



Thames Valley
Cancer Alliance



Oxford University Hospitals
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EXPERIENCE-BASED CO-DESIGN PROJECT TO IMPROVE OUR AFTERCARE AND FOLLOW-UP FOR PAEDIATRIC CANCER SURVIVORS AFTER THEIR END OF TREATMENT

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| PROJECT OVERVIEW | TVCA SHOWCASE READING | 7TH NOVEMBER 2023 |



“Not knowing who or where to turn to made getting back into a ‘normal’ life difficult. The whole experience would have been better if could have had support much quicker.”

INTRODUCTION

Personalised care for childhood, teenage and young adult survivors of cancer:

Reducing health inequalities and utilising learning to integrate post-covid and digital work practices into modern late effects care.

£54,957 funding

12 month project



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WHAT ARE LATE EFFECTS?



Long-term survival rate > 80% for children with paediatric malignancies



Treatment can lead to adverse long-term health related outcomes -> Late effects



Late effects contribute to high burden of morbidity

60-90% developing one or more chronic health condition
20-80% severe or life-threatening complications during adulthood¹



COG has developed Long-term Follow-Up Guidelines²

Recommendation organized by therapeutic exposure

1. NATIONAL CANCER INSTITUTE, USA LATE EFFECTS OF TREATMENT FOR CHILDHOOD CANCER (PDQ)- HEALTH PROFESSIONAL VERSION, <https://www.cancer.gov/types/childhood-cancers/late-effects-hp>. PDQ#...TEXT=PREVALENCE%20OF%20LATE%20EFFECTS%20IN%20CHILDHOOD%20CANCER%20SURVIVORS.-LATE%20EFFECTS%20ARE&TEXT=60%25%20TO%20MORE%20THAN%2090%20LIFE%20THREATENING%20COMPLICATIONS%20DURING%20ADULTHOOD

2. CHILDREN'S ONCOLOGY GROUP, LONG TERM FOLLOW-UP GUIDELINES, VERSION 5.0, OCTOBER 2018

160 CTYA patients in the Thames Valley treated for cancer each year

130 survivors eligible for assessment within the Late Effects Service each year.

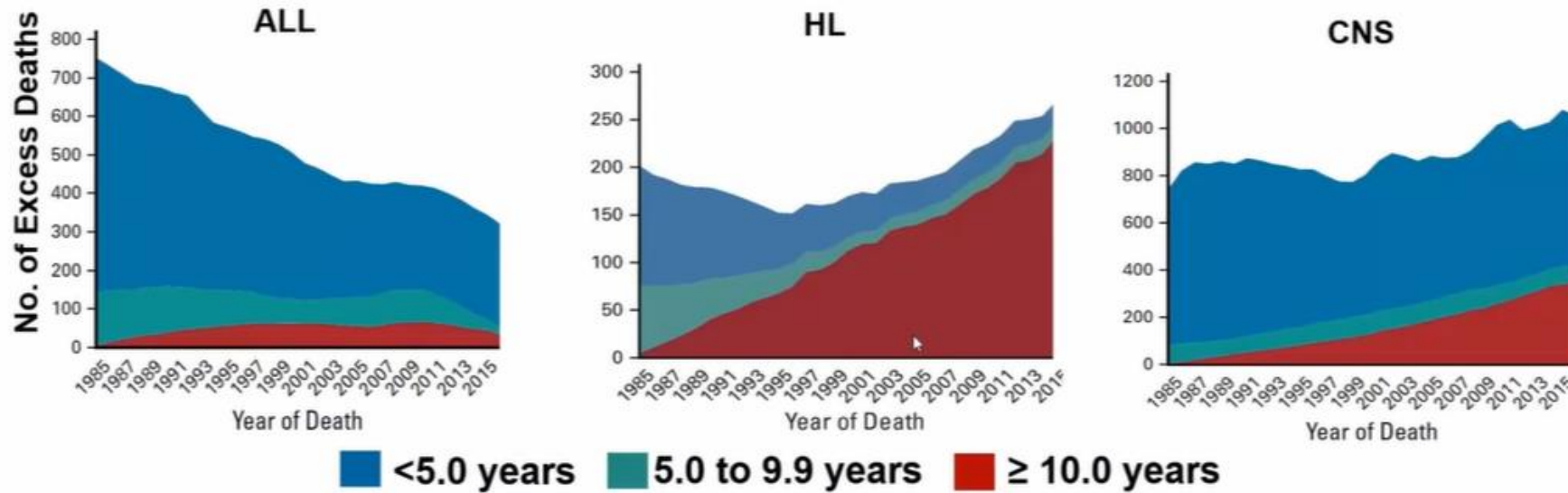
All survivors require support on completion on disease monitoring to enable them to manage and identify late effects

