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teapot TRUST
Bringing colour to young lives

Art therapy to facilitate interaction among children with cystic fibrosis.

C. Fagan, A. Sewell,.
Great North Children's Hospital, Newcastle Upon Tyne, UK

Children with cystic fibrosis (CF) cannot meet each other in person and so miss out on the peer support young people with other chronic conditions are able to enjoy. The paediatric CF team at the Great North Children's Hospital have been working with the Teapot Trust to provide virtual group art therapy sessions for some of our young patients.

AIM
To provide children with CF the opportunity to meet and interact virtually with other children with CF and provide a fun, supportive environment in which they can express their feelings.

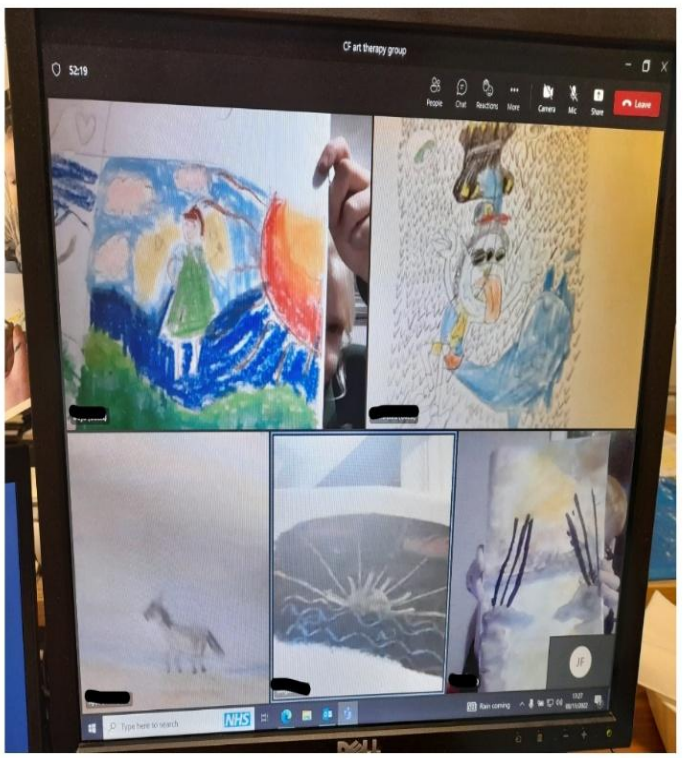
Method

Working together with the Teapot trust we have been able to provide group art therapy sessions for some of our young patients. The Teapot trust is a charity providing art therapy and creative wellbeing interventions for children with chronic or long-term conditions.

Three eight-week courses have run so far, with 9 CF patients between the ages of 5-11 years participating. The children meet weekly for 1 hour via Microsoft teams with an art therapist. All art materials they need are sent to the patients' homes beforehand.

During the sessions which are led by an art therapist, children are encouraged to express and explore thoughts and feelings that can be hard to put into words. They are supported to build resilience and develop positive coping strategies.

At the end of the 8-week course each participant receives a teddy bear wearing a t-shirt with one of their drawings on.



RESULTS
The programme was well received by all the families involved, with the 4 children who benefited most taking the opportunity to complete a second course for those closer in age.

Conclusion

It has been an amazing way to help children with CF interact with each other, as well as a platform for them to talk about worries and fears such as needle phobia.

Making and sharing art as part of a group helps children experience peer support, a sense of community and connection to others, as well as building resilience and confidence through group interactions.

THE great north CHILDREN'S HOSPITAL

Aortovascular specialist nurse

AORTIC SURVEILLANCE PROGRAM - FREEMAN HOSPITAL

SCOPE:

- FOR PATIENTS WITH THORACIC AORTIC DILATION REQUIRING SURVEILLANCE AND/OR SURGICAL INTERVENTION.
- ALSO, FOR PATIENTS REQUIRING ONGOING SURVEILLANCE POST AORTIC DISSECTION.

RATIONALE:

- MULTIPLE NHS STRATEGIES RECOGNISE THE NEED FOR CHANGE IN THE NHS; NHS LONG TERM PLAN, PEOPLE PLAN, NHS LONG TERM WORKFORCE PLAN. THIS INCLUDES DEVELOPING ADVANCED PRACTICE ROLES TO ADDRESS THE COMPLEX NEEDS OF PATIENTS.
- THE AORTIC SERVICE CONDUCT FOLLOW-UP APPOINTMENTS, BOTH FACE-TO-FACE AND VIA TELEPHONE, AND PROVIDE CONTINUOUS CARE AND MONITOR PATIENT PROGRESS. THERE WILL BE A FOCUS ON ENSURING ANNUAL SCANS ARE CARRIED OUT, RESULTS ARE COMMUNICATED PROMPTLY, AND ANY NECESSARY FOLLOW-UP ACTIONS ARE TAKEN. THIS HAS THE POTENTIAL TO SUPPORT A REDUCTION IN SERVICE COMPLAINTS /ADVERSE EVENTS AND REDUCTION OF RISK DUE TO EARLY INTERVENTION AND TREATMENT.
- THE AORTIC SERVICE WILL ALSO WORK CLOSELY WITH GPS AND COMMUNITY SERVICES TO ENSURE A HIGH LEVEL OF ONGOING CARE OUTSIDE OF THE HOSPITAL ENVIRONMENT.

ROLE/RESPONSIBILITIES OF AORTOVASCULAR NURSE SPECIALIST:

- IN LINE WITH THE 2024 ESC GUIDELINES FOR THE MANAGEMENT OF PERIPHERAL ARTERIAL AND AORTIC DISEASES THE NURSE FOCUSES ON PROVIDING GUIDANCE TO PREVENT FURTHER COMPLICATIONS THROUGH PROPOSED LIFESTYLE CHANGES AND/OT SECONDARY PREVENTION STRATEGIES.
- WORKING CLOSELY ALONGSIDE THE AORTIC CARDIOTHORACIC CONSULTANT DEVELOPING A PATHWAY FOR PATIENTS WITH AORTIC DISEASE. INCLUDING SETTING UP AND MAINTAINING A NURSE LED SURVEILLANCE SERVICE FOR MONITORING PATIENTS.
- PARTICIPATE IN THE POST-ACUTE AORTIC DISSECTION AND THORACOABDOMINAL CLINICS ALONGSIDE THE AORTIC CARDIOTHORACIC CONSULTANT.
- PROVIDE SUPPORT AND GUIDANCE TO PATIENTS WITHIN THE AORTIC PROGRAMME. PROVIDE SUPPORT AND GUIDANCE FOR STAFF CARING FOR PATIENTS WITHIN THE AORTIC SERVICE ALONGSIDE THE CLINICAL EDUCATORS.
- ALONGSIDE THE AORTIC CARDIOTHORACIC CONSULTANT DEVELOP AND REVIEW CLINICAL PROTOCOLS AND GUIDELINES TO PROVIDE CLINICALLY EFFECTIVE EVIDENCE-BASED PRACTICE FOR PATIENTS WITHIN THE AORTIC SERVICE.
- PROVIDE GUIDANCE AND CLINICAL EXPERTISE THE SUPPORT THE MDT IN THE MANAGEMENT OF PATIENTS WITH COMPLEX AORTIC CONDITIONS.
- PARTICIPATE IN AUDIT AND RESEARCH TO ENSURE CLINICALLY EFFECTIVE EVIDENCE-BASED PRACTICE.
- PARTICIPATE IN DATA COLLECTION TO THE MAJOR AORTIC DATABASE, INCLUDING AORTIC DISSECTIONS.
- PARTICIPATE IN THE WEEKLY ARRA MDT MEETINGS SHOWING A PROACTIVE INVOLVEMENT IN THE REFERRING PROCESS, OUTCOMES, AND ADMINISTRATION/PREPARATION.
- WORK ALONGSIDE THE NATIONAL TESTING CRITERIA FOR RARE AND INHERITED DISEASES/ GENETIC SERVICE TO IDENTIFY PATIENTS REQUIRING GENETIC SCREENING HELPING TO SAFEGUARD PATIENTS AND THEIR FAMILIES.

