
>
> Q. CHAIR: Or give you answers as to maybe what happened in the individual circumstances?
>
> A. Yes."[282]

304. When speaking to Dr Swart she expressed her views further regarding the Trust's complaint process:

> "Q. DR. SWART: Let's go back to the complaint process. You wrote a letter to the Trust. Did anybody from The Trust ring you up and talk to you about what you wanted to achieve with the complaint?
>
> A. No. I rang in several times to speak to people, and people were to ring me back but never phoned back, so then I put it in writing. Before I put it in writing, I made a phone call to say I wanted to speak to somebody.

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[281] TRA-01866, line 25 to TRA-01867, line 11

[282] TRA-01868, lines 10-23

Q. DR. SWART: But did you get a phone call to say "We've received your written complaint. It would be helpful to discuss the main points of it so we can give you a good answer", or anything like that?

A. No, no, no. I sent them the letter telling them what my issues were and nobody from the Trust ever came back to discuss those. …

Q. DR. SWART: You worked for the Trust. What has this left you in terms of a feeling about complaint processes in general? If you could go to the Trust and say, look, you know, I would like you to consider a different way of doing it, what would your suggestions be?

A. Well, I think when a complaint comes in it, is all about self-preservation and protection of yourself. Or themselves.

Q. DR. SWART: What would it take to change that? What are some suggestions? If you were to go in a quiet room with someone and say look?

A. Well, it's hard to beat face-to-face.

Q. DR. SWART: We have heard your story today and we can see the impact it has had.

A. It is hard to beat the face-to-face. You know, I think if you can't meet someone, a colleague, to discuss a complaint, it doesn't say much for the general public trying to make a complaint."[283]

305. Patient 82's daughter also made the point that none of the doctors who saw her father ever queried the dosage of Bicalutamide that he had been prescribed and was visibly upset at this point in her evidence:

> "I would have expected Dr. Thwani [sic] and Mr. Tyson and Mr. O'Brien to have known that. Yet, Mr. Thwani [sic] and Mr. Tyson seen Daddy's medication and never queried why he was on a low dose of Bicalutamide. … It looks like to me that there were two other doctors with knowledge of urology that should have questioned the use of Bicalutamide and tamoxifen in Daddy, and didn't.

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[283] TRA-01873, line 4 to TRA-01874, line 11

> Daddy took a dizzy spell one day in the main street in [redacted by USI] and he was referred to a geriatrician. I understood that to be an expert in the care of the elderly and medicine suitable to that age group. He never questioned it. In fact, he actually reduced furosemide and clopidogrel at that review, and never questioned. …
>
> You know, there again he seen a cardiologist, Mr. Menown, and complained of fatigue, and there was no mention of it being down to Bicalutamide or tamoxifen, it wasn't questioned. From, I mean, a cardiologist -- right, if hormone treatment is detrimental to somebody with Daddy's acknowledged cardiac condition, was the cardiologist not concerned that Daddy was being prescribed a drug from another practitioner and yet didn't consult with that practitioner to say, well, look, you know, his heart condition is causing me concern, does he really need to be on this or can we do something different? [sic]"[284]

The Inquiry considered it appropriate to contact Mr Thwaini and Mr Menown to seek their comments on the points made by Patient 82's daughter, we obtained written responses.[285]

306. Mr Matthew Tyson in evidence indicated that his role as a urology trainee entailed providing dictated discharge letters after in-patient care. He dictated a discharge letter for Patient 82 following the supervised injection of Botox into Patient 82's bladder, his knowledge of the Bicalutamide 50mg monotherapy and Tamoxifen was from reading the patient notes and:

> "There was nothing at the time, as a first year registrar, for me to suddenly go "There's a pattern, there's something going on.""[286]

The Inquiry accepts that as a first-year specialist registrar, Mr Tyson may not have realised that this was an unusual prescribing practice. As stated above, the

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[284] TRA-01869, line 6 to TRA-01870, line 23. The knowledge of Mr O'Brien's prescribing practice is discussed elsewhere in this Report, see MHPS and Clinical Aspects chapters.

[285] See WIT-108056; WIT-108008 to WIT-108009

[286] WIT-104213; TRA-08937, lines 17-19

Inquiry eventually managed to contact Mr Thwaini who has left the UK and who had a vague recollection of the patient but said nothing regarding this issue.[287] He subsequently informed the Inquiry that it is his firm view that while he was aware of the prescription of Bicalutamide and Tamoxifen for prostate cancer, he would not have considered that so out of the ordinary that he would raise it, in circumstances where his own involvement was with an unrelated condition. The Inquiry disagrees. As a qualified urologist he ought to have at least commented on the unusual dose, and the Inquiry considers that not doing so was a missed opportunity.

307. Patient 82's daughter also commented that she thought that the Bicalutamide and Tamoxifen prescribed by Mr O'Brien had dropped her father's PSA level and described how Mr O'Brien would call outside working hours to tell her about the latest PSA results when they were not available at clinic. Mr Haynes taking her father off the Bicalutamide worried her that the cancer may 'take off' and it is clear that she and her father were not fully informed as to why:

> "Q. DR. SWART: How could that have been done differently, do you think?
>
> A. How could that have been done differently?
>
> Q. DR. SWART: Yes. What would have made that easier for you, because it is quite easy to understand that that was hard. I mean, you have mentioned that you thought there was a lack of openness and transparency about things.
>
> A. Well, if it had have been said it was the totally wrong medicine that he had been on for ten years, then I would have started to sit up and take notice, whereas I thought somebody else is coming in now and there's a bit of new research, you know."[288]

308. Patient 82's daughter recognised a governance issue:

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[287] WIT-108056 to WIT-108058

[288] TRA-01875, lines 12-24

> "obviously there was some lack of governance in terms of -- well, was Mr. O'Brien operating solely on his own? I mean, that's not recommended. It is recommended that a multi-disciplinary team approach is taken."[289]

309. When asked for her final comments Patient 82's daughter said:

> "It's very disappointing, like, you know. I just thought he was being well looked after and it turns out he hasn't, and I sort of feel I should have been smarter myself. Awful, so it is, you know. But the Health Service is under a lot of pressure and this is what happens when it isn't managed correctly. …
> Like, why did the other urologists not question it? Why did the GP not question it? You know, like, I'm told as a nurse if a doctor writes a medicine and a dose and I don't think it's right or it isn't right, that I'm asked to speak to the doctor, "Is this what you want the patient to have". If I still think it is not what should be given, I'm not supposed to give it. To me, there was a lot of well-qualified people, better than myself, that could have queried that Bicalutamide or tamoxifen. [sic]"[290]

310. The Inquiry recognises the family's perspective that the wider system and culture of governance failed Patient 82 and these matters are addressed elsewhere in this Report.[291]

311. Patient 82's case is another example of poor communication systems in the Trust.

## Patient 5

312. Patient 5's case was one of the nine considered in the SAI review that led to this Inquiry. He underwent a successful nephrectomy in March 2019, for a renal tumour, carried out by Mr O'Brien. Mr O'Brien arranged a follow-up CT scan of the chest, abdomen and pelvis on 17 December 2019 and hoped to review the

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[289] TRA-01876, lines 10-14

[290] TRA-01887, line 4 to TRA-01888, line 2

[291] See Clinical Aspects and Governance chapters

patient in January 2020. The scan report showing a possible sclerotic metastasis in the spine was available on 11 January 2020. Mr O'Brien failed to action the result of that scan, with the consequence that Patient 5 was not called for discussion and further treatment until some eight months after the result was available.

