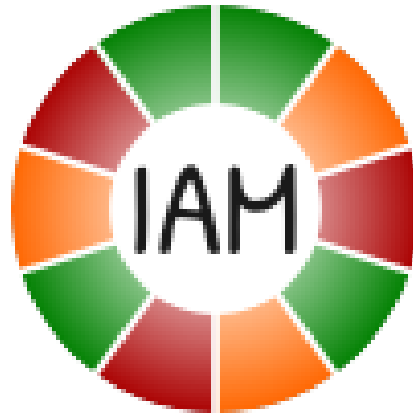


# THE IAM PORTAL



University Hospitals Bristol   
NHS Foundation Trust



WE ARE  
MACMILLAN.  
CANCER SUPPORT



<sitekit>

# Cancer in teenagers and young adults

- Cancer in TYA is rare accounting for <1% of all cancers
- ~2200 new cases every year
- Seven teenagers are diagnosed with cancer every day in the UK
- > 80% of TYA with cancer are alive 5 years after diagnosis
- Commonest cause of non-accidental death in TYA
  - 9% of male and 15% of female deaths
  - 310 cancer deaths per year

*Point of perspective: An average of 331,000 people are diagnosed with cancer in UK/year*

## OPERATIONAL UNITS

- 1 Birmingham Children's Hospital
- 2 Birmingham, Queen Elizabeth Hospital (Young Person's Unit)
- 3 Birmingham Royal Orthopaedic Hospital
- 4 Bristol Haematology and Oncology Centre (Young Person's Unit)
- 5 Bristol Children's Hospital (Adolescent Unit)
- 6 Cambridge, Addenbrooke's Hospital & Oasis Room
- 7 Cardiff, University Hospital of Wales
- 8 Edinburgh, Royal Hospital for Sick Children
- 9 Edinburgh, Western General Hospital
- 10 Glasgow, Beatson West of Scotland Cancer Centre
- 11 Glasgow, Royal Hospital for Sick Children, Yorkhill
- 12 Hull, Castle Hill Hospital
- 13 Leeds General Infirmary (Teenage Unit)
- 14 Leeds, St James' University Hospital (Young Adult Unit)
- 15 Leicester Royal Infirmary
- 16 Liverpool, Alder Hey Children's Hospital
- 17 London, University College Hospital Cancer Centre
- 18 London, University College Hospital (T12 & T13)
- 19 Manchester, Royal Manchester Children's Hospital
- 20 Newcastle, Freeman Hospital
- 21 Newcastle, The Great North Children's Hospital
- 22 Nottingham City Hospital
- 23 Nottingham, Queen's Medical Centre
- 24 Sheffield, Royal Hallamshire Hospital (Young Adult Unit)
- 25 Sheffield, Weston Park Hospital (Young Person's Unit)
- 26 Southampton General Hospital
- 27 Surrey, The Royal Marsden Hospital
- 28 Wirral, Clatterbridge Cancer Centre

