



UCLH Cancer Collaborative
The Cancer Alliance for north and east London

Working in partnership UCLH Cancer Collaborative & Macmillan Cancer Support

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MACMILLAN
CANCER SUPPORT

A partnership built on solid foundations

- Over £14.7m investment into north central and north east London (NCEL) over the last 5 year
- Built on a shared vision of improving outcomes and experience for those affected by a cancer diagnosis
- Investment beyond funding



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Macmillan Integrated Cancer Programme (MICa)

- Embedded within UCLH Cancer Collaborative
- Works as a key partner in the system that has strategic oversight and influence
- Collaborates with patients, providers and commissioners to implement and evaluate system-wide improvements to address issues for those with cancer in the area
- Supported by academic and scientific community, along with voluntary and community sector
- Significant role in influencing partners

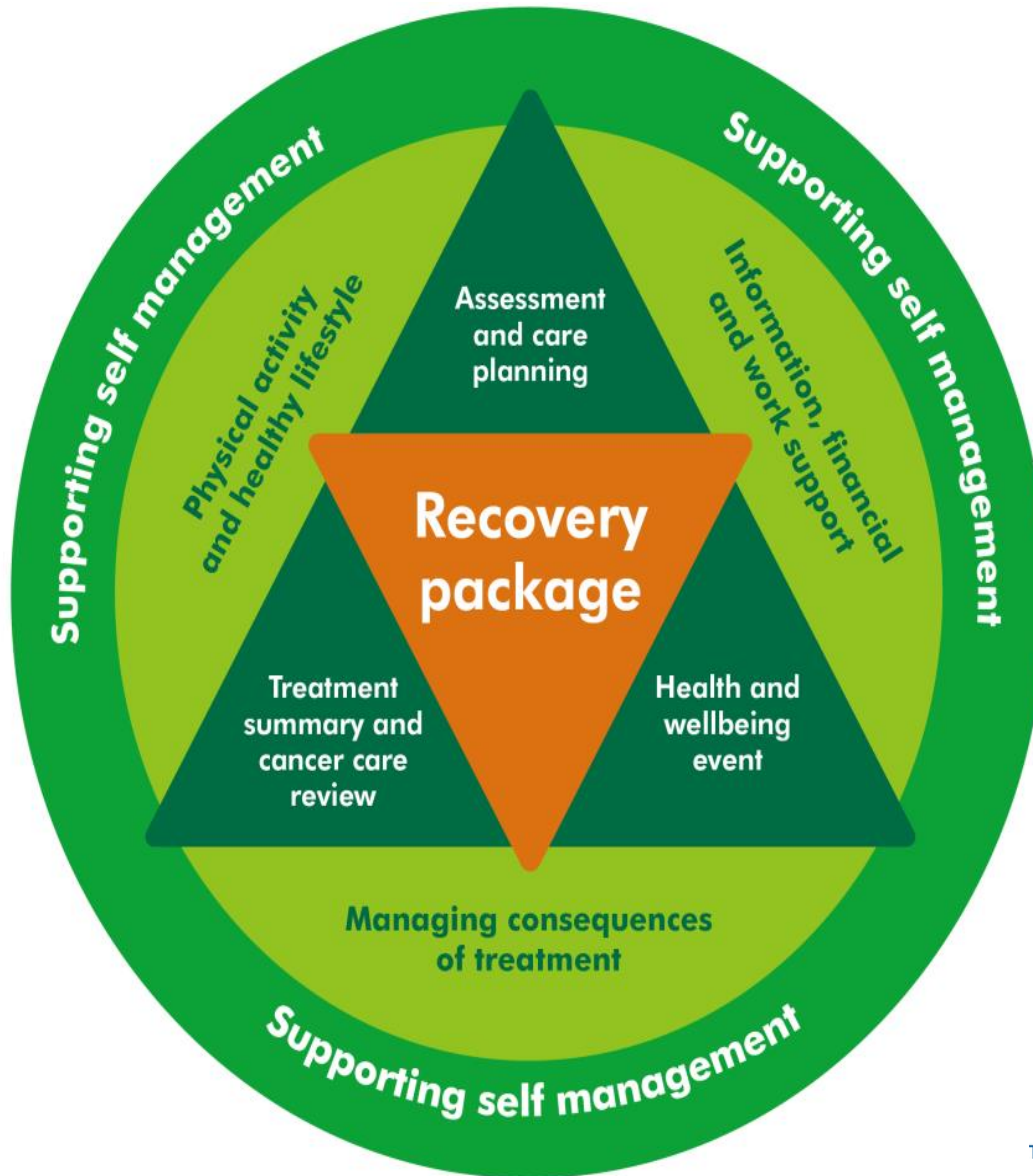
Three key workstreams

- Living with and Beyond Cancer
- Patient Experience and User Involvement
- Primary Care Improvement



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Spotlight on impact

Living with and Beyond Cancer:

- One of the key joint aims is delivery of the Recovery Package – with the aim that 70% of people of cancer will receive this in NCEL
- To support implementation, our partnership has supported identification of needs of our providers to deliver this
- Macmillan Recovery Package project managers embedded in trusts



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Acute Trust Recovery Package Implementation



Avril van der Loo Recovery Package Lead
University College London Hospital

OVERVIEW

Improved follow up in hospital and community, increased focus on health and wellbeing, information and support.