DATA:

-APPROX 100 PATIENTS IN THE LAST 18 MONTHS POST DISSECTION ADDED TO PROGRAMME FOR ONGOING SURVEILLANCE

-450 PATIENTS ADDED TO PROGRAMME SINCE NOVEMBER 2023

-3 AORTIC CLINICS PER FORTNIGHT

-10 TELEPHONE AND 5 FACE TO FACE APPOINTMENTS PER CLINIC CAN BE OFFERED

-1 NURSE SPECIALIST WORKING 18.75 HOURS PER WEEK ALONGSIDE 1 AORTIC CONSULTANT

-10 PATIENTS DISCUSSED ON WEEKLY BASIS AT AORTIC REVIEW MEETING - LED BY AORTIC CONSULTANT

-10 HIGH RISK/POTENTIAL SURGICAL CANDIDATES DISCUSSED FORTNIGHTLY AT AORTIC MDT (ARRA)

Aortic referral form

Our Main Goals include:

Teamwork

Improved outcomes

Patient focused care

HOW DO I LEARN MORE?

FOR FURTHER INFOMRATION PLEASE VISIT THE ONLINE EDUCATIONAL PLATFORM BELOW - THIS IS THE GO-TO RESOURCE FOR HEALTHCARE PROFESSIONALS INTERESTED IN EXPANDING THEIR KNOWLEDGE AND SKILLS IN THIS CRUCIAL AREA

HTTPS://AORTICDISSECTIONCHARITABLETRUST.ORG/

WHAT IF I HAVE A CLINICAL QUERY IN PRACTICE?

FOR NON - URGENT AORTIC SURGERY QUERIES WITHIN THE ORGANISATION AND TO GET AN AORTIC REFERRAL FORM AS ABOVE EMAIL NUTH.NTAS@NHS.NET

THIS MAILBOX IS FOR NON- URGENT REFERRALS ONLY AND IS NOT MONITORED 24/7.

ALTERNATIVELY, FOR ANY URGENT REFERRALS AND/OR ADVICE PLEASE CONTACT THE CARDIOTHORACIC REGISTRAR ON CALL VIA THE NEWCASTLE HOSPITALS SWITCHBOARD. PHONE: 0191 233 6161

Why is the current first year of care pathway not enabling children and young people that are newly diagnosed with Type 1 Diabetes to achieve the target HbA1c of 48mmols/mol

Carly Blagojevic, Paediatric Diabetes Specialist Nurse
December, 2024

QR code to full article

Background

The National Institute for Clinical Excellence (NICE) guideline NG18 for children and young people (CYP) with Type 1 Diabetes (T1D), recommendation 1.2.76 states thats CYP with T1D should aim for a target HbA1c of 48 mmols/mol or lower to minimise the risk of long-term complications (NICE,2023).

Evidence from the Diabetes Control and Complications Trial (DCCT) found that if patients with T1D keep their blood glucose as close to normal as early as possible after diagnosis, this greatly lowers their risk of developing diabetes-related complications (DCCT, 1993).

CYP with a high HbA1c 3 to 15 months after diagnosis had poorer health outcomes in the long term, (Samuelsson et al, 2013).

The median HbA1c in this CYP diabetes clinic after the first year of care is 56 mmols/mol.

Aim

The principle objective of this service improvement proposal is to understand the current care pathway that exists within the first year following a diagnosis of T1D. This will inform the development of an improved, standardised pathway with the aim of meeting the target HbA1c of 48mmols/mol as recommended by NICE NG18

Methods

Process Mapping

A mixed methods approach was used to address the aim of the study.

- Qualitative data was obtained from a process mapping exercise with the multidisciplinary team, of the current first year of care pathway.
- Quantitative data was obtained from surveys of 21 parents/carers and of 6 of their children who were diagnosed between June 2022 and June 2023.

Conclusions

The process mapping and the surveys both identified that unwarranted and artificial variation in the current first year of care pathway for children and young people newly diagnosed with Type 1 Diabetes exists in 3 main aspects of care:

Access to Psychology

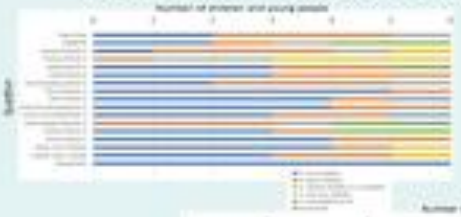
Timing of dietetic advice

Timing and content of advice given by MDT at diagnosis and during the first year

These key findings will inform the development of an improved, standardised, first year of care pathway.

Key Data Outcomes

Parents, carer's, children and young people were asked how helpful they found aspects of the pathway



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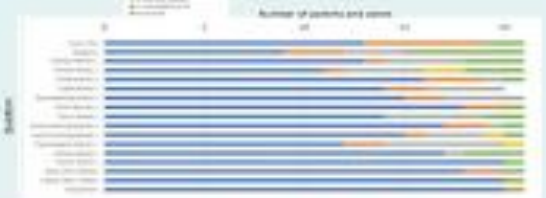
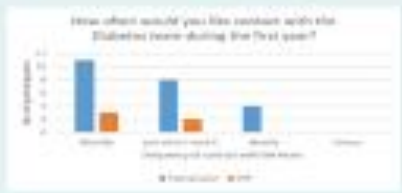
n = 21





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The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Electronic prescribing: A service improvement project

C. Fagan, A. Sewell.
Great North Children's Hospital, Newcastle upon Tyne, UK.

Background

Children with cystic fibrosis (CF) often require acute prescriptions in addition to their regular medications. Historically this has involved the CF team preparing a prescription request, faxing/emailing it to a general practitioner (GP), then the GP generating a community prescription for the patient.

The NHS no longer allows the use of fax and is aiming for paper free prescriptions in the future. The NHS electronic prescription service (EPS) allows prescribers to send prescriptions electronically to a pharmacy of the patients choice, making the prescribing and dispensing process more efficient and convenient for both patients and staff.

Aim:
To implement the NHS EPS currently used in primary care within the Cystic Fibrosis (CF) team, for patients assessed by the team either remotely or in the community. This allows acute prescriptions to be sent directly to a nominated community pharmacy, removing the need for the patient to travel to the hospital site or to involve a GP who has not seen the patient.

Method

The CF team at the great north children's hospital (GNCH) became part of a pilot of secondary care areas given access to EPS.

- CF Consultants and Nurse independent prescribers issued with smart cards and access rights required for EPS as part of a local service improvement project on secondary care prescribing.
- Appropriate training to use the system was given. SystmOne has been adapted for use locally.
- Children are assessed as requiring treatment and an appropriate prescription is generated electronically. This is then sent directly to the patient's nominated pharmacy.

Results

Approximately 30 acute prescriptions per month have been generated since the project began in October 2020. This has resulted in timely prescriptions at appropriate doses and preparations. Feedback from parents indicates a more seamless, responsive service reducing the need for travel to the hospital or interaction with their GP to obtain prescriptions.

Benefits of EPS:
- More efficient and convenient for patients and staff.
- Reduces paper.
- Safer, faster and more efficient.
- Patients don't have to visit their GP for a prescription.
- Patients won't have a paper prescription to lose.
- No need to post prescriptions, saving time and removing the risk of prescriptions getting lost in the post
- replacement prescriptions no longer need to be faxed
- less wastage as appropriate dose/preparation prescribed

Conclusion

The implementation of EPS has saved time for families and improved safety by ensuring the person assessing a child is generating the prescription. It also reduces GP workload as the prescription is issued directly from secondary care. Ongoing work is underway to procure and implement a more permanent system.