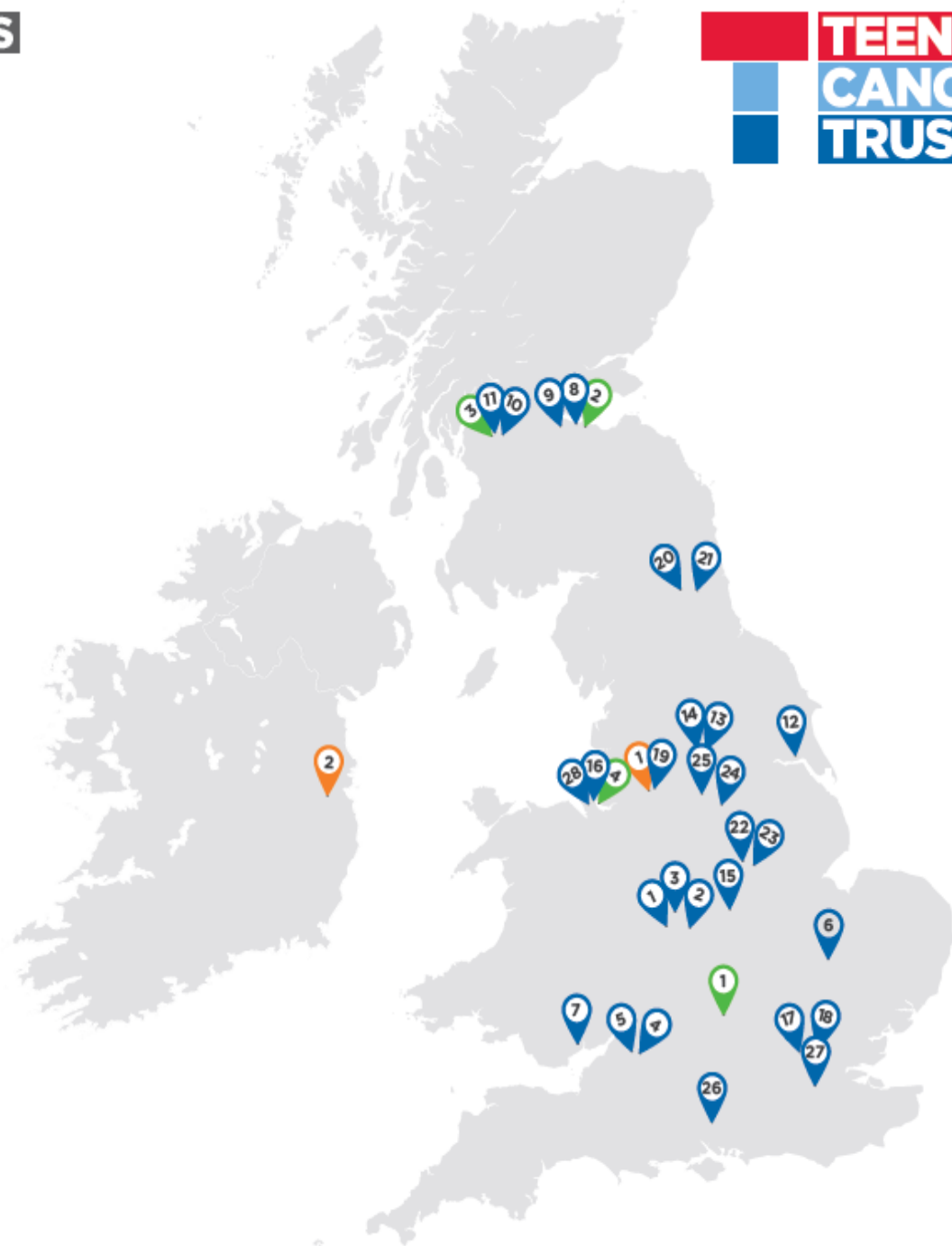
## UNITS IN DEVELOPMENT

- 1 Oxford, Churchill Hospital
- 2 Edinburgh Royal Hospital for Sick Children (Reprovision)
- 3 Glasgow, Royal Hospital for Sick Children (Reprovision)
- 4 Liverpool, Alder Hey Children's Hospital (Replacement)