Following risk stratification, a proportion of these patients will require ongoing follow-up in tertiary care every 1-3 years after they become adults.

The need for and the size of this service is expected to grow steadily

POPULATION

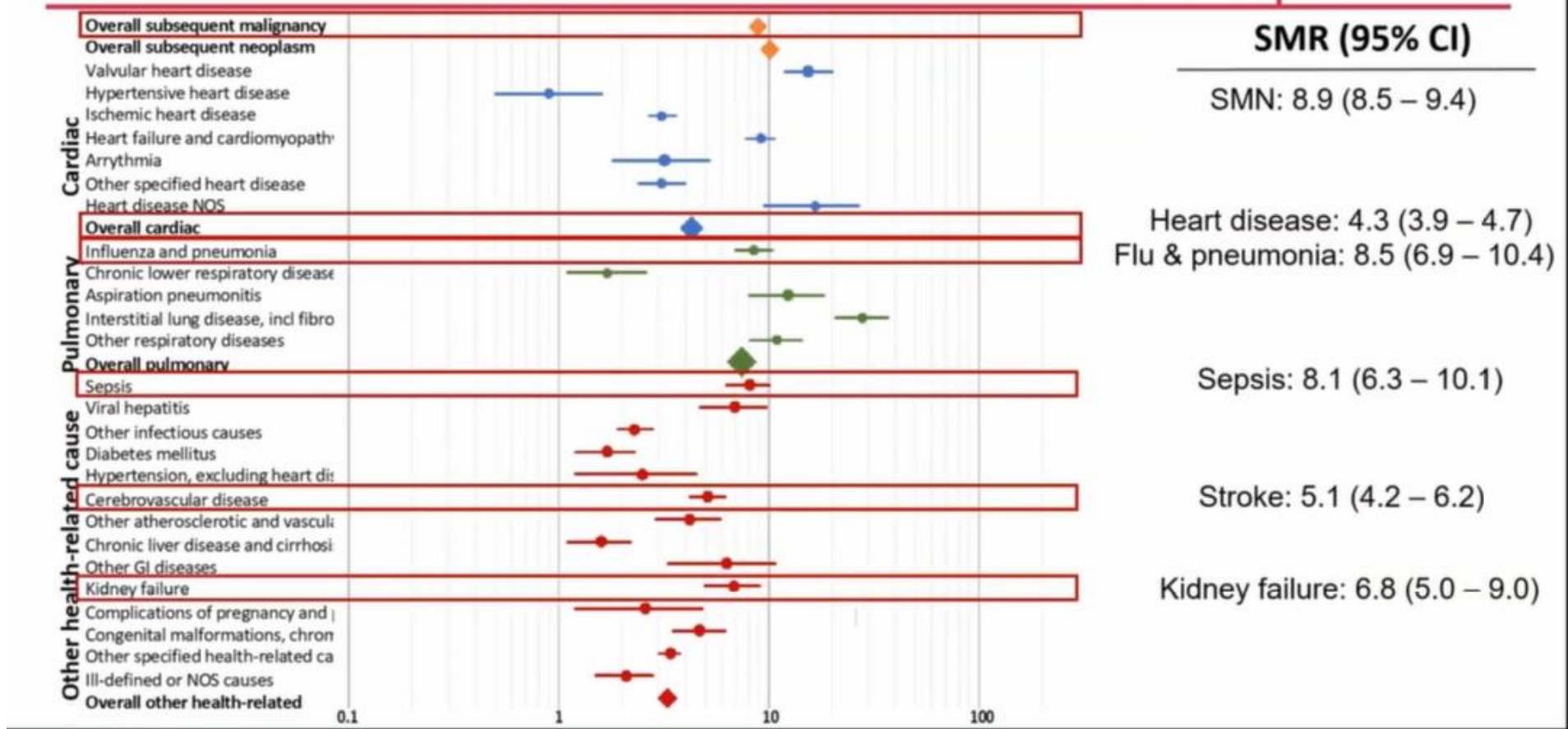
Rethinking Success in Pediatric Oncology: Beyond 5-Year Survival