THE great north CHILDREN'S HOSPITAL

Nurse Specialists
Paediatric Forensic Service

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

The Children and Young People's Clinic (CYPC) cares for a range of children, including children with genital conditions, children who need forensic assessments and children where there are concerns about female genital mutilation (FGM).

We see children and young people with concerns about sexual abuse. If a child or young person has been sexually abused or sexually assaulted, either recently or in the past, it is essential they receive the care and support they need as quickly as possible. During their time with us, **our focus is on putting their needs first, listening to the voice of the child and working with them to promote their health needs.**

Paediatric Sexual Assault Referral Centre (SARC)

The Paediatric Sexual Assault Referral Centre (SARC) is based in the Children and Young People's Clinic at the Great North Children's Hospital. It provides a 24/7 service for the assessment of children and young people up to the age of 16 years (and sometimes beyond) who have experienced sexual assault or sexual abuse within the preceding 7 days. Children are referred by the Police or children's social care, or by other health professionals.

Referral pathway...

Hi... my name's Charlie. I'm going to tell you about my visit to the Children and Young People's Clinic

What children and young people tell us...

Feedback from our recent CQC inspection of SARC services

For 21 years, the team at CYPC have provided a first-class service for child victims through:

- collection of forensic samples which can provide vital DNA
- collection of physical forensic evidence which supports the Police and Crown Prosecution Service in successful prosecution of offenders
- Promoting health needs such as emergency contraception, investigation and treatment of sexually transmitted infections and post HIV exposure treatment.
- Onward referrals are also made for counselling.

The Paediatric Forensic Network (PFN) team ensures that the child/young person and their parents or carers are supported throughout their visit to the clinic and beyond .

'In general patient care and treatment, safeguarding, staff recruitment, auditing, staff support, record keeping, and governance systems were good. The current environment is limited due to ongoing building work; however, the team have made the best of it. The team demonstrated caring attitudes and put the patient at the centre of their work'.

The future of CYPC and the specialist nurse role...

- We are excited that, following building renovations, we will be moving to our newly refurbished, specialised Paediatric SARC in September 2025 (located on level 3 of the New Victoria Wing, RVI).
- From October 2025, all SARCs will be required to meet the ISO 15189 quality standard which sets the specific forensic requirements of dedicated services to provide high quality healthcare alongside forensic medical examination. Ongoing hard work continues across the CYPC team to support the application to attain ISO 15189:2022 accreditation.
- We continue to develop the specialist nurse role, including through completion of specialist training courses planned this year in forensic nursing and the reviewing of the development of our role as leaders in contraception and counselling within the service.

THE great north CHILDREN'S HOSPITAL

Can Lipid Clinic Patients Be Safely Discharged? A Retrospective Audit of Consecutive Patients Discharged fror the Newcastle Lipid Clinic in 2020

Muhammad Abbas*, Carol Ferriman, Misk Osman, Purba Banerjee, Fiona Jenkinson, Ahai Luvai.
Department of Chemical Pathology and Metabolic Medicine, Newcastle upon Tyne NHS Foundation Trust

Introduction

The Newcastle upon Tyne Hospitals NHS Foundation Trust Lipid Clinic annually receives more than 1,000 referrals compared to an established capacity for only 600 new patient appointments. As part of a quality improvement initiative aimed at efficient utilisation of constrained capacity, the clinic developed a robust discharge policy.

Methods

Patients who were treated to NICE recommended targets with well tolerated mono- or combination therapy were discharged to their GPs with a plan for annual structured review, blood test monitoring and criteria for re-referral.

A total of 293 patients were discharged in 2020. Electronic records held in the Great North Health Care Record, Cerner Millenium EPR and Sunquest ICE in 2021 – 2023 were interrogated for evidence of adherence to the discharge plan. Audit parameters included reasons for discharge, annual lipid measurements, ongoing lipid modifying therapy, failed discharge (re-referral within weeks) and other outcomes of interest.

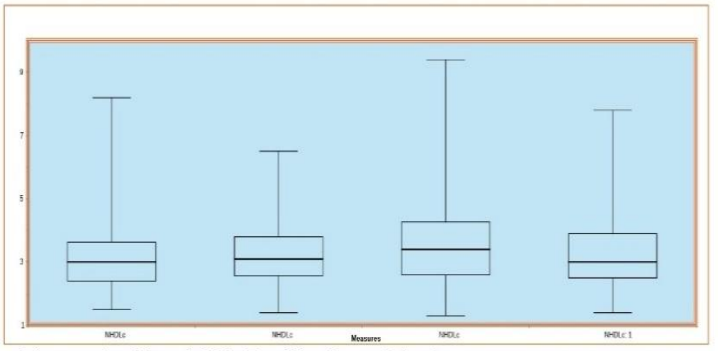


Figure 1 : Non HDL Profile Post Discharge

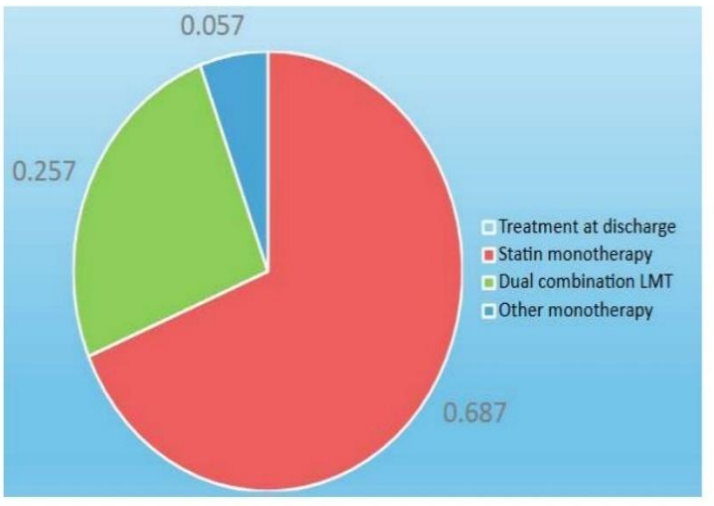


Figure 2: Treatment at Discharge

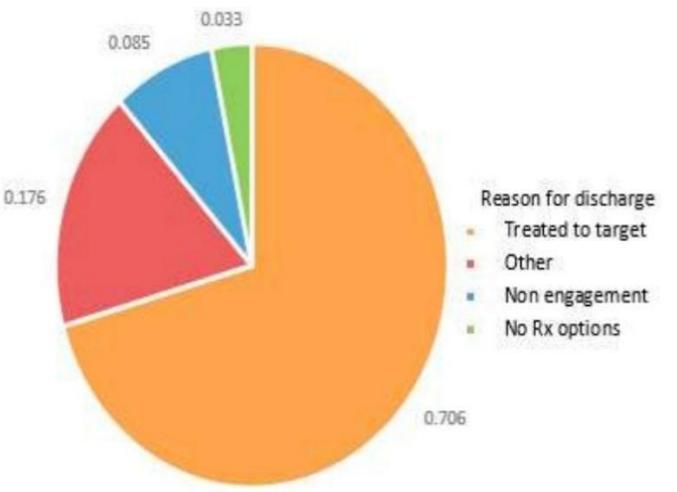


Figure 3: Reason for Discharge

Results

The main reason for discharge was treatment to target (70.6%), while non-engagement accounted for 17.6%. 68.7% were discharged on statin monotherapy with 25.7% on dual combination therapy. Most discharged patients had a clinic follow up duration of 2-5 years. Less than a quarter of patients did not have annual lipid measurements in each of the audited years. For those with lipid measurements, median total cholesterol, triglyceride and non-HDL cholesterol did not increase between 2021 and 2023. Only 14 patients (4.7%) had no evidence of ongoing lipid management. It was difficult to assess the reasons for patients not getting annual review however the reported level of follow up was achieved during the COVID pandemic years. Interestingly patients discharged for non engagement were subsequently followed up more frequently suggesting easier follow up in community.