313. According to the hospital's Patient Administration System (PAS) this scan was not looked at by Mr O'Brien until 12 July 2020. The Inquiry understands that there is an audit function on the PAS system which allows you to see when a scan has been accessed and by whom. That audit function appears to indicate seven months after they became available, Mr O'Brien accessed the results of the CT scan on 12 July 2020.

314. Mr O'Brien says that he saw a hard copy of the scan with the patient's chart in late February or early March 2020. In his lengthy written response to the SAI review report he said:

> "My secretary had retained [Patient 5's] hospital chart in her office to await the report of the CT scan performed on 17 December 2019, so that his chart would be available for his intended review in January 2020. She transferred the chart with the report of the CT scan to my office on some unspecified date following receipt of the report. As she did not track the transfer of the chart from her office to mine, it has not been possible to determine when it occurred. It is probable that it was during February 2020 due, once again, to my not being able to review [Patient 5] during January 2020 due to the inadequacy of outpatient review capacity. In fact, he still remained on the list for review at my oncology review clinic in June 2019.
>
> I always returned to my office each evening of every working day in the hospital. On doing so, I could find that my secretary had left a hierarchy of administrative tasks requiring attention. The most urgent could be positioned on my chair so that I could not sit down without being aware of it. I would find a number of hospital charts would be left on my desk, some which I had requested, others accompanied by the reports of investigations which had

been requested. In addition, there would be a much greater number of hard copy reports of investigations without hospital charts, particularly the large numbers of reports of investigations requested during triage of referrals, as well as messages, queries and requests to contact patients or their relatives etc. I would firstly review the reports accompanied by hospital charts as that released most desk top space at which to begin working. I would then place the hospital charts on a shelf in my office to deal with at a later time when available. This was a necessity so that I could log on to my computer to address those tasks sent by email, and all this after attending firstly to those administrative tasks involved in arranging future admissions etc.

While I do not have a record of the date, I believe that it was either in late February 2020 or early March 2020 when I reviewed the report of the CT scan and the recommendation of a radioisotope bone scan. I do so as my dominant concern was with regard to exposing [Patient 5] to the risk of Covid by having him attend Craigavon Area Hospital for scanning. I called with the radiographers in the Department of Nuclear Medicine to enquire whether they were continuing to arrange radioisotope scans and what measures were in place to minimise the risk of Covid to patients attending. I considered that arranging for [Patient 5] to attend a rather confined department at Craigavon Area Hospital at that time, initially for intravenous injection of radioisotope, and to return later for scanning, exposed a vulnerable, comorbid, 89 year old man to a potentially lethal risk greater than deferring further assessment of the recently reported CT findings.

I later considered arranging further CT scanning to be performed at South Tyrone Hospital in April 2020. However, by then, society was heading towards lockdown due to the Covid pandemic, and elective clinical services were being progressively cancelled. Outpatient clinics were cancelled to eliminate the risk of Covid posed to patients and staff attending, as well as facilitating redeployment of staff to other more urgent needs. Again, rightly or wrongly, it was my overwhelming concern that [Patient 5] was at greater risk by being requested to attend hospitals for scanning during that first wave of the pandemic than by deferring such scans until such time as the associated risks may have been reduced."[292]

315. Despite this explanation the family say that the least Mr O'Brien ought to have done in February 2020 was to tell their father the result and allow him to decide whether to have a further scan. Mr O'Brien did not do so.

316. There is, in any case, no record of Mr O'Brien's review of the scan and nor has he suggested that he discussed the need for a further scan with anyone else. Mr O'Brien states that having not been in his office at CAH since March 2020, he returned briefly on 21 June 2020 to collect the clinical records of two patients regarding whom he intended to prepare reports during July 2020. It is unclear whether Patient 5's records were among those records collected by Mr O'Brien in June 2020. In any event, no further action was taken in respect of the scan at that time. Finally, Mr O'Brien states that he had just begun to progress the administration of Patient 5's case on 12 July 2020 when he read the letter, sent by Mr Haynes in his role as Associate Medical Director (AMD) the day before, which instructed Mr O'Brien not to access or process patient information in light of the concerns which had emerged in June and July.[293]

317. In seeking to explain the failure to action the CT scan, Mr O'Brien states that had he not received this letter, he would have made arrangements for Patient 5's further assessment and management. Again, there is no suggestion that Mr O'Brien alerted anyone to the need of further assessment and management in light of the scan report which was first available in January 2020.

318. The Inquiry is satisfied that if Mr O'Brien did access Patient 5's scan in February as he claims and did nothing because of the risk of covid to his patient, then he has demonstrated a paternalistic attitude towards his patient which is unacceptable in modern medical practice. This attitude is also at odds with the

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[292] PAT-002272 to PAT-002273

[293] AOB-02534 to AOB-02536

attention to Patient 5 and his family following the nephrectomy operation, as described to the Inquiry by Patient 5's daughter below.[294]

319. Mr Haynes sent a letter to Patient 5 on 29 July 2020 telling him about his CT result and apologising for the delay. He said there was a possible abnormality on the CT scan that required further investigation with a bone scan. That scan was carried out on 06 August 2020 and confirmed that Patient 5 had metastatic prostate cancer.

320. At a review on 12 August 2020, Mr Haynes discussed treatment options with Patient 5 and commenced ADT. Patient 5 was also made aware that a referral to oncology remained an option.

321. The SAI report into Patient 5's care concluded that the management of his renal tumour was "exemplary",[295] but that the abnormal findings on the post-operative review scan should have been noted and acted upon by Mr O'Brien. The Review Team observed that it would be unusual for a renal cell carcinoma to produce a sclerotic metastatic bone deposit, and other options should have been considered.

322. Patient 5 developed a further primary bowel cancer incidentally picked up on a routine CT scan in February 2021 but he was unfit for surgery. Patient 5 died from his cancer in 2022.

323. The Inquiry heard from Patient 5's daughter who spoke to us in September 2022. She described the treatment her father received as "a story of two halves":

> "I would describe the care that he received in terms of his kidney cancer, the nephrectomy was excellent. Mr. O'Brien was so supportive of us a family. He presented as a very intelligent, articulate, knowledgeable man. He seemed to have a genuineness, a genuine interest in Daddy. He, you know, had a great

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[294] See paragraph 323

[295] PAT-001938

> sense of engagement and was able to build up a rapport with Daddy and us as a family. We trusted him and we valued that support, and we are... you know, Daddy was very clear that he was very grateful to Mr. O'Brien. He felt that he had exemplary care in terms of his kidney. You know, we felt at that juncture Daddy's life had been saved as a result of the nephrectomy. So, I could not fault the care around Daddy's kidney and the nephrectomy."[296]

324. This was a view shared by many of Mr O'Brien's patients and consistent with the skilled service he was considered to deliver.