Williams et al, *J Clin Oncol*, 2021

Discrete Causes of Death Compared to the US Population

CCSS



COMMONEST LATE EFFECTS IN OUR CLINICS

Functional adaptations required due to limb discrepancies, asymmetries or prosthesis

Anxiety/depression or past trauma challenges in psychological function

Challenges with cognitive impairment reducing education/vocation/employability or difficulty adjusting to changes in career outcomes/goals

Issues related to understanding fertility status, trying for children or coming to terms with infertility, early menopause, relationships

Adjusting to less dependency within family/parent relationships balance of power and autonomy

Fear of cancer recurrence / symptom surveillance

Issues with obesity, anorexia

Challenges with healthy lifestyle versus risk taking behaviours



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OVERVIEW

- AIM
- METHODOLOGY
- TIMETABLE
- CURRENT STATUS & NEXT STEPS
- PRELIMINARY RESULTS

AIM



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- Identifying obstacles and gaps that stand in the way of an efficient and holistic service for paediatric cancer survivors after their end of treatment across the Thames Valley;
- Bringing survivors and staff together to co-design workstreams to improve the service during this project and develop a roadmap for implementation for the next 5 years.



METHODOLOGY

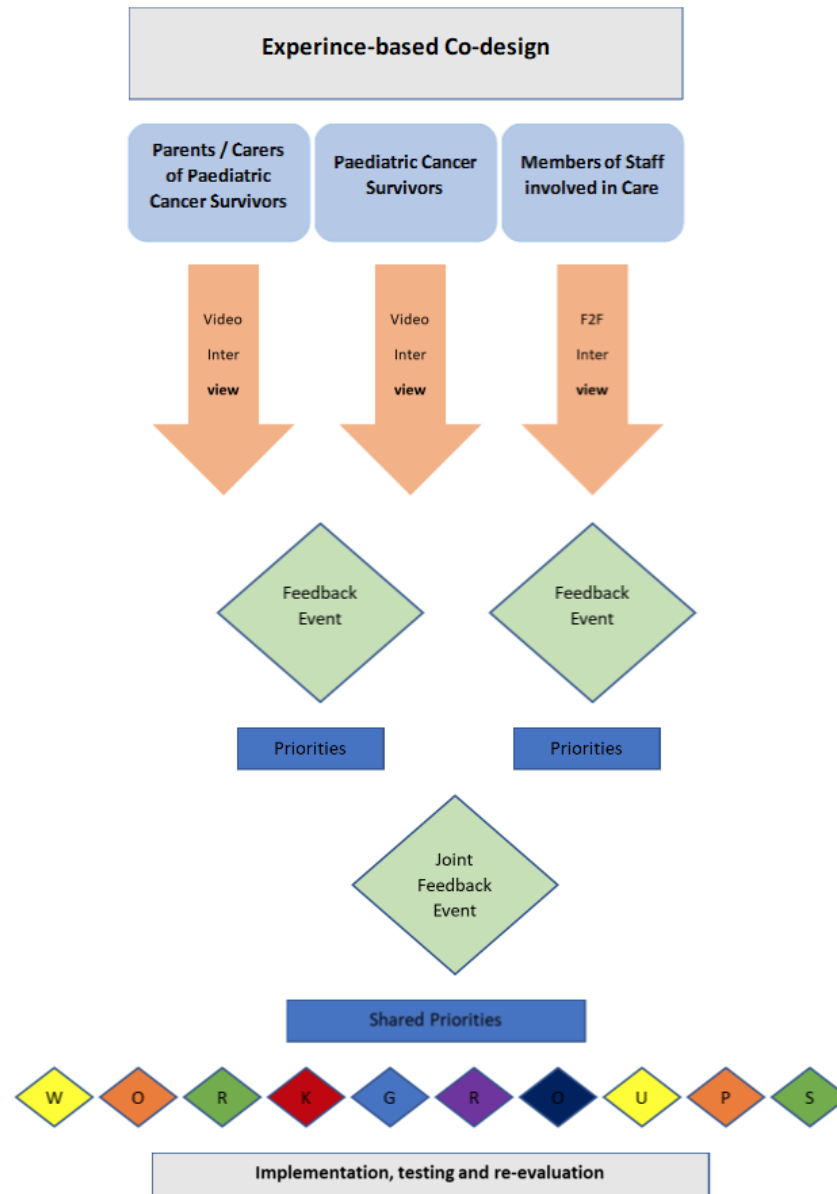


Experience-based Co-design (EBCD)