Conclusion

Most lipid patients who are treated to target can safely continue follow up in primary care

Contact:Muhammad.abbas7@nhs.net

A new shot at HIV care: Establishing an injectable antiretroviral clinic

NHS
The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Background

Antiretrovirals are highly effective medicines which have transformed HIV into a manageable long-term condition. However, the lifelong need for daily oral medication can lead to challenges such as pill fatigue, adherence issues, and stigma for people living with HIV. The introduction of complete-regimen injectable antiretrovirals (iARV) marks a significant evolution in HIV care, but also presents challenges requiring a new multi-professional approach.

Clinic leadership

A joint nurse and pharmacist-led iARV clinic was established in 2023. This required:

- Establishing roles and responsibilities
- Referral and governance processes
- Ordering, storage and administration of drugs
- Data collection and audit
- Training – including non-standard site of administration
- Preparing patient information leaflets and resources
- Patient and staff engagement
- Establishing local interpretation of NHS England commissioning criteria i.e. what is 'patient need'?
- Scoping clinic and staff capacity
- Inclusive approach to patient selection and prioritisation

Clinical aspects

iARV is a complete two-drug regimen of cabotegravir (Vocabria®) and rilpivirine (Rekambys®) given by separate ventrogluteal IM injections at months 1, 2, and then every two months for life. It can be initiated with or without an oral lead-in phase. Patients must meet NHS England eligibility criteria and commit to ongoing appointments. The injection window is +/- 7days, with any delay beyond this increasing the risk of treatment failure and multi-drug treatment failure.

Eligibility criteria

- Viral suppression
- BMI <30 preferrable
- Previous resistance
- Genotyping
- Hepatitis B status
- Patient commitment
- Patient need

Research

The team has contributed to the following iARV research activity:

Multicentre service evaluation of injectable cabotegravir and rilpivirine delivery and outcomes across 12 UK clinics (SHARE LAI-net), HIV Medicine, 2024, 25 (10)

Cabotegravir and Rilpivirine Real World Experience (CORAL) - A non-interventional, mixed-methods, prospective cohort study

Patient education

Patient counselling regarding:

- Appointment schedule
- Personal commitment
- Oral lead-in pros/cons
- Side effects, analgesia
- Adverse drug reactions
- Bloods/monitoring
- Failure/resistance risk
- Drug interactions
- Safety-netting
- Future switch options
- Research activity

Patient experience

- 28 patients treated
- 26 initiated, 2 transfers in
- 2 transfers out, 1 failure, 1 RIP, 1 switch back to oral

"The injections have been liberating"

"It lets me just forget about it [HIV]"

"It makes life easier"

"It takes away the dread of taking tablets"

"I prefer better than taking tablets"

Patient demographics

Female / male	6 / 22
Heterosexual / MSM	11 / 17
Age <40 / ≥40	16 / 12
Ethnicity: 18 White, 8 Black, 1 Asian, 1 Other	

Challenges and the future

- Scoping demand and capacity
- Engaging with all patient groups
- Offering flexibility in appointments
- Improving equitable access
- Managing viral blips
- Less frequent injections

Abstract ID: 144
Lung Cancer Nursing UK Conference
19th -20th June 2025

How developing a post-diagnosis HNA nurse led clinic can enhance patient care

English, H., Harris, D. and Anderson, V.
Lung Cancer Nurse Specialists, RVI Hospital, Newcastle upon Tyne

Introduction

The holistic needs assessment (HNA) addresses the physical, psychological, social and practical concerns of cancer patients at key points in their cancer journey to address the patient's specific needs and goals (Macmillan, 2025). These are often not offered routinely. As a service improvement we wanted to increase the number of HNA's we offer and proactively (rather than reactively) offer additional post-diagnosis support. We set up a nurse led post diagnosis telephone clinic in which we complete the initial HNA and offer additional nursing support. This reduces the need to cover everything at the point of diagnosis. Patients receiving a cancer diagnosis struggle to absorb information provided - research suggests patients only remember 10% of what they are told. Early post diagnostic support is critical for patient well-being, treatment adherence and navigating the care system.

Aim

To evaluate the implementation of a nurse led telephone clinic incorporating a holistic needs assessment for patient is newly diagnosed with lung cancer.

Method

- Participants: patients diagnosed with lung cancer at RVI Hospital
- Intervention: telephone-based consultation with a lung cancer CNS within 1 week of diagnosis
- Tool used: Macmillan HNA template
- Data collection: patient reported concerns (emotional, physical, practical)
- Referral outcomes
- Patient's satisfaction survey

Results

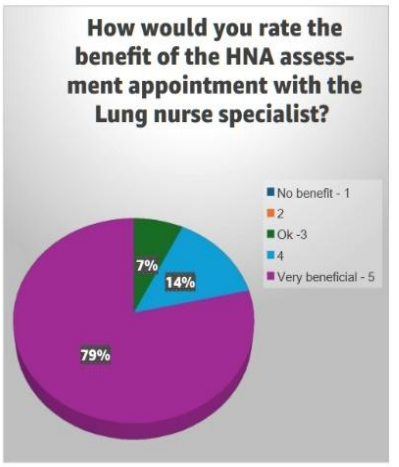
- Sample size 14
- Top reported concerns - Fatigue, breathlessness, anxiety/fear
- Referrals made - psychology, lung cancer outpatient therapy team, benefits and financial advice

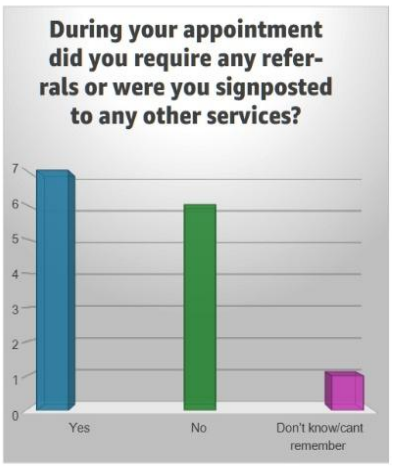
Discussion

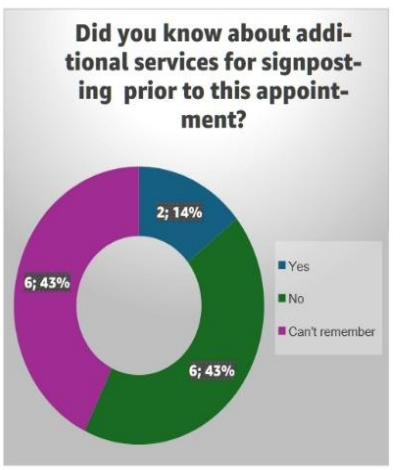
Nurse led telephone clinics offer timely support, reduce hospital foot fall and facilitate early identification of their needs. The HNA support structured, person-centred conversations that guide referrals and interventions. The early intervention enhances continuity of care and may reduce emotional distress during the early phase of diagnosis. A personalised care and Support Plan is created which can help patients' self manage, along with contact details of helpful organisations or services.

Conclusions and Implications for Practice

The implication of nurse led post diagnosis HNA telephone clinics is feasible, effective, and well received. There is strong potential for wider rule out across the lung cancer pathway. Future focus is on long term outcomes tracking, integration with electronic patient records.







Hayley just took the time to explain what I had tried to understand from all the booklets and leaflets i had been given and helped make sense of what was going to happen next.

I just felt like I have needed to speak to someone and having this call gave me that opportunity.

If I had any concerns, then this telephone call gave me the opportunity to speak to someone about them.

Is there something we did particularly well? Just the fact that someone is there and wants to help and support you when at times things are really tough.

100% having the support from David, he's been so helpful and supportive to us both, he doesn't just check up on my wife he's concerned about my wellbeing too which shows how much he goes above and beyond

Is there something we did particularly well? Having that named person for support and contact

Vicki was really helpful, she gave me her number and told me to contact her if I had any questions or was worried about anything, and when I was given the cancer diagnosis my head was all over the place so It was good to be able to talk through my concerns with a nurse.