325. She went on to describe what happened after her father had his follow-up scan in December 2019:

> "Daddy had his scan, follow-up scan, in December '19 and it was available from 11th January. Daddy was clear at that point in time that he -- in the previous instance, my sister had phoned up for the result of the scan and then it had been followed up by a letter. Daddy was clear at that point in time that he didn't want us to call, ring up about the scan. He had complete trust in Mr. O'Brien and felt that if there were any concerns, that Mr. O'Brien would be in touch. That was his view and we had to respect that.
> We did not know anything about the result of the scan until we were contacted by Mr. Haynes, which I think was towards the end of July. … He explained to me that there was a suspicion, something suspicious on Daddy's scan. From memory, I was very distressed, very upset, very angry. You know, Mark Haynes was the ultimate gentlemen and calmed me down and talked me through everything and the ramifications. My first thought was had there been microscopic spread and had Daddy's kidney cancer spread. Mr. Haynes explained that that was unlikely, that it was potentially a prostate cancer. I was completely shocked. I guess I had a naive approach, thinking if Daddy had been scanned before and he has been in hospital, you know, why was this not

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[296] TRA-01890, line 19 to TRA-01891, line 4

> discovered, number 1, before; and, number 2, why has the scan not been followed up in a seven to eight-month period."[297]

326. Patient 5's daughter started to carry out her own research regarding her father's diagnosis:

> "I started to do some generic reading around radiological investigations in Northern Ireland and prostate cancer, you know, diagnosis. I emerged [sic] myself in the world of PSA tests, the gold standard being a PSA test and an MRI; the pros and cons of the false negatives and the false positives. But also I read the RQIA previous investigations into review of radiological investigations in Northern Ireland, where the issues seemed to be the delay in investigations were at the juncture from the Radiology Department to the clinician, not from the juncture of the clinician once it had been delivered virtually. So, I had assumed that that potentially was what had happened."[298]

327. When she spoke with Mr Haynes in July 2020 he explained that her father's care would be looked at in the SAI review and explained to her what that was.

328. She described the effect on the family of learning that her father had to have a bone scan:

> "Then Daddy went for - was it a bone scan - for a scan. You know, we were absolutely terrified. You know, Daddy was completely shocked, distressed and anxious when we heard about a potential prostate cancer. The fact it had metastasised in his bones, we knew this was extremely serious. He was worried sick and we were worried sick that it would have spread in the interim because of the delay. That was just our human view rather than based on any clinical information.
> Daddy went for his scan. You know, it indicated further spread. We had a follow-up meeting with Mr. Haynes, who explained, you know, the next -- the

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[297] TRA-01893, line 6 to TRA-01894, line 7

[298] TRA-01894, lines 9-22

> way forward for Daddy. Daddy was trying to be positive, to look at treatment options. You know, he didn't have -- you know, I don't know how he dealt with it mentally or emotionally because it was so traumatic, but he was focused on what are my options now moving forward, what is my treatment going to be, and what do I have to deal with."[299]

329. She went on to describe the symptoms that her father experienced and how the family tried to help with alleviating his symptoms.

330. She confirmed that when he was diagnosed with kidney cancer no CNS was assigned to him. The SAI report stated:

   - "Patient 5 was not referred to a Cancer Nurse Specialist or Keyworker to support him with his diagnosis. Nor was [sic] any contact details given to him. The Northern Ireland Cancer Services recommendations for Peer Review include that "all newly diagnosed patients have a Key Worker appointed, a Holistic Needs Assessment conducted, adequate communication and information, advice and support given, and all recorded in a Permanent Record of Patient Management which will be shared and filed in a timely manner"(1). This did not happen and was detrimental to the patient's experience.
   - The review team are of the opinion that a specialist nurse would also have been a failsafe for identifying the delayed scan report and bringing it back to the MDM sooner."[300]

331. Patient 5's daughter spoke about the family's experience of CNSs. She perfectly reflected the benefits to patients and families of the need for such support to be provided to all cancer patients, which contrasts acutely with the problems of not having access to such support as demonstrated in the case of Patient 1:

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[299] TRA-01896, lines 7-26

[300] PAT-001937

> “I will say, reflecting back on our experience of not having a clinical nurse specialist when Daddy had his kidney cancer, compared to having two clinical nurse specialists when Daddy had his prostate cancer and his bowel cancer, there was no comparison. We were able to ring the nurses and ask them for advice and support. It was an absolutely amazing service. I don't feel -- I think it was alluded to in the SAI report that the scans may have been followed up quicker. I think the role of a clinical nurse specialist is so much more than that. It is about holistic assessment of your needs; it is about having a port of call, someone to advise, someone to support. Having been able to compare and contrast the two experiences, they were absolutely phenomenal, and I cannot thank them enough for the support that they gave us and Daddy.” [301]

332. As regards the CNSs acting as a ‘failsafe’ her view was:

> “I think that is one aspect of it, in tandem with the support services that we were provided. Having someone to call, you know, you are not feeling as if you're a ship without a rudder, you have someone you can speak to. Even about minor issues such as, you know, is sage useful for hot flushes. You know, Daddy is feeling a bit under the weather, there's some nausea. Having that port of call when are you going through this horrific journey was of great benefit to us. [sic]”[302]

333. Patient 5’s daughter told us how her father was initially reluctant to meet with the Review Team, but on reflection agreed to do so:

> “primarily because he felt it was important to find out what went wrong, and to prevent this from happening to other patients in the future was his motivation and that was our motivation.”[303]

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[301] TRA-01898, lines 3-18
[302] TRA-01899, lines 5-14
[303] TRA-01900, lines 9-12

334. The family met with Dr Hughes and Mrs Kingsnorth on 11 January 2021.[304] The family's engagement with the SAI Review Team was described in positive terms as this exchange with the Chair shows:

> "Q. CHAIR: We have seen the notes of that meeting with him but it certainly seemed from my reading of it - and I'm interested to know your view - it certainly seemed a frank discussion that you had with both of them where you were able to put the family's views and ask the questions that you wanted answers to?
>
> A. Absolutely. I mean, it was a difficult situation. You know, COVID was under way. We went over to the Trust for a face-to-face. You are sitting across a large room with face masks on. You can't pick up on nonverbal cues or reassuring smiles. You know, I cried a lot throughout it. I'm the crier in the family. I found it very, very difficult and very, very distressing, and very difficult to control my emotions, but at the same time [we] had answers that we felt needed to be answered to protect -- to find out what had happened to Daddy but also to protect patients in the future, I suppose, are the two reasons for that.
>
> We were able to be open and honest in terms of our feelings. We could not have felt more supported. You know, Dr. Hughes and Patricia Kingsnorth could not have been more empathic. They gave us time, they did not rush us, they did not take over the meeting. Everything was explained carefully to us and it was as positive as it could have been."[305]

335. Nonetheless the family still had questions and so a second meeting took place which, from the family's perspective was equally positive:

> "I cannot fault the contact from the Trust and the support that we experienced throughout the SAI process. I don't think there's anything. You know, COVID got in the way. Having two virtual consultations is always very difficult as well.

