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Immunotherapy toxicity service at the Royal Free London NHS Foundation Trust

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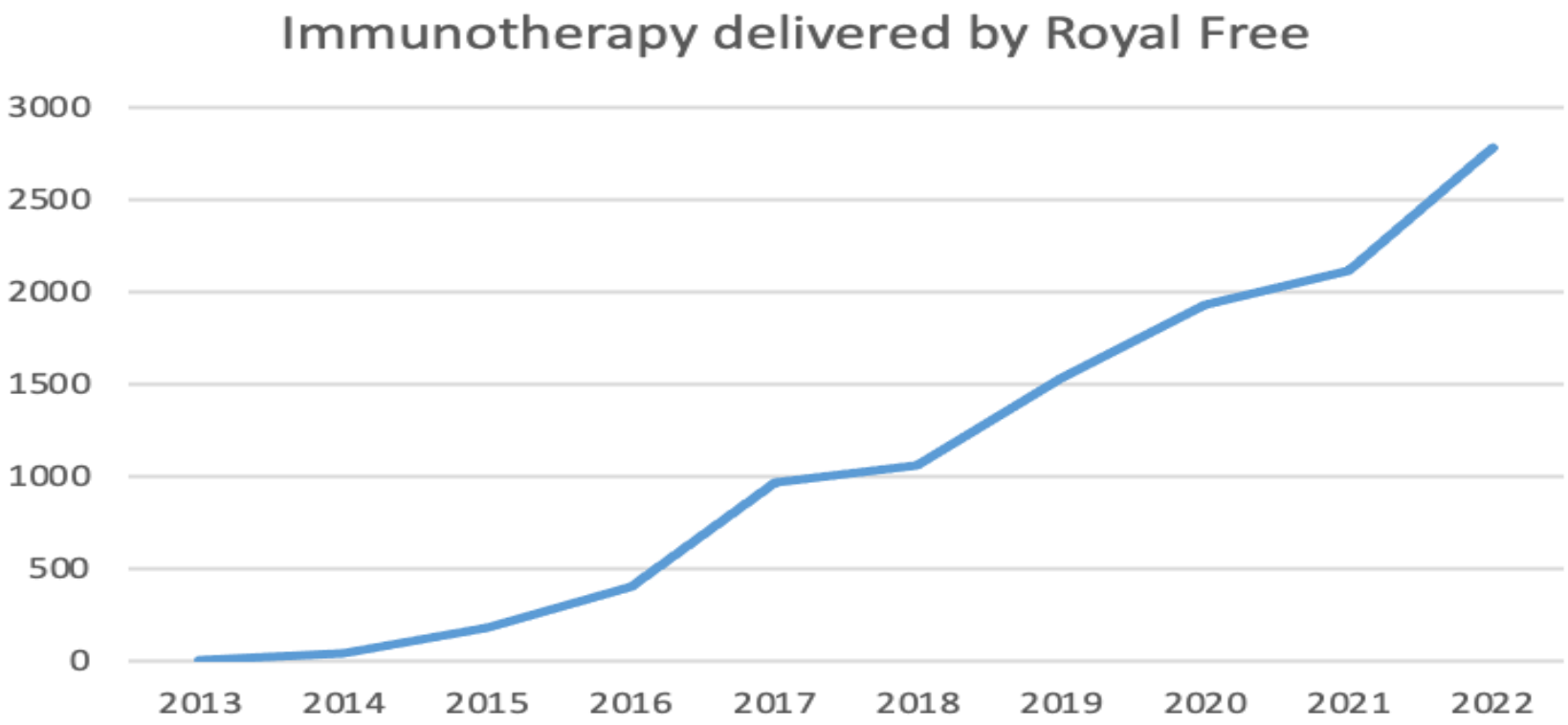
Why did we need a service?

What is the scale of the issue ?
Where are the main pinch points?
What resources are we currently using?
What can I implement easily?
What reorganisation can we do?
What do I need to achieve a ‘service’?
How do we balance cost and demand?
What outcomes can we achieve?