I feel very overwhelmed and as if I have been bombarded with so much information and there is only so much you can read, and you just need someone to explain things to you. So I had a list of questions which we went through and I have a follow up call to address more of these in further detail.

During your appointment did you require any referrals or were you signposted to any other services? Maggies & Lung cancer support Group. I was sent their leaflet with my letter.

During your appointment did you require any referrals or were you signposted to any other services? Benefits advice & to smoking cessation - who contacted me the next day

Healthcare at its best with people at our heart

Providing advice and information to women with cystic fibrosis on their reproductive choices

S.Parker, A. Duffy, S.J. Bourke

Adult Cystic Fibrosis Centre, Royal Victoria Infirmary, Newcastle upon Tyne, UK

Introduction

•Pregnancy in wwCF should ideally be planned so that maternal health can be optimised, teratogenic drugs avoided, and genetic counselling considered.

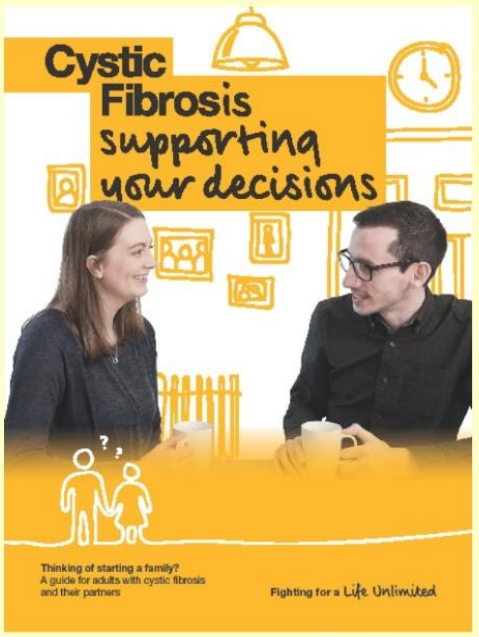
•We aimed to provide wwCF with detailed information and advice to inform their reproductive choices.

Methods

• On transitioning to our adult service wwCF are informed that they have near-normal fertility, that pregnancy is best planned, contraception needs to be considered and a partner can be tested for CF carrier status.

•As part of the annual review process, we introduced a nurse-led women's health consultation for all wwCF using a proforma about relationships, sexual activity, contraception, plans for pregnancy, HPV vaccination, cervical screening, and menopause, as appropriate to the stage of their life course.

•We present the data on pregnancy planning from these consultations.



Results

Contraception

•95 Women
•67 having heterosexual sex
•9 trying to achieve pregnancy
49 using contraception to avoid pregnancy
-24 long acting method (injection, implant)
-14 combined oral contraception
- 5 progesterone only pill
-11 condom contraception

9 (13%) did not want to become pregnant but not using contraception

Pregnancy

•35 pregnancies in 26 women

•12 (34%) were unplanned and partner had not had CF carrier testing before pregnancy

•3 underwent termination of pregnancy

•2 pregnancy by assisted reproduction with in-vitro

•7 miscarriage/early pregnancy loss

Summary

•Contraception use by wwcf is sub-optimal
•Many pregnancies are not planned
•Partners often had not had cf carrier testing

The women's health consultation facilitated discussion of options, risks and choices for pregnancy and family building.

Conclusion

•A yearly women's health consultation, focused on CF-related issues, ensures that the CF service has a formalised approach to providing wwCF with information and advice on their reproductive choices.

References

1.T. Kazmerski et al. Ped pulmonol 2022; 57:s75-88.

2. CF Trust UK. Cystic fibrosis supporting decisions.

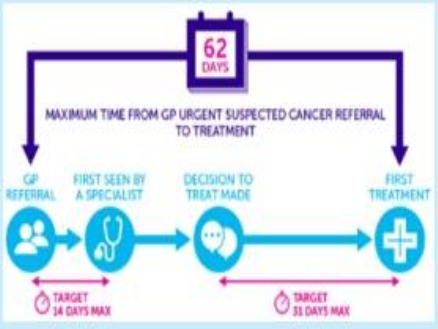
Suspected Cancer in Adults GI Symptoms (Fast track)

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

NHS Northern Cancer Alliance

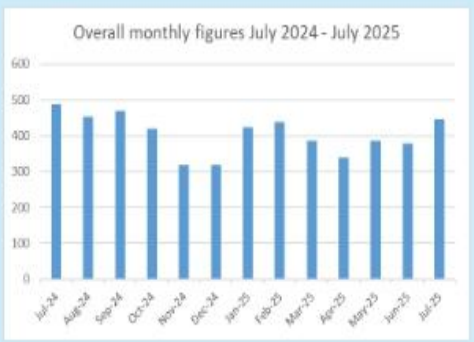
The 2 week wait team consists of 6 consultants, 6 CNS and 1 administrator. As of September 2024 the CNS team became responsible for the results and clinic capacity increased.

Referred via GP → Triaged by CNS → Sent direct to test for either Endoscopy or CT / Reviewed in clinic → Investigations requested if appropriate and if patient is fit enough → If not fit discharge back to GP → CNS acts on results, refer onto appropriate MDT's, discharge back to GP. All patients are notified of outcomes in writing



All referrals are triaged within 24-48 hours of receipt, first appointments are scheduled within 14 days, results/diagnosis are communicated within 28 days.

From July 2024-July 2025 we received a total of 5268 referrals, averaging over 400 per month



The CNS team carries out 6 nurse led clinics each week, we reviewed 1347 patients from July 2024 – July 2025

Recent data (July 2025) shows 3 patients breached (patient choice)

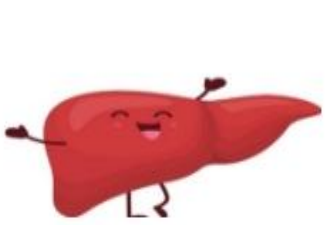
Get tested. Get treated. Get cured.

Get rid of Hep C campaign is funded by Gilead Sciences LTD November 2022

Viral Hepatitis MDT

Screen. Treat. Protect. Prevent.

ED BBV opt out pilot: Hepatitis C Campaign: Early Detection Pilot endorsed and funded by WHO, Gilead, UKHSA, NHSE



Ab e p24 iGg HIV

s HCV e

c Ag s Ag c

P24 iGg Ag HBV e

ED BBV The NHS England Prevention team, in partnership with NHS England's Hepatitis C Elimination Programme, initiated the ED BBV opt-out testing pilot. This program began in April 2022 - involves routine blood-borne virus (BBV) testing in ED for adults having blood tests, with an opt-out option.

Consent and opting out – common law, and endorsed by NHSE and UKHSA for public health protection

HCV Georgia, with a high prevalence of HCV infection, launched the world's first national hepatitis C elimination program in April 2015. A key strategy is the identification, treatment, and cure of the estimated 150,000 HCV-infected people living in the country.

EDP Pilot started 2023 to screen out liver disease and improve health outcomes.

Changes● Challenges● Monitoring in progress● Benefits●

NECODN National management of HCV infection providing Trust wide referral and nationwide surveillance and management of HCV through referral pathways across charities and primary and secondary Healthcare.

Liver Health for all

Track and trace, Charities, Nurses, Doctors, Audit, Data collection, Secretaries, Referral Co-ordinators, MDT

Cancer Clinical Nurse Specialist Workforce Project
Project Overview August 2025

Sarah Cleary, June Allen, Dawn Harper, Catherine Oakley

NHS Guy's and St Thomas' NHS Foundation Trust

Guy's Cancer Charity

Background:
- 2 year project funded by Guys Cancer Charity
- Workforce of almost 100 Cancer Clinical Nurse Specialists (CNS) across Guy's, St Thomas', The Royal Brompton and Harefield
- Specialisms include: Breast, Gastroenterology, Gynaecology, Haematology, Head and Neck, Lung, Skin and Urology

Project Overview:

Year 1 (from January 2025):
- Review Cancer CNS workforce across the Trust
- Identify gaps in the service and areas for improvement.