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[304] Minutes of the meeting are at PAT-001954 to PAT-001960

[305] TRA-01900, line 17 to TRA-01901, line 13

> Dr. Hughes and Patricia had face masks on during the virtual meeting, so it is more difficult and it is more stressful but they made it as easy as possible for us, and they did everything they could to clarify circumstances for us, took on board our feedback and acted accordingly. So, I was very impressed by the process."[306]

336. It is often easy for those involved in any Inquiry to forget about the impact that learning about failings in health care can have on a personal level. The following exchange clearly articulates what it can mean:

> "Q. CHAIR: In terms of the impact on you and your father, how did you as a family, how did you feel when all this came to light?
>
> A. I'm not going to get upset; I promised that I wouldn't. I think we're appreciative of all the apologies that have been given in the hearings to date, and the language used is "anxiety and distress". For me, it doesn't cut it. For me it was harrowing, it was horrific, it was traumatic, it was distressing, it was long term, it was an emotional roller coaster, it was devastating, it was shocking. It was all of those emotions. It was difficult for us to deal with as a family. Daddy was our life; our life revolved around him. He reared us as a single parent. So, you know, he was part of our lives 24/7.
>
> Coming from the background that I come from, I just could not understand how it could have happened. I had a lot of questions and was reading and reading and reading to try to make sense of protocols and safeguards that were in place and yet this happened, and why. Our biggest concern was for Daddy. Daddy went into lockdown in March '20. In lockdown, no physical contact with his family, apart from my sister going in just to leave his food literally at the kitchen door. He was in lockdown; he was isolated. You know, we were protecting him. And in tandem with that, he had undiagnosed cancers on top of his recovery from his nephrectomy. That is horrific in itself. I don't know how Daddy

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[306] TRA-01902, lines 17-27

> had the strength to deal with what he did but he was resilient. Coming here today to speak to the Panel is nothing compared to what he went through. It was the most traumatic and horrific experience of our lives as a family, I think."[307]

337. She told Dr Swart that what shocked her most in learning about what had happened in respect of her father's care was:

> "Where Daddy's scan was not acted upon over a seven to eight-month period, and the subsequent diagnosis of prostate cancer."[308]

338. In light of not understanding how governance in the Trust failed to protect her father, Patient 5's daughter became involved in the Trust's 'Task and Finish Group', a service user group in the Trust set up to implement the recommendations of the SAI report. From the Inquiry's viewpoint this gave her a somewhat unique perspective on many of the issues that we had to consider in terms of patient safety. She found her participation to be a positive experience:

> "I mean, the motivation for becoming involved in the group was my background in [personal information redacted by USI] for many years, but also that sense of responsibility and duty, and Daddy saying put your education to good use, go and take part in this group, do as much as you can to ensure this does not happen to other patients and their families in the future, you know?
>
> The group, I have never met such a more open, warm and welcoming group of professionals. I felt I wasn't there as a silent partner. I felt very much listened to. You will know from looking at the minutes that I wasn't shy in terms of putting my personal opinions forward in terms of governance, in terms of issues, in terms of the action plan generally. I think they are a very, very committed group who really want to make a difference and ensure that the correct governance, policies and procedures are in place; that the action plan

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[307] TRA-01902, line 28 to TRA-01904, line 3

[308] TRA-01908, lines 7-9

> is clearly mapped to current policy and procedure expectations, benchmarks and standards; and also - which I think is particularly important - that there is a clear evidence base on which to measure the success of the action plan and the enhancements *in situ*.
>
> Sarah Ward was my contact for the group, and Mr. Ronan Carroll chaired the group. I feel that I was there as a layperson, in effect, as a daughter of a patient, and I think I would defer to the clinical and governance experts to give an overview of the progress to date. There was regular updating, and I know there were regular reports to the overarching urology quality assurance group. I would not suggest anything different in terms of how I was treated, welcomed in terms of the conduct of the group and in terms of their embracing me working as a partner within that group.
>
> I had great support from the family liaison officers, from the PPI staff. You know, it was a very, very positive experience but it was a difficult experience because this affected us and our family and our story. But that made me more motivated to ask questions and to probe and to make suggestions."[309]

339. When she was asked by the Chair if she would like to see more general involvement in issues of governance for patients and families she said:

> "Absolutely. I think, you know, there are guidelines in terms of approaches to service user involvement in SAIs and groups. I think it is really, really important that -- I hate the term "service user" and I hate the term "lessons to be learned". I think they dehumanise the situation. We are people, we are real families and we need a voice. I think, moving forward, I know that the urology group had suggested disbanding the Task and Finish Group after 12 months at the last meeting. At the last meeting I said I didn't feel that was appropriate. I felt that service users' families needed to continue to be involved in the action plan and involved, you know, in the progress to date and to continue to be updated, that it shouldn't just stop at that juncture. So, it was agreed that the group would meet again at regular intervals, which I was really pleased about.

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[309] TRA-01904, line 22 to TRA-01906, line 7

> I think, moving forward, families need a voice at the table, whatever table that is. That is reviewing, monitoring and critiquing the effectiveness of the action plan moving forward, and also identifying any further enhancements and changes that need to be raised or changed as a result of the evidence base moving forward. I think we have a unique voice in that we have experienced it. I think we have the opportunity to raise issues as non-employees of the Trust and to give that kind of objective viewpoint which I think is really, really important."[310]

340. Patient 5's daughter questioned the application of the RQIA recommendation regarding the monitoring of scans:

> "For me, that is a concern for me. When the NIPACS system came into fruition in Northern Ireland, I think in 2010, you know, one of the aspects that were heralded was that instantaneous ability to click a mouse and you would be able to see a scan to prevent any delay in follow-up, not relying on paper and hard copies. That was supposed to be a system which was foolproof and which would enhance the governance and, I suppose, the timely dissemination of scans and results moving forward. For me, the Department of Health spent an awful lot of money on that. I read in one digital health article, it was £50 million for the new phase, perhaps between 100 and 132 million for a five-year contract. If you are spending that amount of money - which I know it was BSO who commissioned it, I know there's a leading NIPACS coordinator within BSO and one within the Trust - if you are spending that amount of money on the system, I would like to think - and I don't know anything about its functionality - but you would like to think that there would be some way of monitoring clinician follow-up."[311]

341. The Inquiry has seen clear evidence that known risks to patient safety were not monitored or audited regularly. The issue of failure to act on radiology reports is one such risk which has been the subject of much attention over many years. In

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[310] TRA-01906, line 17 to TRA-01907, line 16