Immunotherapy (RFL 2019-2022)



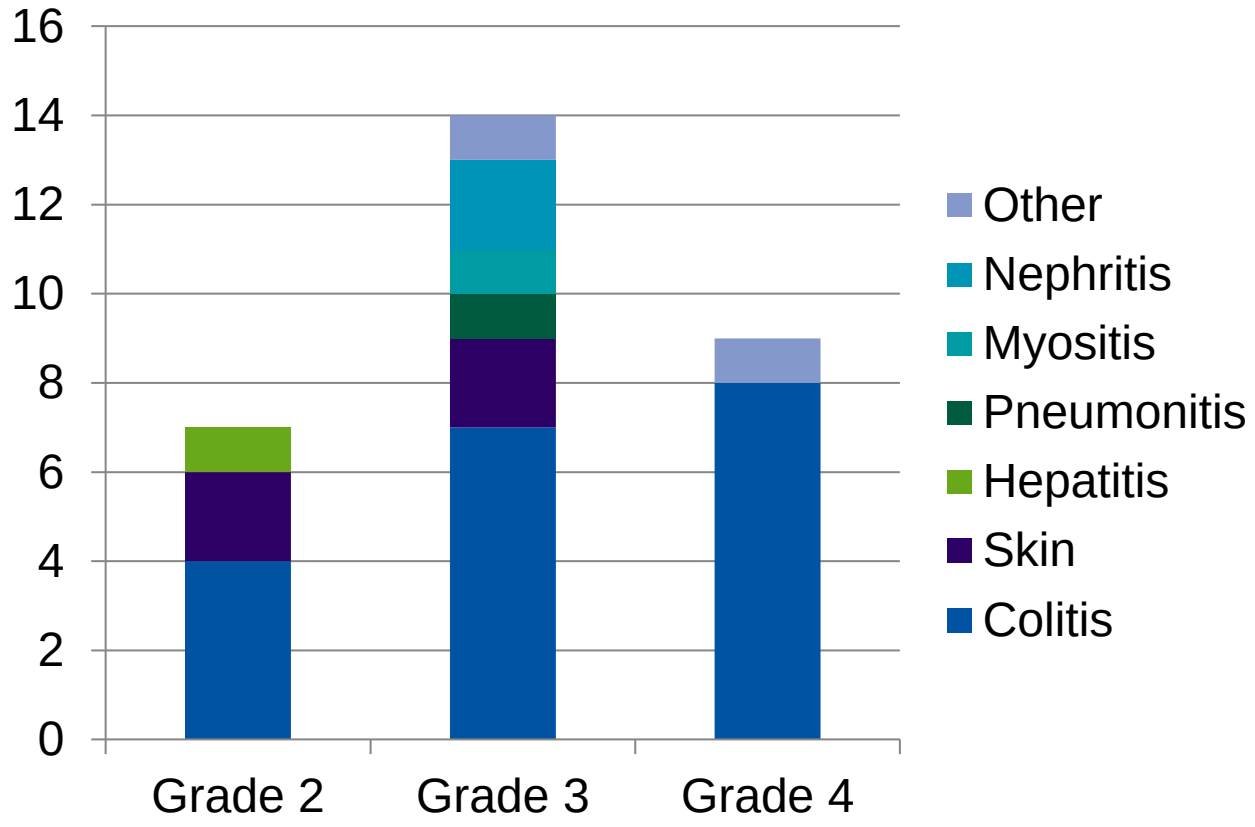
Local toxicity data - inpatients

2019 Royal Free only

Total 811 admissions under oncology

Of which 56 patients on immunotherapy

26 of which were admitted due to immunotherapy toxicity



Patient focused interviews – feedback

- *Generally very positive about experience and clinical teams.*
- *Criticism of the way pre- immunotherapy talks were delivered, impersonal and without time to ask questions and not all patients felt fully prepared for all side effects.*
- *“I didn’t report the symptom because I assumed it was normal, I was walking with a stick before I called them”*
- *Theme of feeling when treatment finishes patients have a lot of uncertainty about follow up and fear of abandonment.*
- *Everything was going really well and suddenly I’ve got 15 tablets to take and my treatments been stopped*
- *Feels like this is an experimental drug that no one has seen before*