Year 2 (from January 2026):
- Implement and evaluate new ways of working.
- Workstreams: Core Roles, Workloads and Health & Wellbeing

Project Milestones (month completed):
- ✓ Project set up (January)
- ✓ Established Steering Group (February)
- ✓ Met with every Cancer CNS team (March)
- ✓ Map out current Cancer CNS Workforce (March)
- ✓ Established Patient & Carer Advisory Group (May)
- ✓ Cancer CNS Workforce Survey (July)

Cancer CNS Workforce Survey:
- Survey open for respondents between 6th June – 11th July
- 62 responses (2/3rds of total workforce)

Cancer CNS Workforce Survey Aims
- Collect baseline measures e.g. job satisfaction, stress and burnout levels
- Gain more in depth understanding of all the work Cancer CNSs do
- Gather ideas for improvements from the Cancer CNSs
- Understand what areas of Cancer CNS role are most in need of improvements

Job Satisfaction:
- Average rating of overall experience of working as a Cancer CNS: 3.84 out of 5 (3.84 Average Rating ★★★★☆)
- 58% look forward to going to work
- 69% are enthusiastic about their job

Stress and Burnout:
- 35% find their work emotionally exhausting
- 32% displayed signs of burnout using single item measure

Cancer CNS Workloads:

Activities Cancer CNSs feel they spend too much time on:
1. Coordinating appointments
2. Sending and responding to emails/messages
3. Emailing/messaging patients
4. Follow up actions for patient calls/emails
5. Preparation, follow up and admin for MDT/consultant clinics

- Cancer CNSs have high workloads that are difficult to define and measure
- The survey findings suggest Cancer CNSs spend too much time on administrative tasks
- Improving administrative processes may help reduce this workload for Cancer CNSs

Activities Cancer CNSs feel they don't spend enough time on:
1. Involvement & engagement in research
2. Developing education resources
3. Involvement & engagement in audits & quality improvement
4. Involvement & engagement in service development
5. Own professional development

- The 4 Pillars of Practice are: 1. Clinical, 2. Leadership & Management, 3. Education, 4. Research
- Cancer CNSs don't feel they spend enough time on research, education and management activities

Next Steps:
- ❑ Patient & Carer Survey
- ❑ Multidisciplinary Team (MDT) Survey
- ❑ Benchmarking against other Trusts
- ❑ Shadowing of Cancer CNS teams
- ❑ Process mapping
- ❑ Focus groups
- ❑ Literature review
- ❑ Develop a Cancer CNS demand & capacity tool
- ❑ Implement & Evaluate new ways of working using Plan, Do, Study, Act (PDSA) method & mapping to Aspirant Cancer Career and Education Development (ACCEND) Framework

Cancer CNS Engagement:
- Team engagement has been key to the success of the project
- The project lead has been meeting with the Cancer CNSs regularly
- A Cancer CNS Intranet Page and Monthly Bulletin have been created

References:

- Macmillan Cancer Support. (2017) Cancer workforce in England: A census of cancer, palliative and chemotherapy speciality nurses and support workers in England. Available at: https://www.macmillan.org.uk/_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotherapy-speciality-nurses-and-support-workers-2017_tcm9-325727.pdf [Accessed 11 August 2025].
- Health Education England. (2023) ACCEND Career Pathway, Core Cancer Capabilities and Education Framework. Available at: https://www.hee.nhs.uk/our-work/cancer-diagnostics/aspirant-cancer-career-education-development-programme/accend-framework [Accessed 11 August 2025].

Total Pancreatectomy and Islet Auto-Transplantation (TPIAT)

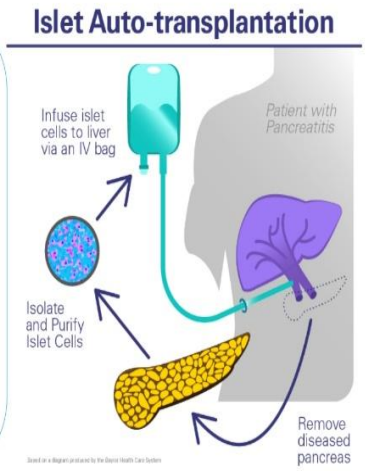
Vicki Applegarth – Type 3c, Islet/Pancreas Transplant DSN

What is TPIAT?

TPIAT (Total pancreatectomy and Islet auto-transplantation) is the removal of a whole pancreas with isolation of islet cells and then transplanted (infused) into the liver through the portal vein.

Indications

- Chronic pancreatitis
  - Hereditary
  - Alcohol (abstinent)
  - Idiopathic
  - With no pre-existing diabetes



Goals

- Improve quality of life
- Relieve severe pain
- Eliminate pancreatic cancer risk
- Prevent unpredictable blood glucose control
- Prevent severe hypoglycaemia and DKA risk

The DSN Role

- Part of the TPIAT MDT
- Support at regular clinic appointments
- Diabetes Education prior to surgery
- Support during inpatient stay
- Providing TPIAT education to other services and DSNs
- Support on discharge
- Initiating technology
- Organise and attend MTT
- Weekly/Bi-weekly follow up

TPIAT Diabetes Care Pathway

Pre-assessment
- Introductory consultation (consultant/ **DSN**)
- MTT
- Carb counting (dietician)
- Diabetes training **(DSN)**

Admission (TPIAT)
Daily review **DSN**/ Diabetes consultant
Libre start prior to discharge **DSN**

1-2 weeks after surgery
Phone joint appointment Diabetes/ carb counting (**DSN**/ consultant and dietician)

28 days
- MTT
- Diabetes review (consultant/ **DSN**)
- Dietician review?

3 months
Joint appointment Diabetes/ carb counting (**DSN**/consultant and dietician)
Discuss technology
3 month MTT

6 months
- MTT
- Diabetes review (consultant/ **DSN**)
- Dietician review?

12 months
Joint appointment Diabetes/ carb counting (**DSN**/ consultant and dietician)

What Patients Think – Anonymised Patient Outcomes

Thematic Analysis through Patient Questionnaires

- Importance of diabetes team support
- Implication in transition to home
- Reduced anxiety around condition
- Importance of understanding diabetes before surgery
- Positive effect of training before surgery

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

Ward 34- Transitional Care

What we have achieved so far...

Ward Opening

Transitional Care was offered as a specialist service on the postnatal ward. We have now opened our stand alone bespoke ward in April 2024

The team

We are a lovely team made up of Specialist Nurses, Midwives, Nursery nurses and Maternity Support workers.

Science behind the service

We now provide a 24 hour service for preterm babies and babies requiring extra monitoring. This service can be provided with mums staying with their babies, working alongside us as partners in their care and where possible reducing neonatal unit admissions.

Our Aim

Our ultimate goal is to keep mothers and their babies together with a specialist neonatal nurse on hand 24/7 to assess, analyse and deliver patient care.

What makes us proud?

Charity Support

The charity provide invaluable support to parents and their babies.

Triage System

We have a Triage number for community midwives to refer babies in who are jaundice or have significant weight loss that is manned by the specialist nurse.

We now have 24/7 support

Having specialist advice 24 hours a day, we hope that this will in hand improved patient outcomes.

Feedback so far

Feedback so far has been positive, with some feedback to say this has been an improved experience on ward 34.

Response to meningococcal vaccination and duration of protection in aHUS patients on Eculizumab

Christine Maville[1], Patrick Walsh[1], Ray Borrow[2], David Kavanagh[1] and Claire Turnbull[1]

National Renal Complement Therapeutics Centre, Newcastle upon Tyne, UK[1]
UK Health Security Agency Meningococcal Reference Unit,[2]

Introduction

- C5 inhibitors (C5i) Eculizumab and Ravulizumab have revolutionised the management of atypical haemolytic uraemic syndrome (aHUS).
- Pharmacological blockade of the terminal pathway of complement is a known risk factor for meningococcal infection.
- To mitigate risk, patients commenced on C5i are vaccinated against MenACWY and Men B and prescribed antibiotic prophylaxis.
- Response to vaccination is established ~ 6 weeks post initial or booster vaccination and annually thereafter for the duration of treatment.
- A booster is recommended if any titre is low.