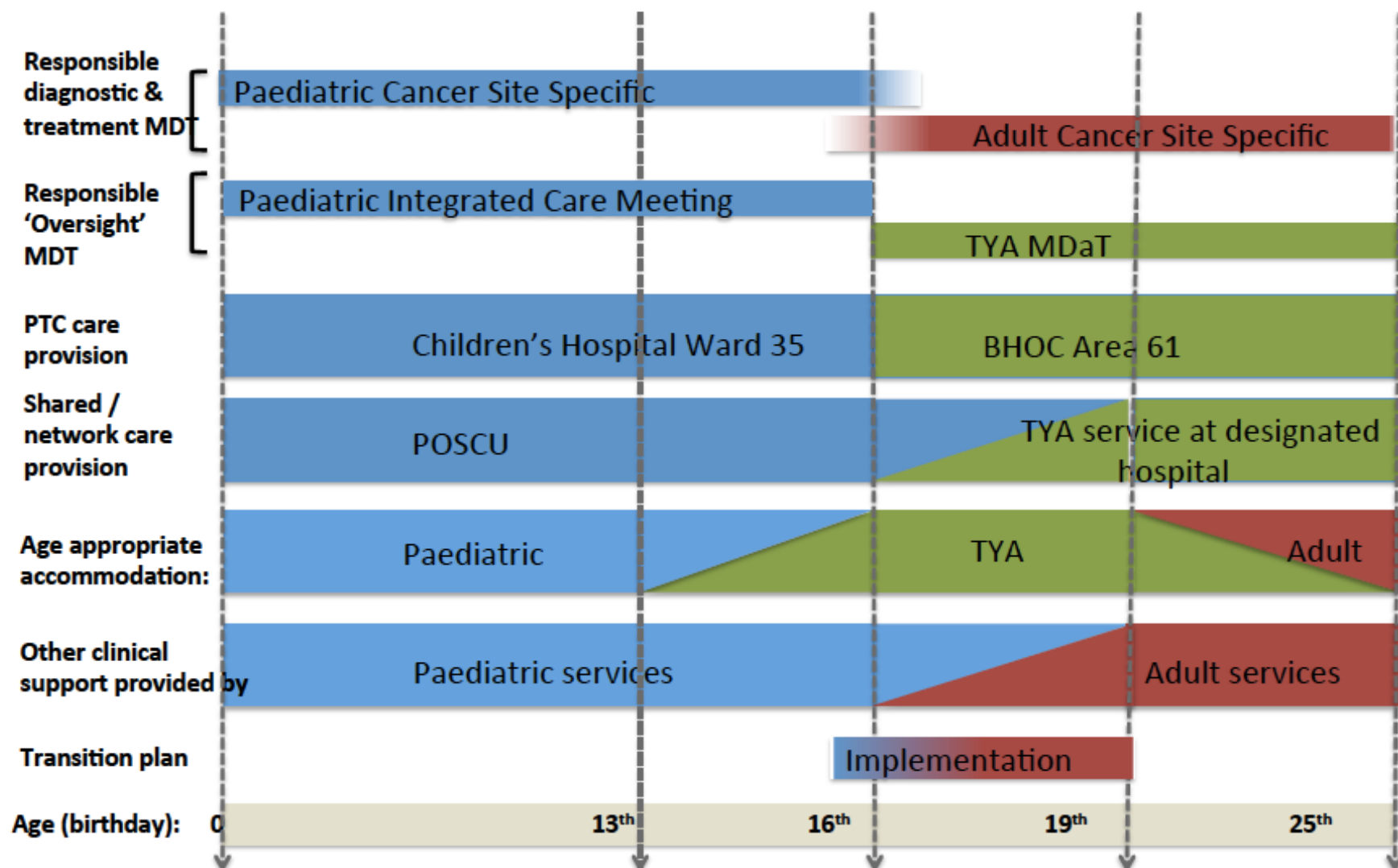
## ASSOCIATED UNITS

- 1 Manchester, The Christie Hospital (Young Oncology Unit)
- 2 Dublin, Our Lady's Hospital

N.B. Some operational units will be replaced in time by another unit sited within a new hospital development



## Age and aspects of care for newly diagnosed CTYA with cancer in the South West



# South West Network Model of Care

- TYA cancer services in the UK has benefitted from a model of centralised care.
- Considered not the optimal model in the South West of the UK
- Challenges
  - Geography
  - Travel times to the PTC
- Possible to deliver high quality care at the designated hospital