- brings patients and staff together to co-design and improve services³
- Recent research
 - found EBCD projects to achieve sustainable change
 - Co-design process is motivating for staff and engaging for patients³



3. POINT OF CARE FOUNDATION TOOLKIT, [HTTPS://WWW.POINTOF CAREFOUNDATION.ORG.UK/RESOURCE/EXPERIENCE-BASED-CO-DESIGN-EBCD-TOOLKIT/STEP-BY-STEP-GUIDE/2-EXPERIENCE-BASED-CO- DESIGN/](https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/step-by-step-guide/2-experience-based-co-design/)



METHODOLOGY



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Inclusion criteria: Paediatric Cancer Survivors/Parents

- After the end of treatment
- Oxford PTC
- Thames Valley

Inclusion criteria: Staff

- Working with/in paediatric oncology
- Secondary care
- Thames Valley

Exclusion criteria

- Paediatric cancer patients
- Active treatment for primary tumor or relapse
- Palliative care

Expected benefits

- Improvement of service structure, patient experience, MDT work, clinic attendance
- Reduction in health inequalities
- Patient empowerment
- Timely recognition of late effects

STAFF SCOPING

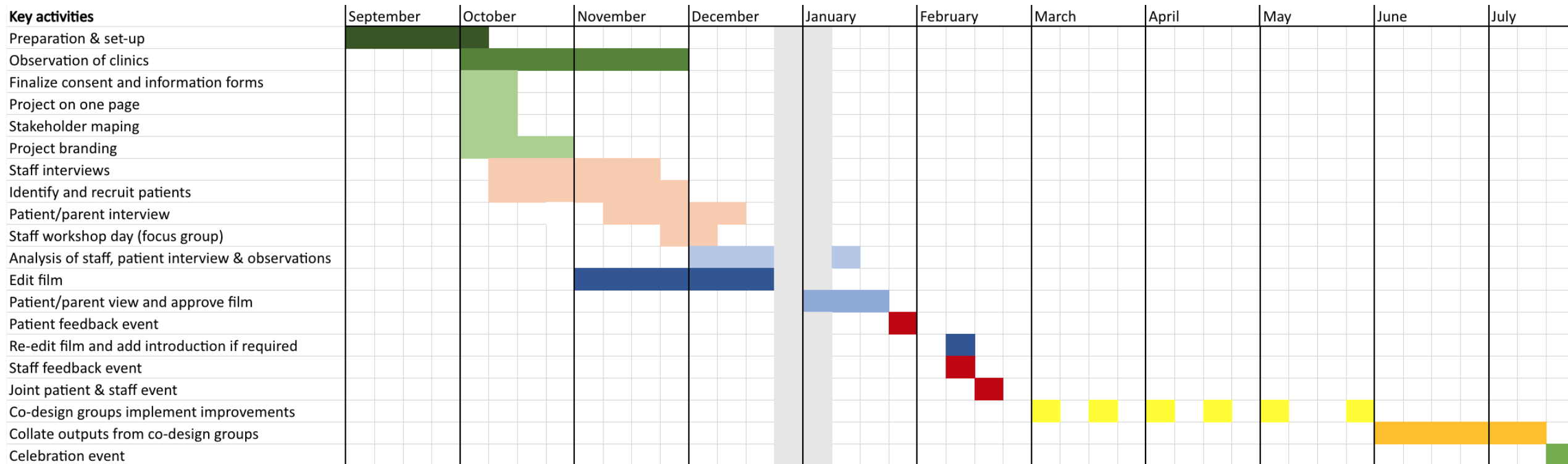
3. POINT OF CARE FOUNDATION TOOLKIT.
[HTTPS://WWW.POINTOF CAREFOUNDATION.ORG.UK/RESOURCE/EXPERIENCE-BASED-CO-DESIGN-EBCD-TOOLKIT/STEP-BY-STEP-GUIDE/2-EXPERIENCE-BASED-CO- DESIGN/](https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/step-by-step-guide/2-experience-based-co-design/)