[311] TRA-01908, line 25 to TRA-01909, line 17

the absence of foolproof electronic systems patients should be protected by ensuring that regular assurance reports based on either audit or ideally continuous measurement of key data are scrutinised by governance systems. Patients who are kept fully informed about plans for their care including an expectation of timescales can also improve safety in many areas by being able to question when things do not happen as expected. Patient 5's daughter, a lay person, recognises this need:

> "I think reflecting on the evidence to date within the Inquiry, the DARO system, I don't understand why there's a separate system. It sounds as though the systems within the Trust are not talking to each other. I'm not an IT expert but, for me, I still have concerns about the ineffectiveness of the follow-up and tracking mechanisms in terms of clinicians looking at a scan, because the DARO process for me seems to rely on human intervention, whereas I feel with the technology that we have available to us now, why was there not an escalating opportunity where, if a scan had not been looked at, that that would have been escalated to another level within the Trust immediately and the issue would have been addressed. So there's a system issue for me as well.
> …
> You know, it is clear: If a scan is not followed up quickly, that is a risk to the patient. It is not an administrative issue, it is a risk to a patient.
> I personally feel that more could have been done to drill down to the actual processes and systems and whether they were fit for purpose, would be my personal view."[312]

342. In terms of the systems, Patient 5's daughter expressed the view:

> "I think it is more than a Trust issue, I think this is a regional issue, I think it is a systems issue. You know, I think it's an issue in terms of, you know, why do we have NIPACS but then we have DARO. I think it is an infrastructural issue that needs to be -- it is a bigger conversation because it affects thousands and

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[312] TRA-01909, line 19 to TRA-01910, line 29

> thousands of patients. I know the Trust have invested, and now it is moving on to pathology results, isn't it, NIPACS? I'm not an IT expert but I do think that the IT systems and the monitoring systems do need a bigger look at external to the Trust. I think that's something that the Department of Health should do as that overarching agency. I think that's a core responsibility of theirs."[313]

343. The Inquiry notes that the encompass programme currently being rolled out across Northern Ireland's Health Trusts is designed to implement a comprehensive, resourced, and accountable infrastructure that ensures scans and other critical clinical actions are properly monitored and acted upon. The Inquiry hopes that it is effective in ensuring that this is the case but recognises that it is but one limb in improving patient safety and clinical accountability.

344. Patient 5's daughter recognised the resource issues faced by the Trust and by the urology services. She advocated for the recruitment of urologists internationally as well as incentivising students to train in the discipline.[314]

345. Her involvement in the Service user group enlightened her as to the scale of the issues facing the Trust:

> "I suppose I didn't have an understanding, really, of the infrastructure within governance within an organisation. I didn't know how huge it was; I didn't know how many policies, procedures and standards. It is a massive, massive arena and I think it is one that should be resourced effectively. I would say that all Trusts could do with as many resources as possible to track and to ensure that there are effective governance arrangements in place. That would be in terms of people having time to do that; it would be time to reflect and critique and measure against standards. It would also be the structures around the

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[313] TRA-01911, lines 15-29

[314] The Inquiry learned from Dr O'Kane that the Trust engaged in an international recruitment drive that succeeded in securing three consultant urologists from India: TRU-309784. When the Inquiry sought an update from the Trust as to their placement, we were advised that one started on 19/02/2024 but was leaving in August 2025, the second started on 03/05/2024 and the third started on 01/06/2024 and left April 2025: TRU-434077 to TRU-434078.

> supporting technology and the supporting administration. I think it is a whole arena within itself and it is much vaster than I thought it was."[315]

346. This comment points to a need to have information systems that pick up continual measurement of key metrics that serve as signals to ensure compliance with important standards allowing clinicians, managers and leaders to read signals before major problems occur. More is said about this elsewhere in this Report.[316]

347. When speaking with Mr Hanbury, Patient 5's daughter discussed the lack of communication from the Trust and how the family had to contact the Trust to ascertain the result of a scan that took place in June, prior to the December scan. She made the point that, had they had a CNS, that would have helped with the communication, as being a point of contact. She told the Chair that prior to the meeting with Mr Haynes she was unaware of the existence of [cancer] nurse specialists:

> "No, at that juncture I wasn't aware. You'd think that I would know that in terms of my background but no, I wasn't aware of the existence of clinical nurse specialists or their role and function and how important it was until it was mentioned at the SAI meeting, and then I read up on the role and function and recognised that, you know -- I think, you know, people say why did you not complain. If you don't know what the baseline expectations are in terms of what you're entitled to, then you don't complain. If we had known that, if it had have been indicated to us that your dad should have a clinical nurse specialist allocated to him, if that hadn't been done, we would have followed that up but that was not indicated to us at any juncture. But certainly the two nurses, the urology nurse and the colorectal nurse, were both allocated promptly and were present at the meetings to support us throughout Daddy's journey. [sic]"[317]

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[315] TRA-01912, line 26 to TRA-01913, line 11

[316] See Governance and Medical Management and Leadership chapters

[317] TRA-01917, line 15 to TRA-01918, line 3

This evidence and that of others who had CNSs highlights their value. Their role is so much more than chasing up things for patients, they provide a high level of care and invaluable support for patients and their families. The assignment of a key worker is mandatory for all cancer patients, but it is crucial that compliance is total. Full compliance with Peer Review Standards should be regularly assessed by the Trust in order to ensure that standards are maintained and not regarded as optional in any way.

348. Patient 5's daughter also commented on the lack of quoracy in MDTs when questioned by Counsel regarding the final version of the SAI report and very low quoracy numbers for MDT, something which was not escalated sufficiently at that time:

> "I felt it was important to note that the multi-disciplinary team, the attendance and the quorate levels was of great concern to me. I cannot remember if we suggested that that be added into the report or not, I cannot remember."[318]

349. In closing, Patient 5's daughter had prepared a statement that she read to the Inquiry, the Inquiry considers it important to repeat it in this Report in order to show the impact on one family and its view on what should be done:

> "Chair and Panel members and everyone present here today, thank you for giving me the opportunity to tell my father's story and the impact that these events had on my father and my family. I would therefore like to read out the statement pertaining to the failings on my father [Patient 5]'s cancer journey, who sadly passed away on [personal information redacted by USI].
> I feel that my father, [Patient 5], was failed by Mr. O'Brien, the Department of Health, and the Southern Health and Social Care Trust. Initially as a family we were indeed aware that after my father's kidney removal, there was no guarantee there had been no microscopic spread from his tumour which could become evident at a future date. Fortunately, a June 19th CT scan revealed

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[318] TRA-01920, lines 10-14

no sign of disease. At this time we were all unaware that my father also had an undiagnosed prostate cancer.

Whilst we appreciate the extensive evidence presented in this Inquiry and the detailed response by Mr. O'Brien, we still don't have an answer to our main concern: Did the lack of prompt action and follow-up with my father's CT scan on 17 December '19 affect his prognosis? My father's cancer metastasised further in intervening months. We are not talking seven to eight weeks, nor seven to eight days, we are talking seven to eight months.