# TYA Services South West Cancer Service



# South West Network Model of Care (2)

- Developed a network model of care
- Partnership across the South West
  - 1 Principal treatment Centre
  - 6 designated TYA networked hospitals
- TYA specialist nurse posts linked to the PTC and designated hospitals.
- Partnerships with 3<sup>rd</sup> sector
  - Capital and revenue investment



# South West Network Model of Care (3)

*‘The overriding principle in the provision of services must be safe and effective services as locally as possible, not local services as safely as possible’ (NICE, 2005)*

- Addresses the key principles set out in the Teenage Cancer Trust ‘Blueprint of Care’
- In line with the future of the health service as articulated in the NHS England Five Year Forward View
- Teenage Cancer Trust Northwest (NW) Pilot project
  - Improvement of patient pathways and patient experience
  - Age-appropriate support and site specialist expertise are offered at the earliest point.



# South West Network Model of Care (4)

- TYA Multi-disciplinary Advisory Team (MDaT)
  - Weekly meetings
  - Uses online WebEx system
  - Allows teams from across the SW to take part
- Patients have access to tumour specific expertise and age appropriate support from specialist staff
- This model is now well developed

# On Target Programme

**ON TARGET**

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*“..supported towards the achievement of a life as it would have been lived without the intrusion of cancer, or as the patient has decided to recreate it..”*



# Over arching philosophy

- Co creation with service users & professionals
- Following the patient pathway
- Signposting to & sharing of existing resources by working with partners
- Making effective use of I.T. platforms

# Our high priority themes



1. Psychological / Emotional Support
2. Physical Wellbeing
3. Work
4. Support to those around the patient ( 'Networkers')
5. Engagement with Primary Care
6. Staff Training
7. Supporting Holistic Needs Assessment

# Our high priority themes

1. **Psychological / Emotional Support**
2. Physical Wellbeing
3. Work
4. Support to those around the patient ( 'Networkers)
5. Engagement with Primary Care
6. Staff Training
7. **Supporting Holistic Needs Assessment**

# Psychological/emotional support

- Lack of psychological wellbeing
- Work to increase access to online Level 1-2<sup>1</sup> wellbeing support
- '*Help*' website for psychological and emotional support -  
[www.tyahelp.co.uk](http://www.tyahelp.co.uk)

(<sup>1</sup><https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-773375005>)

# Supporting Holistic Needs assessment

## ➤ The national context:



# Supporting Holistic Needs assessment

- Assess the **impact** on all aspects of a young person's life
- **Identify** and discuss **individualised needs**
- **Empowerment** and **self management**
- Develop a domain based **framework** when working in **partnership** with Teenagers and Young Adult's (TYA)
- **The Integrated Assessment Map or IAM was developed**





# The IAM – a simple beginning

***‘To develop a mechanism whereby we ensure that all TYA cancer patients in the South West receive the best possible care and support’***

- A simple framework for MDaT discussion
- To capture patients priorities and needs
- To facilitate communication and relationship building
- To have a uniform approach to TYA care in the network
- To educate staff in holistic needs of TYA patients

# The IAM Portal



- Electronic platform for TYA patients and professionals
- 10 domains linked to developmentally appropriate online resources
- Assessed independently or in partnership with professionals
- Accessible 24/7 for communication for non-urgent follow up

# IAM 10 Domains



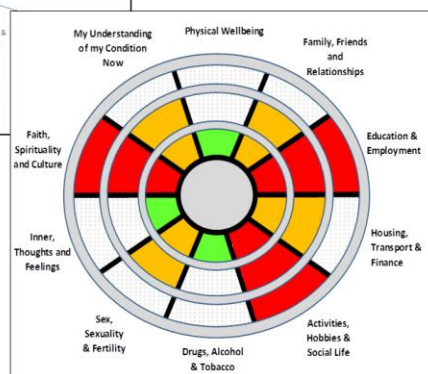
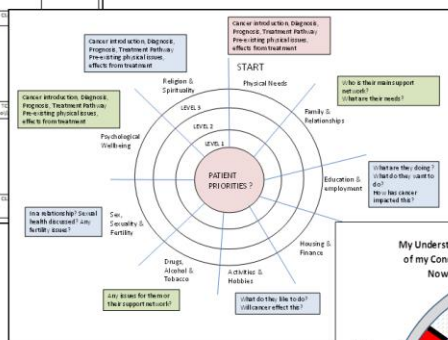
- Where I am now
- Physical wellbeing
- Family, friends & relationships
- Education & work
- Housing, transport & finance
- Interests & social life
- Lifestyle
- Sex, sexuality & fertility
- Thoughts & feelings
- Faith, spirituality & culture