Aims

- Measure the response rates of patients on C5i receiving ACWY vaccination and re-vaccination.
- Measure the minimum time patients exhibit protective titres by serotype.
- Seek to understand cases of meningococcal infection within patient group.

Methods

- 223 aHUS patients (non-transplant) received C5i between 2011 and Jan 2025.
- Combined number of years on treatment = 967
- Response to vaccination (A,C,W,Y) was measured at the UK Health Security Agency Meningococcal Reference Unit, and a titre ≥8 was considered in the protective range.
- There is no assay to assess response to vaccination against men B in individuals on C5i.
- Analysis of response to the A serotype titre ceased in 2022 as there were no cases in UK for > 20 years.
- Reviewed cases of meningococcal infection for those on C5i.

Results

Initial vaccine response

- There was a >85% response to initial MenACWY vaccination for all serotypes measured (Fig. 1)

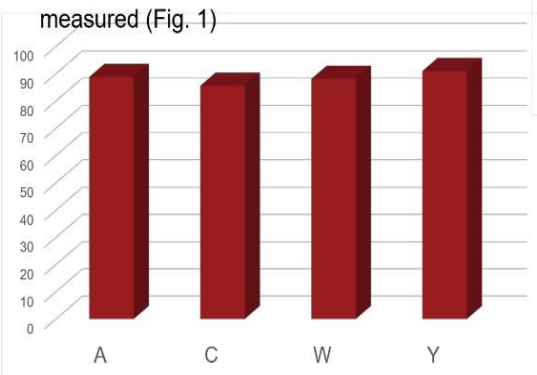


Figure 1 Percentage response to initial ACWY vaccination

Duration of initial vaccine response

- The mean combined duration of protective cover for all 4 serotypes is 12 months (Fig. 2)

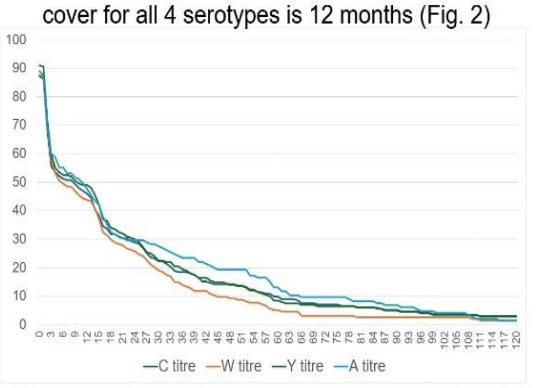


Figure 2 Minimum time covered with protective titre by serotype (initial vaccine)

- In ~30% of patients, titres wane to non-protective levels by 6 months (Fig. 2)
- There is minimal variation in duration of protection across serotypes (Fig. 2)

Re-vaccination response

- There was a >95% response to re-vaccination for all serotypes measured (Fig. 3)

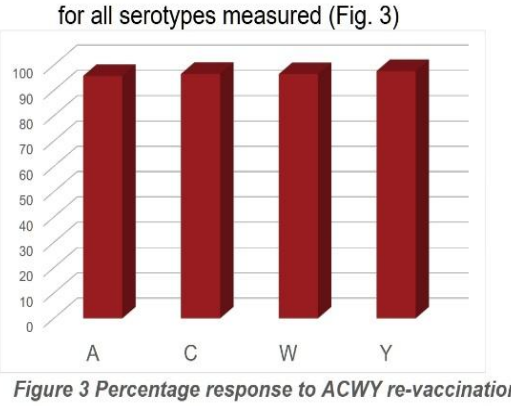


Figure 3 Percentage response to ACWY re-vaccination

Duration of re-vaccination response

- The mean combined duration of protective cover for serotypes C, W & Y is 14 months (Fig. 4)

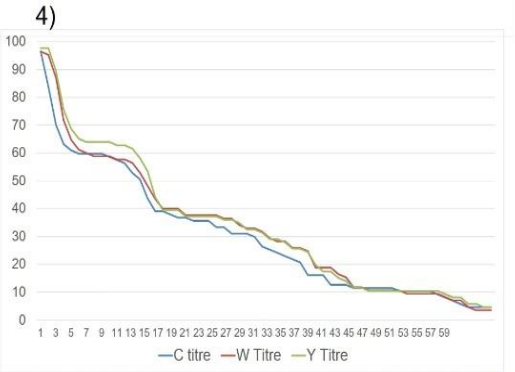


Figure 4 Minimum time covered with protective titre by serotype (re-vaccination)

- In ~35% of patients titres wane to non-protective levels by 6 months (Fig. 4)
- There is minimal variation in duration of protection across serotypes C, W & Y (Fig. 4)

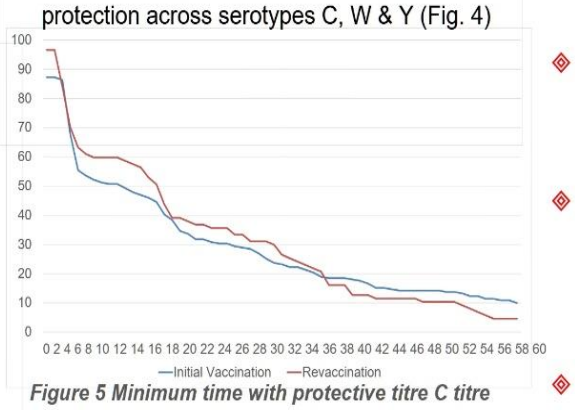


Figure 5 Minimum time with protective titre C titre (vaccination vs re-vaccination)

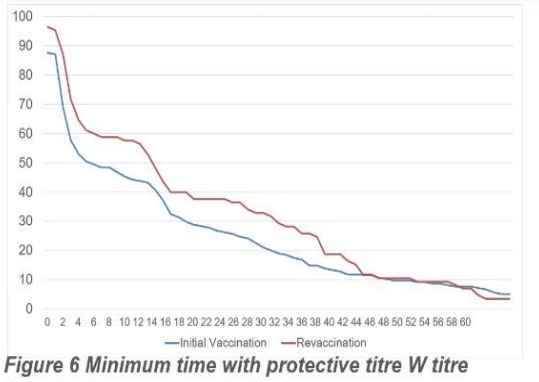


Figure 6 Minimum time with protective titre W titre (vaccination vs re-vaccination)

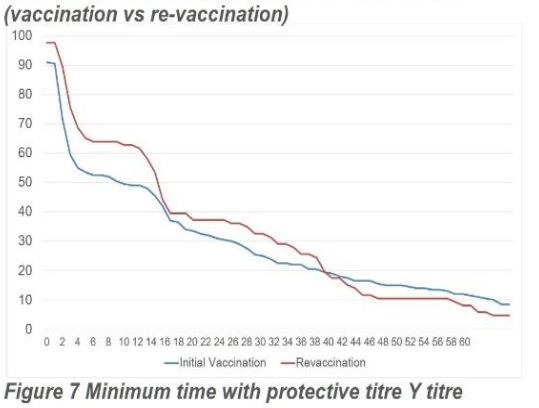


Figure 7 Minimum time with protective titre Y titre (vaccination vs re-vaccination)

- Duration of response is comparable across serotypes C, W & Y for initial vaccination and re-vaccination (Figs. 5, 6 & 7)

Meningococcal sepsis cases

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6
Age	25	20	22	18	19	3
ACWY vaccination	Yes	Yes	Yes	Yes	Yes	Yes
Bexsero (B) vaccination	No*	Yes	Yes	No*	Yes	Yes
Protective titres	No	Yes (low Y)	Yes	Yes	Yes	Yes
Antibiotic prophylaxis	No	Non-compliant	Penicillin	Non-compliant	Non-compliant	Penicillin
Serogroup	B	B	Non-groupable	Non-groupable	B	Non-groupable
Penicillin sensitive	Yes		No		Yes	Yes
Mortality / Morbidity	No	No	No	No	No	No

*Not routinely given at time started on C5i

Conclusions

- Good response rates to initial vaccination and re-vaccination.
- This cover falls off rapidly in ~ 30% of patients
- Duration of protective cover is comparable among all serotypes.
- Despite vaccination & prophylaxis the incidence of meningococcal sepsis was 620/100000 patient years (620x background rate).
- Cases of meningococcal infection predominantly affect young adults.
- In two thirds of cases, non-compliance to antibiotic prophylaxis was evident.
- Meningococcal cases support the need to give MenACWY vaccine as no confirmed ACWY serotypes identified.
- One patient still presented with a penicillin sensitive meningococcal infection despite adequate vaccination, titres and prophylactic antibiotic adherence.
- In the 6 cases of meningococcal sepsis, there was no mortality or morbidity.