Mr. O'Brien, in his statement, which I received yesterday, described how this delay came about, detailing his administrative processes and his rationale. He suggested he reviewed the scan results in late February or early March 2020. However, at a very minimum the results of the scan should have been communicated to my father once the scan had been reviewed. Surely he had a right to know at that juncture rather than not being informed until late July 2020.

My father should have been allowed to make an informed choice on whether to attend for an additional scan. We appreciate that COVID-19 measures also came into effect.

When I reflect on my father's circumstances, he was neither protected nor safeguarded and was not reviewed post-CT scan, even though there were clear governance policies and procedures. These serious governance issues and failings need to be addressed by the Department of Health, and the Trust. An arm's length approach to governance does not seem to be working when I reflect on my father's circumstances. More rigorous oversight by the Department of Health of governance in the Trust is required, in my opinion.

In addition, if unannounced inspections do not currently take place across Trusts with regard to governance, doing so would provide a realtime [sic] snapshot of practice.

The longevity of the concerns with regards to the lack of prompt follow-up of scans is worrying, harrowing and upsetting. Had they been addressed or resolved, we perhaps might not be where we are today, in the middle of another public inquiry. It was the [sic] first noticed almost ten years ago that scans were not being followed up promptly, yet it has happened to my father again. In my opinion, and based on the hearings to date, there appears to be ineffective leadership in the Trust at different levels where risk factors were not sufficiently addressed, escalated, and dealt with appropriately. Chief executives should have taken ownership and responsibility of addressing serious concerns in order to maintain public confidence in the Trust.

In terms of Trust culture, work needs to be done in changing the Trust culture to ensure the staff are not afraid to raise professional practice issues and feel supported to do so. The systems tracking patient scans and monitoring the follow-up scans by clinicians is not fit for purpose, in my opinion, and should be reviewed. Remember, patients and their families are not just a number, a statistic on a PowerPoint reflecting lessons to be learned. Instead of lessons to be learned, it should be mandatory changes and enhancements required, closely monitored by the Department of Health and its associated arm's length organisations to safeguard patients.

We no longer have my father in our lives. We continue to grieve and mourn him every day. The public inquiry, although necessary, is difficult and distressing for us as a family. We hope that eventually it will provide closure and will make a difference and safeguard patients in the future, which was [Patient 5]'s wish."[319]

## Conclusions

350. The Inquiry has considered the evidence it read and heard from patients and their families. It notes a series of failures on the part of the Trust and its employees articulated by them. Some of these were identified in the SAI reports. The Inquiry finds that they include:

- Poor communication with patients generally including a failure to write directly to patients.
- Lack of openness and transparency with patients.
- Failure to triage patients referred to the Trust.
- Failure to fully inform patients of the MDT process.

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[319] TRA-01921, line 2 to TRA-01924, line 11

- Failure to advise patients of MDM recommendations.
- Failure to ensure fully informed discussion of treatment options and consent.
- Failure to document what a patient has been told in the medical record and in written correspondence to the patient and the GP.
- Failure to ensure that a CNS/key worker was assigned to every cancer patient.
- Failure to adequately investigate complaints in a timely manner and respond to complaints in a patient centred way. This includes not having conversations to agree the main points of the complaint and the failure to offer a meeting in order to detail how the complaint has been investigated, dealt with and whether changes have been implemented.
- Failure to explain the process of selection of patients for waiting list initiatives in the private sector leading to uncertainty as to why an individual was selected.
- Selection of patients for the private sector apparently not completed with clinicians' input.
- Failure to understand the impact on the patient and family of a transfer to the private sector.
- Failure to complete preoperative assessment and the correlated failure to give the patient the opportunity to ask questions.
- Failure to transfer notes to the private sector.
- Failure to monitor the prescription and use of Bicalutamide.
- Failure to escalate issues.
- Failures in the Trust governance systems in terms of ensuring that results are looked at when ready and actioned immediately where necessary.
- Failure to have systems to measure and or audit key functions such as triage times and times to stent replacement/removal.
- Inquorate MDTs and failure to adequately address this.
- Failure to investigate and process SAIs quickly.

351. Moreover, a feature of the evidence we heard was a tolerance of the situation by patients. This was particularly true of the older generation who tolerated the lengthy waits for treatment or hearing about results, and who generally believed that 'doctor knew best', even after deficiencies in care were known to them.

352. The best patient safety outcomes need full patient partnership in care. The Inquiry considers that this has not been a prominent feature in Trust governance systems and recommends that systems are put in place both in this Trust and across the region to allow patients to participate fully in their care. It notes that the encompass system currently being rolled out ought to allow patients access to their medical notes and records, however, more needs to be done to give patients a voice in their care.

### Patient and Client Council

353. The PCC was created on 01 April 2009 as part of the reform of Health and Social Care (HSC) in Northern Ireland.[320] It is tasked broadly with representing and promoting the development of the public in health and social care. The PCC is an Arm's Length Body (ALB) of the Department to whom it is accountable but is wholly independent of all other HSC bodies.

354. The Inquiry heard from the current Chief Executive of the PCC, Ms Monaghan on 21 February 2024. Like many bodies the organisation has had its resources cut in recent years which has affected its ability to fulfil its statutory functions and required it to prioritise actions in light of that reduced resource. Ms Monaghan told the Inquiry how many of the organisation's powers are so caveated in the legislation that it affects what the organisation can do on behalf of the public:

> "I think the challenge for us is that essentially the way in which the legislation is caveated means that there is an opportunity there to involve the PCC and to pay due regard to our views. However, other bodies are essentially free to

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[320] It was set up under the Health and Social Care (Reform) Act (Northern Ireland) 2009 and The Patient and Client Council (Membership and Procedure) Regulations (Northern Ireland) 2009.

> ignore it and the PCC doesn't have control over ensuring that we are involved, when we're involved and ensuring that that is done consistently. You can see that reflected at times in areas of work where we might expect to be involved or are written into it without knowledge of it. I think that is definitely a challenge."[321]

355. Patients can contact the PCC directly with regard to any issue they have relating to their or their family's care. The PCC assesses the need and reacts accordingly:

> "That, in terms of advocacy, can be right through from advice and information or an issue that might be resolved in a matter of days, or it might be something that requires more in-depth case work. Unfortunately that can also extend into the formal complaints process, SAIs, engagement with NIPSO and other bodies as well. So we try to look at that issue in the person that's coming to us holistically and address the issues in that space."[322]

356. In terms of the PCC role in relation to the complaints process Ms Monaghan said:

> "what we are hearing from people who come to PCC for support is that there is regional inconsistency in terms of how people are experiencing the complaints process, the length of time that it takes for a complaints process to be undertaken, the fact that they experience it as a largely administrative process which often doesn't address the issues that they have originally raised a complaint about."[323]

This is certainly consistent with what the Inquiry heard from those patients and families who complained.