The Need

The Solution

The Opportunity

- Increasing diagnosis and Survival.
- Lack of support around fatigue, continence, fear of recurrence, stoma care, sexual function



Recovery Package

Survivorship
Package

Living With and Beyond Cancer

Recovery

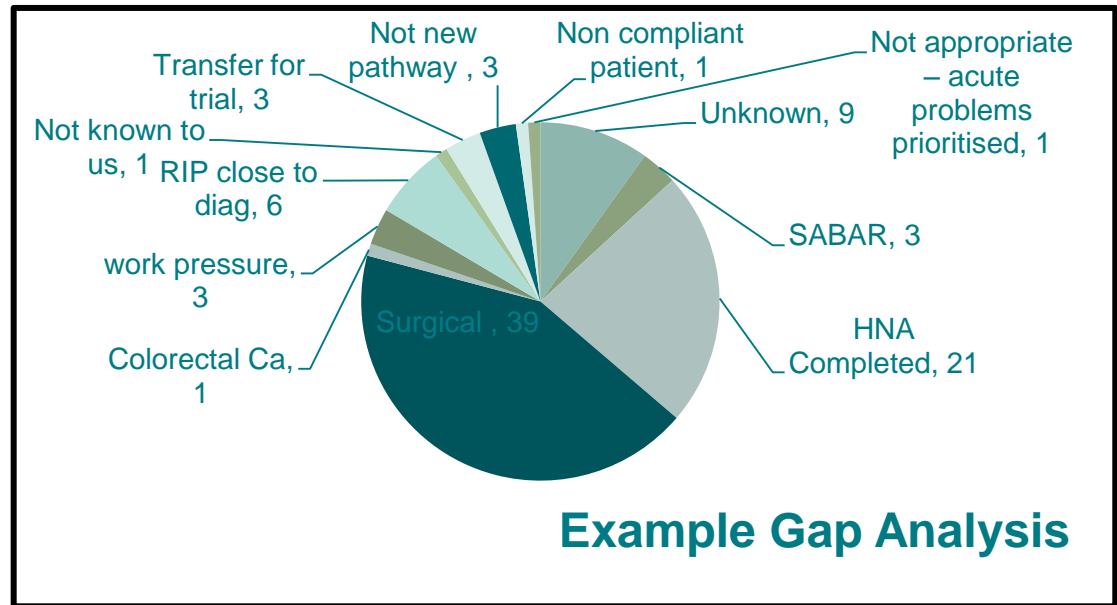


Holistic Needs Assessment at

UCLH

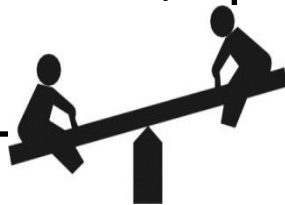


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Common Challenges:

- Appropriateness
- Timing/pathway issues
- High volume tertiary referrals
- Staffing!



Key Improvements

- ✓ Pathway adjustments sensitive to patient need, ensuring quality interventions.
- ✓ Substantial increases lung and prostate from under 5% to over 50%.
- ✓ Exploring use of Cancer Support Workers
- ✓ Transition to "e"

Introduction of eHNA: Our Patients Concerns

eHNA use	
Q1 16-17	No data
Q2 16-17	No data
Q3 16-17	17
Q4 16-17	60
Q1 17-18	89
Q2 17-18	200



Aim all HNAs to be "e"
from April 2018

Q2 Top Concerns

Row Labels	Sum of Concern Scores	Count of Concern
Worry, fear or anxiety	663	104
Tired, exhausted or fatigued	582	92
Pain or discomfort	440	70
Sleep problems	439	67
Eating, appetite or taste	385	66
Sadness or depression	378	63

Haem		
Concern	Sum of Score	Count of Score
Tired/exhausted or fatigued	42	6
My appearance	15	2
Changes in taste	15	2

Breast		
Concern	Sum of Score	Count of Score
Sleep problems/nightmares	28	5
Worry, fear or anxiety	31	4
Anger or frustration	25	3

LGI		
Concern	Sum of Score	Count of Score
Tired/exhausted or fatigued	10	2
Eating, or appetite	10	1
Children	8	1