TIMELINE



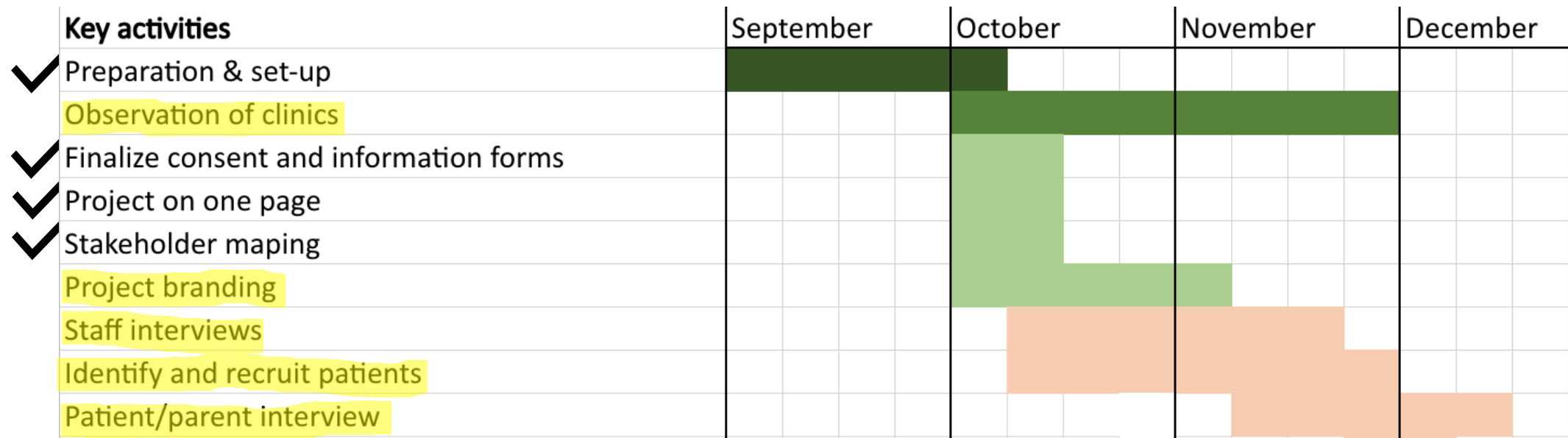
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CURRENT STATUS



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- ✓✓ Updating OUH Media & Communication team
- ✓✓ CMO approval
 - Organizing patient/parent filming days

NEXT STEPS

9th Nov. and 21st Nov.