Challenges within immunotherapy

- Novel therapy in many areas
- Timing of adverse events
- Multiple side effects together
- Training for all health care professionals – primary care, A&E, ward staff
- Patient information
- Speed of change in practice
- Length and advocacy of treatment duration
- Survivorship and long term effects

Macmillan lead nurse role

Macmillan pump primed role for 2 years with specific objectives;

1. Better clinical practice and pathways are introduced
2. Clinical support is well coordinated across the treatment pathway
3. Dedicated CNS support and specialist management of complex pathways
4. Patients are carers get answers when they need them and are well informed

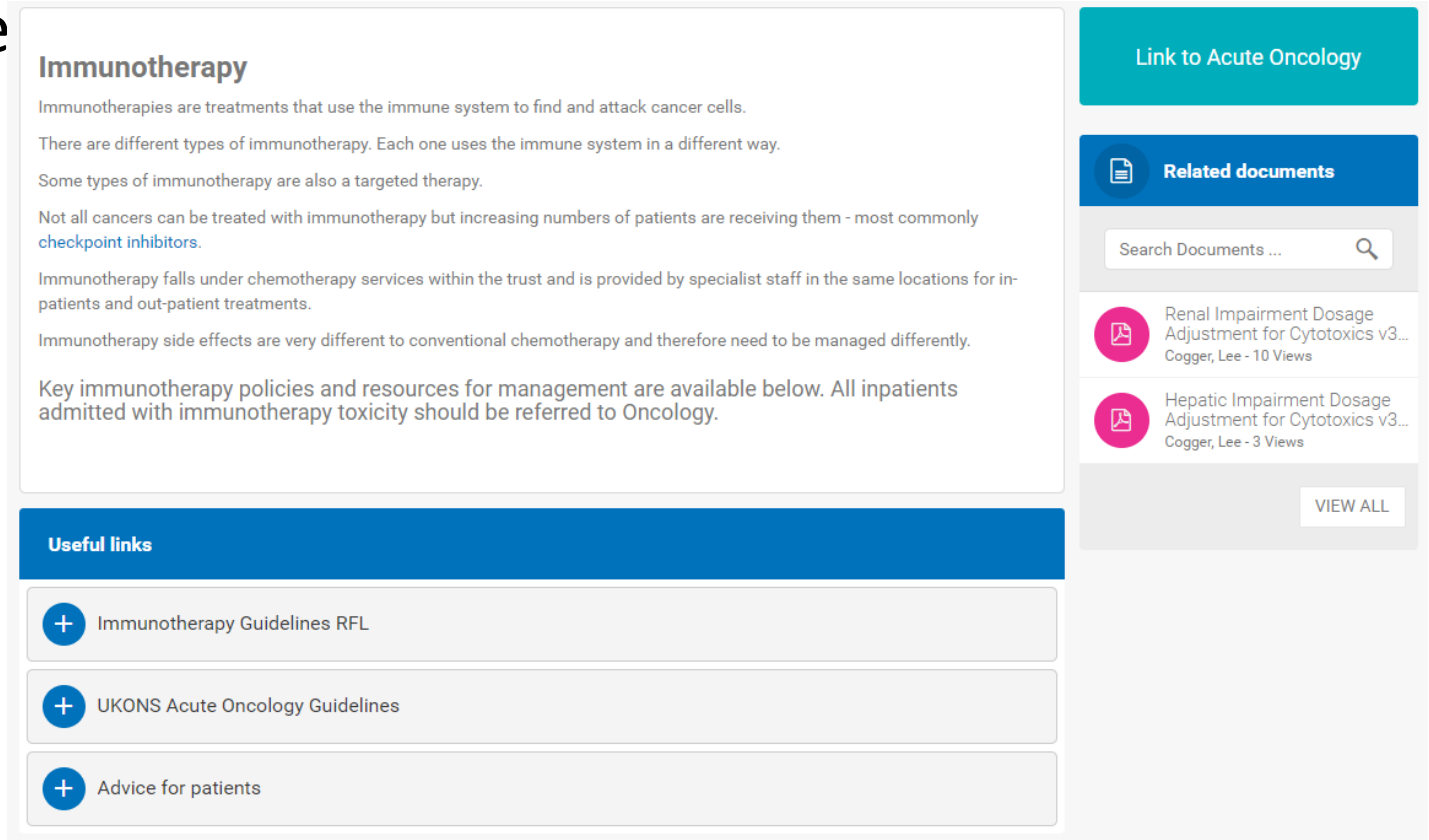
- Improvement in pathways
  - management of toxicity
  - reduce time to diagnostics
  - reduce the need for inpatient care
- Nurse prescribing
- Audit
- Patient information
- Staff education