CUP		
Concern	Sum of Score	Count of Score
Washing and dressing	8	1
Worry, fear or anxiety	8	1
Pain	8	1

Gynae		
Concern	Sum of Score	Count of Score
Tired/exhausted or fatigued	51	9
Sleep problems/nightmares	32	5
Hot flushes/sweating	27	4

Head and Neck		
Concern	Sum of Score	Count of Score
Worry, fear or anxiety	130	17
Tired/exhausted or fatigued	108	16
Pain	108	14

Lung		
Concern	Sum of Score	Count of Score
Other relatives/friends	7	1
Getting around (walking)	7	1
Pain	7	1

Urology		
Concern	Sum of Score	Count of Score
Sleep problems/nightmares	50	7
Tired/exhausted or fatigued	40	7
Changes in weight	24	5

Sarcoma		
Concern	Sum of Score	Count of Score
Transport or parking	9	1
Grocery shopping	6	1
Hot flushes/sweating	6	1

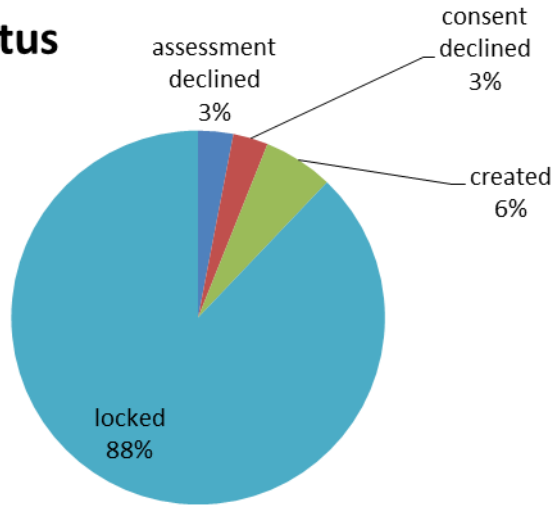
Radiotherapy	
Row Labels	Count of Concern
Tired/exhausted or fatigued	13
Sleep problems/nightmares	9
Memory or concentration	8

Gynaecology eHNA Profile



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eHNA Status



Overall Activity

assessment declined	1
consent declined	1
created	2
expired	
locked	29
pending	
submitted	
(blank)	
Grand Total	33

Locked HNA by Pathway Stage

Row Labels	Count of Asst. ID
End of treatment	19
Start of treatment	5
Initial cancer diagnosis	3
(blank)	1
Other	1
Grand Total	29

Top Three Concerns

Gynaecology	Count	Sum
Exercise and activity	11	11
Health and wellbeing	11	11
Thinking about the future	10	70

Diagnosis	Count	Sum
Tingling in hands or feet	3	23
Changes in weight	2	19
Nausea or vomiting	3	18

End Of Treatment	Count	Sum
Tired, exhausted or fatigued	5	29
Thinking about the future	3	21
Uncertainty	2	15

Concerns Per Assessment

Total Assessments	29
Total Concerns	201
Average Concerns	7


Top Actions

Information given	7
Referral to psychologist	3
Advised to contact GP	3

Treatment Summaries



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University College London Hospitals 
NHS Foundation Trust

Dr «gp_sname»
«gp_add1»
«gp_add2»
«gp_add3»
«gp_add4»
«gp_add5»
«gp_pcode»

Directorate of Urology
University College Hospital at Westmorland Street
16 – 18 Westmorland Street
London
W1G 8PH
Mail Address
Ground Floor Central
25U Euston Road
London
NW1 2PG
Administrative Enquiries
☎ 020 3447 9290
Fax: 0203 4479303/4564901
Pathway Coordinator email: stacey.neequay@uclh.nhs.uk
web: www.uclh.org

Treatment Summary

«date_letter_created»

Dear Dr «gp_sname»,

Re: «fname» «sname» «add1» «add2» «add3» «add4» «add5» «pcode»
Hospital number: «hospid» NHS number: «nhsno»

Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and ongoing management plan are outlined below. The patient has a copy of this summary.

Diagnosis: Penile Cancer	Date of Diagnosis:	Staging
Summary of Treatment and relevant dates:		Treatment Aim:
Possible treatment toxicities and/ or late effects: Post-Surgery Urethral stenosis, spraying of urine Possible LUTs Genital and/or lower limb lymphoedema		Advise entry onto primary care palliative or supportive care register Yes / No DS 1500 application completed Yes/No Prescription Charge exemption arranged Yes/No
Alert Symptoms that require referral back to specialist team: New penile lesion / bleeding from penis Palpable groin lumps		Contacts for re referrals or queries: In Hours: 07852219921 Out of hours: Leave message on above Other service referrals made: (delete as nec) District Nurse AHP Social Worker Dietician
Secondary Care Ongoing Management Plan: (tests, appointments etc) Ongoing 3 months clinical examination with ultrasound or CT scan		

- Numbers increasing slowly
- Mix of Doctor/Nurse led models
- Pre populated templates popular with nursing staff
- Nurse led end of treatment clinics, working really well
- Challenge include appropriate person, time & process!
- Dictation into a template can be tricky!