# The evolution of the IAM.....



Physical needs (all symptoms, fatigue, pain, vomiting, mouth/health, etc, weight, weight, nausea/vomiting, diarrhoea/constipation, sensory impairment, mobility)	Pre-existing symptoms Symptoms from tumour: Temporary symptoms from treatment: Long term symptoms:  Needs arising/transfer referred to (2) (3) (4) (5) (6) (7) (8) (9) (10) (11) (12) (13) (14) (15) (16) (17) (18) (19) (20) (21) (22) (23) (24) (25) (26) (27) (28) (29) (30) (31) (32) (33) (34) (35) (36) (37) (38) (39) (40) (41) (42) (43) (44) (45) (46) (47) (48) (49) (50) (51) (52) (53) (54) (55) (56) (57) (58) (59) (60) (61) (62) (63) (64) (65) (66) (67) (68) (69) (70) (71) (72) (73) (74) (75) (76) (77) (78) (79) (80) (81) (82) (83) (84) (85) (86) (87) (88) (89) (90) (91) (92) (93) (94) (95) (96) (97) (98) (99) (100)
Family and other relationships (relationships, siblings, partner or parent support needed?)	
Education & Employment (main place of work, education/employment, point of contact, any exams or tests of importance, interests, what are the aspirations)	
Housing & Finance (Type of housing, lives with who, care costs, accessibility, transport, immediate short and long term financial worries, Any referral for grants etc already made?)	



# How is it used?



- Logons to the IAM portal is allocated via a member of the team and can download app
- Complete as assessment identifying their need in partnership or independently
- Green/amber/red
- Key points – diagnosis, relapse and EOT
- IAM domains is the agenda to facilitate the MDaT discussion



# What it is not



- Not a checklist
- Not a psychometric test or negate the need for other assessments
- Does not provide a 24/7 response to acute distress
- It is not given to the young adult without explanation



# Integrated Assessment Mapping (IAM) Portal

South West TYA Cancer Service  
University Hospitals Bristol NHS Foundation Trust  
Macmillan  
Teenage Cancer Trust  
Sitekit

# The IAM Portal



The 'IAM' (Integrated Assessment Map)  
– a TYA Specific Holistic Needs Assessment



The 'Help' website for online wellbeing  
resources - [www.tyahelp.co.uk](http://www.tyahelp.co.uk)



SWIMMS  
MDT management system



**IAM Portal**



# 1. The IAM Portal offers....



## ➤ TYA patients:

- individual access to a TYA specific holistic self assessment tool
- explore and document their needs
- obtain information and support from an framework of resources for self management.
- is be accessible as website and as an app



## 2. The IAM Portal offers....



### TYA clinical teams:

- access to individual patient self assessment
- inform MDT and other discussions
- Patient voice at the centre of MDT discussions
- individualised care plans can be formulated

### Professionals:

- access to the Portal
- same wide range of information and resources



# 3. The IAM Portal offers.....



## **TYA services and provider Trusts:**

- access to a patient management system for managing MDT's and documenting its discussions
- reporting activity
- analysing patient need and assessing service demand

## **The NHS and its Voluntary Sector Partners:**

- access reports of aggregated data from anonymised patient records
- providing a profile of TYA patients and their needs