357. When asked what she saw as the biggest deficit in terms of the complaints process she told Dr Swart:

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[321] TRA-11292, lines 2-13
[322] TRA-11296, lines 2-11
[323] TRA-11306, lines 2-10

> “I think timeliness of response, understanding of the expectation of responding to complainants and what they are trying to seek from that process. Understanding from people's experience in the process. Often what we see is trying to -- a focus less on the outcomes and how people experience a complaints process as opposed to the administration of a complaint. I think greater training and awareness around the impact of why somebody is coming to complain, what patient experience might at an earlier stage feed in to an awareness would really assist, as opposed to an administrative response to complaints, which is about following a process and maybe losing the person in the middle of that.”[324]

358. The PCC also tries to support patients and families who are going through the SAI process. Ms Monaghan set out how the organisation did this, advocating and liaising on behalf of patients and families at all stages of the process as well as providing constructive challenge:

> “unfortunately our experience in a lot of our case work has been that we have had experience of cases where the family members have withdrawn from the SAI process partway through because they haven't been satisfied with how the SAI process is being undertaken, or the direction of travel.”[325]

359. In response to questions from Mr Hanbury she explained that families disengaged from the SAI process:

> “That, in our experience, has been because families have been dissatisfied with the SAI process and feel a loss of confidence in the process addressing the issue that is [sic] subject of the SAI, or how the process is being undertaken, or the outcomes they are seeing. Often it is also the case - in case work I've been involved in - that families feel that there isn't parity of voice or they're experiencing a necessary weight being given to that within the SAI

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[324] TRA-11360, line 28 to TRA-11361, line 12

[325] TRA-11311, lines 19-25

> process. Often you are talking about family members who have been pushing and have been engaged in trying to understand what went wrong, to seek acknowledgment of that and to also seek recommendations around what would change that fundamentally to ensure that other family members don't have the same experience. It's an incredibly arduous process that places a huge burden on family members.
>
> What I have seen is the tenacity required can often be too much for family members. They are dealing with a lot of other things going on as well and there's a repeat trauma associated with consistently revisiting that issue. So we have found that the process itself can be retraumatising for people and, as a result, some family members have lost confidence in the process and have disengaged."[326]

360. She made the point that involvement in SAIs requires support from senior members of the PCC and welcomed the Inquiry into Hyponatraemia-related Deaths (IHRD) report's recommendation for a funded advocacy service for patients in SAIs:[327]

> "independent advocacy in SAIs require [sic] specialist practitioners, it requires dedicated time, it is painstaking work. You are dealing with not only the SAI process but also mediating and advocating with family members and panels, with individuals who are often experiencing multi levels of trauma and are perhaps still going through grief and bereavement with respect to the issue. So it requires quite a lot of expertise and time."[328]

361. In her statement to the Inquiry Ms Monaghan set out the PCC's experience of issues found in relation to assisting one family in an SAI process in the Trust. Many of the issues encountered by the PCC reflected what this Inquiry heard about how families were treated. In summation she quoted the family:

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[326] TRA-11356, line 28 to TRA-11357, line 24

[327] TRA-11313, lines 18-21; INQ-10607, Recommendation 37(iv)

[328] TRA-11312, line 25 to TRA-11313, line 4

> "The SAI process certainly caused further harm to my family, not the investigation itself but the lack of engagement and communication, lack of openness and willingness to answer all requests asked. We were not treated as equals."[329]

This speaks to the culture within the Trust not only of handling patient engagement in the SAI process poorly but extending that to the statutory body advocating on behalf of patients.

362. In terms of PCC involvement in urology cases her statement set out the number of cases and some details relating to them, and stated:

> "In conclusion, from our analysis of the limited number of cases relating to Urology services, which span over a 20-year period in the SHSCT area, it would be difficult if not impossible to have identified systemic issues in general, and specifically to the Urology Services Inquiry's Terms of Reference. The concerns raised regarding waiting times, delays in procedures and quality of care, were similar to those shared across all programmes of care and Trusts in Northern Ireland."[330]

363. When asked by the Chair:

> "What one recommendation do you feel would make a difference to patients in Northern Ireland that this Inquiry could make that is different to those that have already been made? Is there one?"

she told the Inquiry:

> "until you have a statutory right to advocacy, as there is in Scotland and in other places, in Northern Ireland I think that there will always be a challenge. Therefore, what I would see as a fundamental change could be both that

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[329] WIT-106704 to WIT-106705, paragraph 201

[330] WIT-106693, paragraph 170

> legislative standing for advocacy. But changes in the interim to guidance and direction that demonstrated an affirmative commitment from the Department and the health Trusts to the role advocacy plays in being a fundamental part of governance and assurance in terms of the quality of services that patients get, and supporting patients to engage around that, I think would make a difference, not just within the health sphere but right across the board in terms of third sector organisations and the experience of the public generally when they have issues that they need to address right across public services. I think that could be a fundamental change."[331]

364. This Inquiry supports this view. A statutory right to advocacy for patients would help to alleviate some of the issues experienced by those patients who spoke to us and ensure that the recommendation of the IHRD for a fully funded advocacy service was delivered.

365. The Health Ombudsman report "Broken trust: making patient safety more than just a promise"[332] found that the NHS lacked accountability and compassion towards patients when things go wrong. That report emphasises the compounded harm that occurs from a failure to listen to and involve patients after things go wrong and describes failure to listen to patients as a causative factor in avoidable harm events.

366. The issue of compounded harm caused by avoidable harm events that are then investigated is clearly demonstrated in the evidence we have heard. It is the Inquiry's view that a statutory right to advocacy for patients should sit alongside an improved complaints service as well as a service to troubleshoot issues for patients before they escalate into complaints.

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[331] TRA-11369, line 9 to TRA-11370, line 5

[332] INQ-20218 to INQ-20258

## Regulation and Quality Improvement Authority

367. The RQIA is the body that registers and inspects a wide range of health and social care services. Inspections are based on minimum care standards that ensure both the public and the service providers know what quality of services are expected. It also has a role in assuring the quality of services provided by Trust Boards reach the standards laid down by the Department of Health and expected by the public.[333]

368. In March 2022 the Trust asked the RQIA to undertake an independent review of the Trust's lookback review or SCRR process. The RQIA reported in May 2023.[334] That review made a number of recommendations regarding the conduct of the process and extension of same. Section 2.2.1 of the review addresses the issue of Patient and Family Engagement, it states:

> "There is a statutory duty of Personal Public Involvement as set out in the Health and Social Care (Reform) Act (Northern Ireland) 2009. Best practice in involvement is to seek the input of service users and families to help shape the review process, particularly around sensitive person-centred communication, the provision of support and a mechanism for sharing concerns. There may be additional valuable information from affected service users / families that will not be evident in the clinical documentation of the clinician under investigation; information from families and carers is particularly vital in those cases where a patient has sadly deceased. Importantly, effective patient and family engagement is crucial in order to adhere to the principles of candour and 'being open'. …
>
> Although the SCRR is not an SAI process, the Expert Review Team is of the view that, as a minimum, patients and families should be informed of the purpose of the SCRR, and that those affected should have an opportunity to provide additional information about their care and treatment. SHSCT outlined

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[333] See RQIA website www.rqia.org.uk

[334] WIT-106486 to WIT-106526: RQIA Review of the Urology Structured Case Record Review Southern Health and Social Care Trust, May 2023.