Health and Wellbeing Events



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Macmillan Support and Information Service
Group Event every 2nd month

University College London Hospitals NHS Foundation Trust

Directorate of Urology
University College Hospital at Westmoreland Street
10-10 Westmoreland Street
London
W1G 6PH
Mail Address
Ground Floor Central
290 Euston Road
London
NW1 2PG
Administrative Enquiries
020 3447 5200
Fax: 0203 447303/4564901
Pathway Coordinator email: stacey.neequay@uclh.nhs.uk
0800 www.uclh.org

Dr «gp_sname»
«gp_add1»
«gp_add2»
«gp_add3»
«gp_add4»
«gp_add5»
«gp_pcode»

Treatment Summary
«date_letter_created»

Dear Dr «gp_sname»,

Re: «fname» «sname» «add1» «add2» «add3» «add4» «add5» «pcode»
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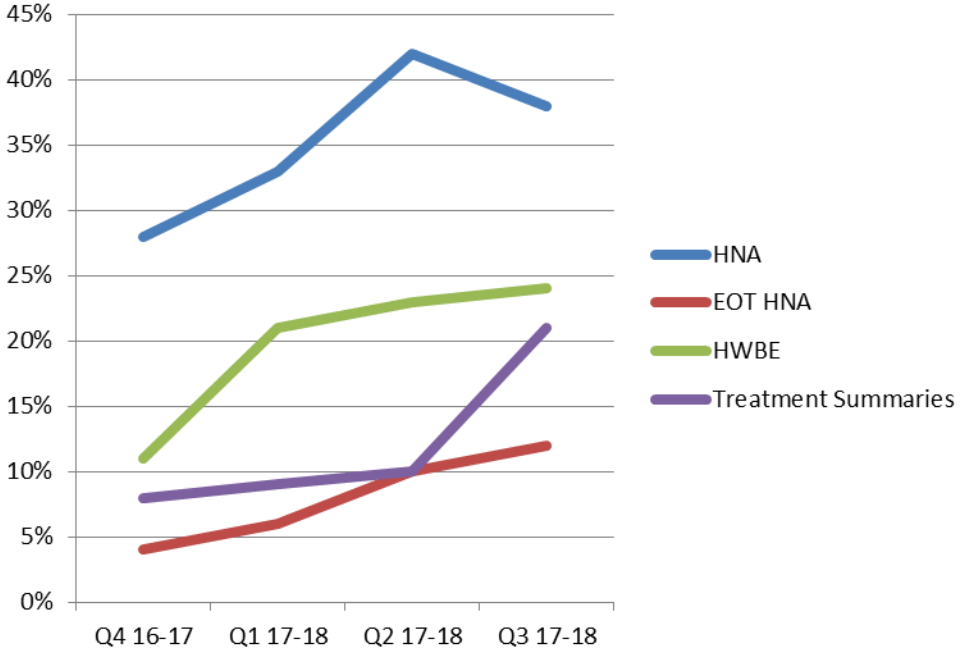
• End Of Treat Clinic

• Group Event

Performance Overview



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Continuous improvement



Not great overall coverage



Quarterly reports

UCLH Trajectory	HNA at Diag	EOT HNA	HWBE overall	TXS
Q1 16-17	164	Not required	86	15
Q2 16-17*	151	Not required	109	36
Q3 16-17	227	Not required	166	46
Q4 16-17	28% (n224)	4% (n32)	11% (n91)	8% (46)
Q1 17-18	33% (n259)	6% (n47)	21% (n164)	9% (65)
Q2 17-18	42% (n318)	10% (n77)	23% (n173)	10% (52)
Q3 17-18	38% (n310)	12% (n95)	24% (n193)	21% (75)

Next Steps

- Integration with Trust systems
- Maintain quality and quantity.....avoid tick box.....
- Link the eHNA data to service improvements and staff training.
- Increasing compliance with metrics and understanding of shortfall.
- Drive improvements in HNA at diagnosis to try and address concerns in patient survey around lack of info
- New teams – Allied Health Professionals
- Evaluating benefits of interventions.
- Data Standardisation



In Summary

- The implementation of the recovery package can be helpful for patients and staff.
- Explore what works for you.
- Crucial to understand the pathways and where RP interventions are supportive to both CNS and patient ... this helps to maintain the quality of the interventions and the systematic incorporation into the pathway.

Contact: avrilvanderloo@nhs.net