Filming days with patients/parents at JR
Copia Productions

Mid-December

Staff focus groups

Early December

Staff Interviews

FILM EDITING AND THEMATIC ANALYSIS



PARENT AND SERVICE USERS FILM VIEWING AND PRIORITY SETTING



STAFF FILM REVIEW AND PRIORITIES SETTING





JOINT VIEWING AND EVENT



JOINT WORKING GROUPS



CELEBRATION EVENT



PRELIMINARY RESULTS

Staff Interviews

16 completed

Semi-structured Interview:

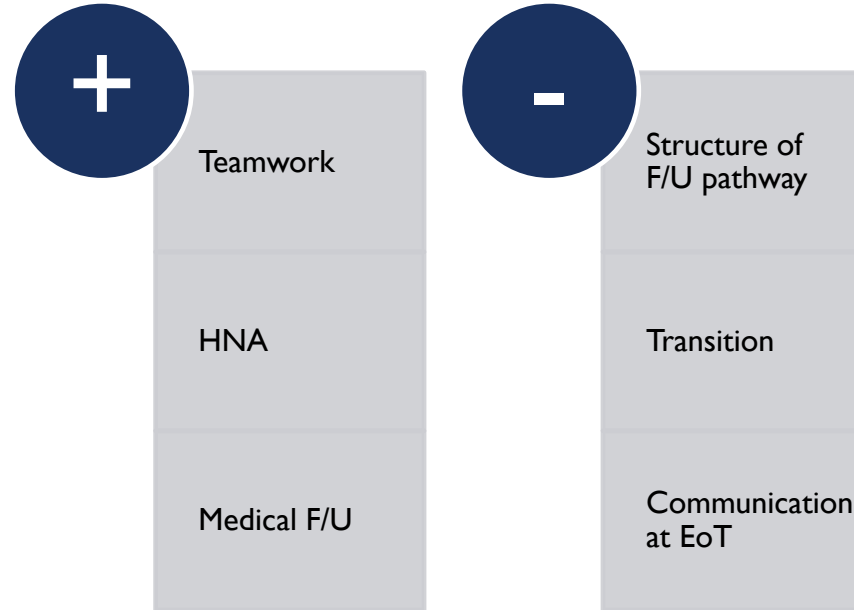
- Preparedness for end of treatment
- Criteria for long-term follow-up
- Late effects of TBI and anthracycline chemotherapy
- Side effects intrathecal MTX
- Resources commonly accessed
- Areas of the service that work well
- Areas of the service in need of improvement
- Timing of educating young people about possible late effects
- Perfect model for Follow-up
- Other models encountered
- Comments

PRELIMINARY RESULTS



Staff Interviews

- Areas of the service that work well
- Areas of the service in need of improvement
 - Common themes identified:



STAFF INTERVIEWS



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"We have the potential to have a great service and now the opportunity to create something that works for us."

Participation window not closed!

- All staff in secondary care within the Thames Valley area that work with/in paediatric oncology eligible

If you would like to share your experience and views

- Please get in touch: katharina.segiet@ouh.nhs.uk

We value everyone's input!

Thank you!



ACKNOWLEDGEMENTS


- Dr. Amy Mitchell, Consultant Paediatric Oncology, JRH Oxford, Project Supervisor
- Thames Valley Children`s Cancer Alliance, Funding of the QI Fellow Position
- Lyndel Moore, TVCA Cancer Clinical Lead for Nursing and AHP
- Dr. H. Abdalla, Consultant Paediatrician, Head of Integrated Quality Improvement
- Hellen Blundell, Lead Nurse for Paediatric Haematology and Oncology
- Jenni Guest, Portfolio and Quality Improvement team lead
- Becky Batey, Paediatric Oncology Secretary



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A night sky with a starry background and a horizon line showing a sunset or sunrise over mountains. The sky is a deep blue with many small stars. A bright star is visible in the upper left. The horizon is a mix of orange and blue, with mountains silhouetted against it.

**“Do the best you can until you know better.
Then when you know better, do better.”**

Maya Angelou



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THANK YOU FOR YOUR ATTENTION !

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