Staff education/ information

Regular training for all health care professionals

Doctors inductions

Bi annual study days



Patient information

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Preparing for your cancer immunotherapy treatment

Information for patients

This leaflet answers common questions about how to prepare and what to expect from your immunotherapy treatment. If you would like further information, or have any particular worries, please do not hesitate to ask your nurse or doctor.

In all cases, a doctor can explain the treatment to you and answer any questions you may have.

How does immunotherapy work?
Immunotherapy enables the immune system to recognise, target, and eliminate cancer cells, wherever they are in the body. Immunotherapy works differently to chemotherapy. It can sometimes take longer to see results so the cancer may appear to get worse before it gets better.

The side effects are different to traditional chemotherapy. Chemotherapy aims to kill cancer cells but also kills the body's 'good' cells. The main side effect with chemotherapy is the risk of infection due to a depleted immune system; this is not the case with immunotherapy.

What are T lymphocytes (T cells) and checkpoint inhibitors?
Our immune system protects us from disease, killing bacteria and viruses. It can also identify and kill cancer cells. One main type of immune cell that does this is called T lymphocytes or T cells. Immunotherapy activates T cells to recognise cancer cells.

Checkpoint inhibitors are a group of immunotherapy drugs which block checkpoint proteins on a type of white blood cell called a lymphocyte. Lymphocytes are an important part of the immune system. When they are active, lymphocytes can attack another cell, such as a cancer cell. But if they receive a certain signal from the other cell, they switch off (become inactive) and do not attack it.

Checkpoint inhibitors also block the signals that switch off lymphocytes. They do this by attaching to either the cancer cell or the lymphocyte. This means the lymphocyte stays active and can attack the cancer cell.

Who will administer my treatment?
Your treatment will be given by members of the of the nursing team who are trained to administer anti-cancer treatment.

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IMMUNOTHERAPY ALERT CARD
24 HOUR URGENT ADVICE LINE
Call 02077940500
and ask for bleep 2237

bowel (this is called colitis) or hormone imbalances related to your thyroid, adrenal or pituitary glands. Immunotherapy can, however, affect any organ of the body.

Steroids work by suppressing the immune system to stop it from attacking your good cells and hopefully improve your symptoms from any side effects.

How long will I have to take steroids?
Everyone is different and each person's body responds differently. You will be monitored closely when you are on steroids to check they are working to reduce your symptoms.

Stopping taking steroids
You should not reduce your steroid dose or stop taking steroids abruptly without advice from your doctor or specialist nurse.

If you have been taking steroids for more than a few days, the dose should be gradually reduced. Stopping too quickly or suddenly can give you problems with your adrenal glands, which make important hormones for the day-to-day function of your body. This is known as 'adrenal insufficiency' and can be dangerous to your health.