Multidisciplinary Collaboration in the provision of Bespoke Cancer Placements for 3rd year Adult Student Nurses

Karen Christie, Julie Hopper, Rachel Orwin

Student nurses; Molly Frazer, Clare Booth, Ornita Islam, Courtney Leightell, Erica Mcluckie

Aims & Aspirations

- Tripartite collaboration between Nurse Specialist, Educator and Practice Placement Facilitator
- Students aspiring to develop in cancer care and engage with ACCEND framework
- Utilise experience capacity equitably across specialties and multi-disciplinary professionals

Project design & data collection

4-week bespoke cancer placement; 3rd year student nurses to apply via an expression of interest form; 5 students selected for 5 cancer specialties

- Week 1-Education day, referrals, screening, cancer pathways, role of Clinical Nurse Specialist & MDT
- Week2-Education day, diagnostics, results, roles of cancer alliance, Macmillan & personalised care team
- Week 3-Treatments, surgical and systemic, Acute Oncology service, Clinical research
- Week4- Palliative & End of Life Care, Hospice, education day and evaluation

Evaluation

Reasons for applying for Spoke

- Understand career pathways
- Understand patient pathways
- Develop knowledge & skills
- Aspiration
- 1st opportunity in cancer
- Add to CV

Highlight of placement

TIME with CNS, MDT, patients, specialist services

Observing difficult conversations

Supporting patients

Research opportunities

Ward 11 e-learning

Bobby Robson Unit

Inreach clinics, supporting patients

Meeting 4 Pillars of Practice

Ed days, clinical ed, SACT, ACCEND

CNS role, autonomy – self-directed learning

Challlenge's & Considerations

Student timetables - 'confusing at times' and restrictive – *consider* greater input from CNS in design

Too much learning offered at a critical 'work-heavy' time in students training – *consider* placements earlier in 3rd year

Recommendations

Develop guidance to replicate bespoke placements across specialties led by Clinical Educators + CNSs

Aim to increase learning capacity and enable CNS's to develop their Education Pillar of Practice

References:Aspirant Cancer Career & Education Development Programme, NHSE (2023). ACCEND Framework | NHS England | Workforce, training and education

The Implementation of '*Malignant Fungating Wounds Guidelines and Pathway*' and its evaluation

Introduction

Malignant Fungating Wounds occur when cancer cells have grown, breaking through the skin surface, invading the dermis and epidermis that creates a lesion, involving supporting blood vessels and other surrounding structures. These wounds are a complication of cancer and may develop in patients with advanced disease, which can be primary, secondary or recurrent malignant disease. These can also be caused by skin lesions, such as squamous cell carcinoma, malignant melanoma or basal cell carcinoma.

Objective

MFW Guidelines and Pathway was implemented following the impact of Covid-19 and the increase referrals. To obtain a better understanding of its success, an evaluation study was carried out to obtain health professionals' knowledge and most importantly, a better understanding of the patient experience.

Results

Malignant Fungating Wound Guidelines and Pathway' was implemented and disseminated to all relevant uses including internal and external user. Among the 243 health professionals contacted, 100 nurses participated in an evaluation questionnaire, the results of which demonstrated an increase in knowledge of 32%.
The 10 patients who were interviewed highlighted that exudate and malodour were their main issues of concern.

Discussion

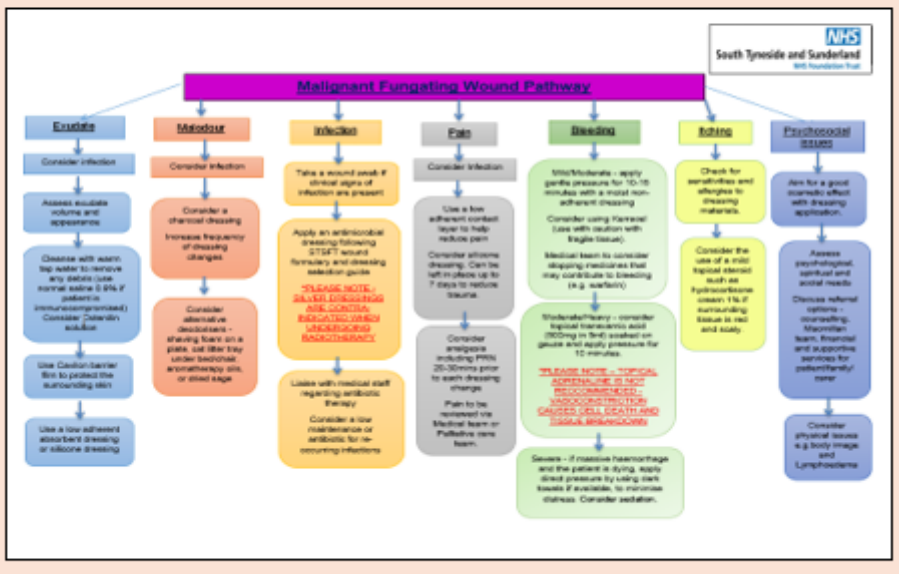
Quality of life is key, by actively listening, respecting individuals wishes but also gaining the patients' perspective viewpoint of their wound and the impact of their symptoms including odour has on their everyday life. We as health care can obtain a better understanding.

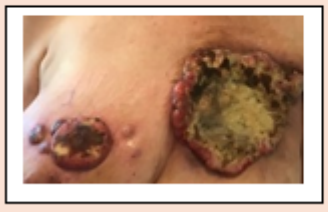
Conclusion

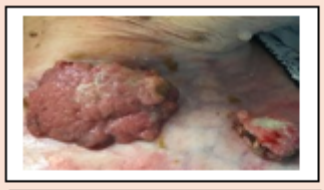
An MFW informational leaflet was created for patients and their caregivers, to draw together a shared-care approach, which will ultimately enhance outcomes for service users, including community and acute settings, in the management of patients and their caregivers.

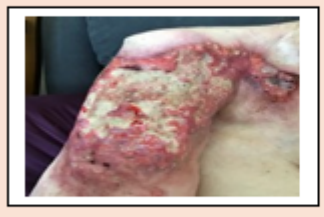
Useful Resources

- Malignant Wounds: Management in Practice (2025) Malignant wounds: Management in practice – Wounds UK
- NICE Guidance - Scenario: Palliative cancer care – malignant skin ulcer I Management I Palliative Care – malignant skin ulcer (2023) Scenario: Palliative cancer care - malignant skin ulcer | Management | Palliative care - malignant skin ulcer | CKS | NICE
- The Implementation of 'Malignant Fungating Wound Guidelines and Pathway' and its evaluation (2025) https://doi.org/10.12928/jowc.2024.0182









Tracy Finley – Tissue Viability Nurse. South Tyneside and Sunderland NHS Foundation Trust