> their process for engaging and involving families. The Expert Review Team is impressed with and commends the significant efforts SHSCT has made in contacting all impacted families, which, given the scale, is a huge undertaking. However, we note recent issues arising regarding the quality of patient information and consider that the arrangements for patient and family involvement in both shaping the process and sharing concerns require improvement.
>
> The Expert Review Team considers that SHSCT PPI team and those external to SHSCT, such as the PHA and Patient Client Council, have been underutilised in ensuring that there are robust arrangements for PPI as part of the Lookback Review and SCRR." [335]

369. The Inquiry saw letters that were written to patients at the outset of the SCRR review and considers that the quality of those letters was not good. For example, the Inquiry had to write to the Trust asking for correction of the description of the Inquiry's work being sent to patients. Moreover, the evidence from Patient 82's daughter was that the family were only informed about the SCRR review once it had been done. The Inquiry endorses Recommendation 10 of the RQIA review that:

> "SHSCT should review their arrangements for the involvement of patients and families to ensure that it fulfils its statutory duty of Personal Public Involvement. SHSCT should consider engaging those with Personal Public Involvement expertise and external partners such as the PHA who have PPI training resources for staff and the PCC who could provide advice and support in the involvement of patients and families as part of the Lookback Review and SCRR."[336]

370. Patient 82's experiences also demonstrate failings in the arrangements for following up and sharing the SCRR findings with patients and family members. This is consistent with the RQIA review's findings. The review sets out what it

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[335] WIT-106504, paragraph 2.2.1

[336] WIT-106504 to WIT-106505, Recommendation 10, paragraph 1

considers to represent good practice for engaging with patients following a review:

> "The Expert Review Team consider the following to represent good practice:
>
> - As far as possible, reports should be quality assured, checked for factual accuracy, and should be written in easy to understand lay language;
> - Patients / families should be provided with a range of options on how they wish to receive the report; one option should be a face to face meeting. They also have a right "not to know" the findings;
> - The Family Liaison Officer should be accompanied by a medical doctor in relaying the findings of the report;
> - Psychological support should be made available to those impacted by the process and findings of the SCRR;
> - If further medical follow-up is required by patients or relatives, there should be Trust arrangements in place to facilitate this in a timely manner; and
> - There should be opportunities for the FLO to debrief with colleagues and timely access to psychological support for the FLO and any others involved in family engagement.
> - Independent advocacy should be considered for patients or families, particularly when cases are complex. The PCC have extensive experience in this area through previous work on SAIs and other Inquiries."[337]

371. Recommendation 11 was for the Trust to:

> "review their arrangements for sharing SCRR findings with patients and families giving consideration to good practice as outlined by the Expert Review Team in this report."[338]

372. The Inquiry agrees that the above represents good practice and notes that the Trust has implemented Recommendations 10 and 11 for the benefit of not only

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[337] WIT-106505, Recommendation 10, paragraph 3

[338] WIT-106506, paragraph 1

those patients and families whose cases are the subject of the SCRR but also more generally in relation to engagement with other patients and families.[339]

373. The RQIA was further tasked by the Department to assess the governance arrangements which contribute to assurance of safe care, within the urology services in the Trust. It reported on Phase II of its work with a report in August 2024, after the Inquiry had concluded its oral hearings.[340] The Inquiry was concerned to learn from that report that, although the Trust has made marked improvement as a result of the issues that have been highlighted to it following all the external scrutiny to which it has been subjected, there are a number of matters evidenced by those who spoke to us that still persist.

374. One issue was need for a more effective and robust governance system when the independent sector is used for waiting list initiative work, particularly regarding the sharing of information and access to patient records with the independent sector. It is crucial that this be rectified in order to avoid the difficulties experienced by Patient 82.

375. Another matter that causes this Inquiry concern is the fact that the RQIA quoted a 2022 Macmillan Review as finding that:

> "Some patients however were not aware of the CNS/Key Worker role, with some patients referring to 'Macmillan Nurses.' A small number of patients reported having had no contact with a CNS."[341]

It is the fervent hope of this Inquiry that such a situation has been rectified since 2022.

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[339] See TRU-183161 to TRU-183173, entitled 'RQIA SCRR Review Recommendations Action Plan', dated December 2022

[340] DOH-72508 to DOH-72563: SHSCT Trust Urology Services Phase II Report Governance and Assurance Arrangements & Patient Views and Experience, August 2024

[341] DOH-72554 to DOH-72555, See DOH-72555, paragraph 2.3.10

376. The RQIA at paragraph 2.3.9 of the Phase II report in a section entitled ‘Patient Information and Feedback’ found that patients received folders containing leaflets of information regarding their diagnoses and treatment plan. This is a welcome development but ought not to be seen as a substitute for a mandated letter to patients.

377. The RQIA report outlined how the Trust now obtains feedback from patients. It noted that patients and families have had the opportunity to provide feedback through Care Opinion on the care provided at the Thorndale Unit and was pleased to note that each of the stories submitted to Care Opinion had received a customised response from the Trust.

378. The RQIA recommendation 11 of the August 2024 report which states that:

> “The Trust should employ a wider range of methods for proactively listening to/gathering patient views and provide examples of how it meets its statutory obligations to involve patients in key decisions about improvement and development of services”[342]

is supported by this Inquiry. The Inquiry considers that greater patient involvement is crucial to the improvement of services, however we consider this requires a regional approach, so that all patients in Northern Ireland are on an equal footing.

379. In conclusion, the Inquiry thanks again those patients and family members who engaged with our work. Their testimony was both powerful and poignant. It clearly demonstrated the impact of failings in care and showed us explicitly the patient perspective regarding the failure of systems to ensure patient safety. Patients and their families were disappointed and surprised that robust systems to safeguard standards of care for patients appeared not to be in place. Equally, they noted the failure to enforce agreed standards of care. Their voices are a compelling reminder that listening to the patient voice must not be tokenistic.

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[342] DOH-72556, paragraph 3

380. The evidence presented demonstrated how listening to patients can give rise to meaningful learning about quality. The Inquiry is of the view that patients must be involved in the planning of services and the continuous improvement in standards which is part of modern healthcare. Unless the involvement of patients becomes more embedded in the way systems operate, then it is likely that change may continue to be inadequate.

381. The Inquiry considers that there is merit in supporting particularly vulnerable groups. Further work is needed to accurately define such groups and to support the best kind of advocacy for them and identify more generally when advocacy is required. The provision of an advocacy service would assist patients and their families to highlight system failures and to raise challenging questions. Such an advocacy service must be empowered to hold systems to account for failure to act. Without this, it is unlikely that we will see an end to the failure to act on recommendations from inquiries at all levels. In the words of one of the patient's relatives who spoke to us:

> "We are people, we are real families and we need a voice."[343]

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[343] Patient 5's daughter: TRA-01906, lines 22-23