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Toxicity clinic

Weekly - Wednesday afternoon

Lead Immunotherapy Nurse clinic alongside Consultant Oncologist clinic

To see patients with new or ongoing toxicity, follow up post discharge, refer to specialties, and feedback to teams and GP

Regular contact for patients off treatment with toxicity

Last 6 months data…

- 281 patients
- Lung, Melanoma, CRC, Upper GI, RCC, Breast
- Colitis, hepatitis, neurological issues, hypophysitis, nephritis, pneumonitis, rheumatoid issues, steroid weaning monitoring and complications of steroids

Immunotherapy Toxicity MDT

- Set up in May 2021 as a pilot
- A fortnightly e-MDT for the discussion of complex immunotherapy toxicity and for all inpatients admitted as a result of toxicity from immunotherapy
- The MDT is supported by the specialist clinicians and led by the Lead nurse for Immunotherapy and a consultant medical oncologist
- Generally between 3-6 cases each MDT, ~170 patients discussed to date

UK Chemotherapy Board

Good Practice Guideline for Immuno-Oncology Medicines

About the UK Chemotherapy Board

The UK Chemotherapy Board provides guidance, oversight and support for the continuing development of chemotherapy services in the UK. Its core membership comprises representatives of The Royal College of Radiologists (RCR), the Royal College of Physicians (RCP), the Association of Cancer Physicians (ACP), the Royal College of Pathologists (RCPath), the British Oncology Pharmacy Association (BOPA) and the UK Oncology Nursing Society (UKONS). The Board also has representation from the four UK nations and from other organisations closely involved in chemotherapy services, including the NHS England Chemotherapy Clinical Reference Group and the Chemotherapy Clinical Information Group of Public Health England (PHE).

Summary

This guidance has been produced by the UK Chemotherapy Board in response to concerns that patients may not be correctly triaged when presenting with serious side effects from immuno-oncology medicines to staff who are unfamiliar with the management of these adverse events. This guidance concerns the systems for ensuring patients are managed safely; it is *not* a clinical protocol for the management of immune-related adverse events.

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Why is an MDT needed?

- Increasing numbers of patients on immune checkpoint inhibitors, therefore increasing numbers with complications
- Complexity of immunotherapy related toxicity
- Reliable expert opinion
- Audit/ disseminate learning from the management of patients with toxicity
- Provides support of nurse led model for Immunotherapy Toxicity Clinic

The MDT

Medical Oncologist – Trust immunotherapy lead

Oncology pharmacist

Immunotherapy specialist nurse

Oncology dietician

Neurologist with specialist interest at Queens Sq Hospital

Dermatologist with dedicated IO toxicity clinic within RFH

Endocrinologist within Royal Free

Respiratory consultant

Hepatologist with dedicated IO toxicity clinic within RFH

Gastroenterologist with specialist interest within RFH

Cardio-oncologist at Barts Hospital

Nephrologist with specialist interest within RFH

Rheumatology

Neurological
- Periph… ne…
- G… s…
- M… lik…
- Hyp…
- Headache

Lungs
- Pneum…

Gastrointes…
- Colitis
- Enterocolitis
- …erforation

Musculoskeletal
- Arthritis
- Myopathies (including…

Endocrinopathies
- Pituitary
  - hypophysitis
  - corticotropin… …crease
  - seconda… …cy
- Thyroid
  - hypo…
  - hyp…
- Pancre…
  - diab…
- Adrenal
  - primary
- Gonads
  - secondary hypogonadism (primary gonadism is also a possibility)

Rare
- Myocarditis
- Epididymitis
- Cytokine releas… …matological …

Skin
- Maculopapular rash
- Erythema multiforme
- Psoriasis
- Stevens-Johnson syndrome
- Vitiligo
- Alopecia

Liver
- Hepatitis

Pancreas
- Pancreatitis

Renal
- …ding

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Future plans

- Network MDT
- Late effects/ lasting effects clinic
- Cardiac screening pilot
- Support group/ tailored survivorship group
- Working with primary care
- Care at home

Outcomes

- Cancer patient experience survey 2022 – information prior to starting immunotherapy improved from 77% to 89% (above national average)
- Improved safe steroid prescribing and monitoring – repeated audit
- Nurse led outpatient management of toxicity – consultant questionnaire reported increased confidence in early discharge due to this resource
- Increase in numbers of patients whose care is managed with specialist input

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Questions?

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