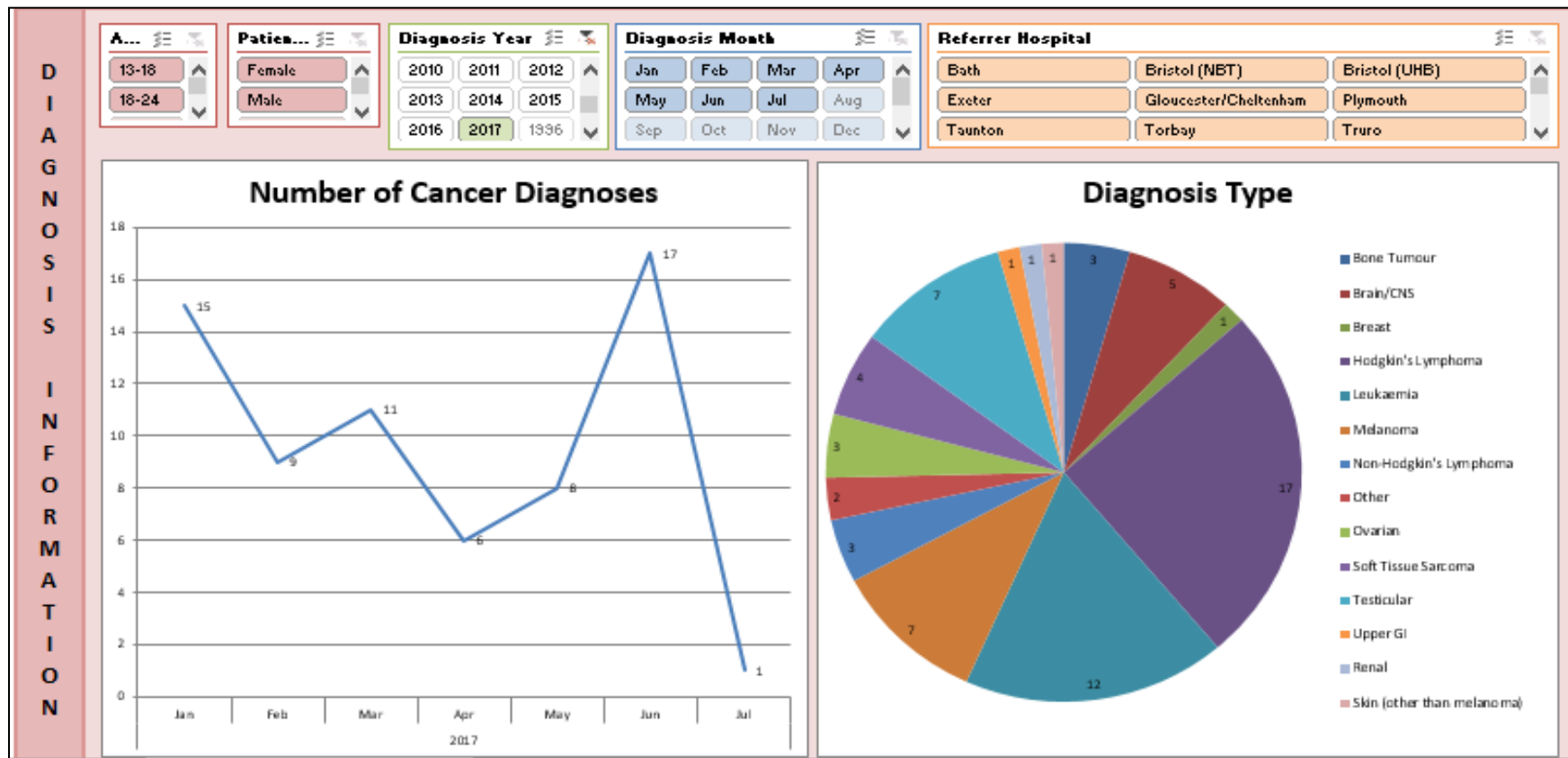
# SWIMMS - South West Integrated MDT Management System



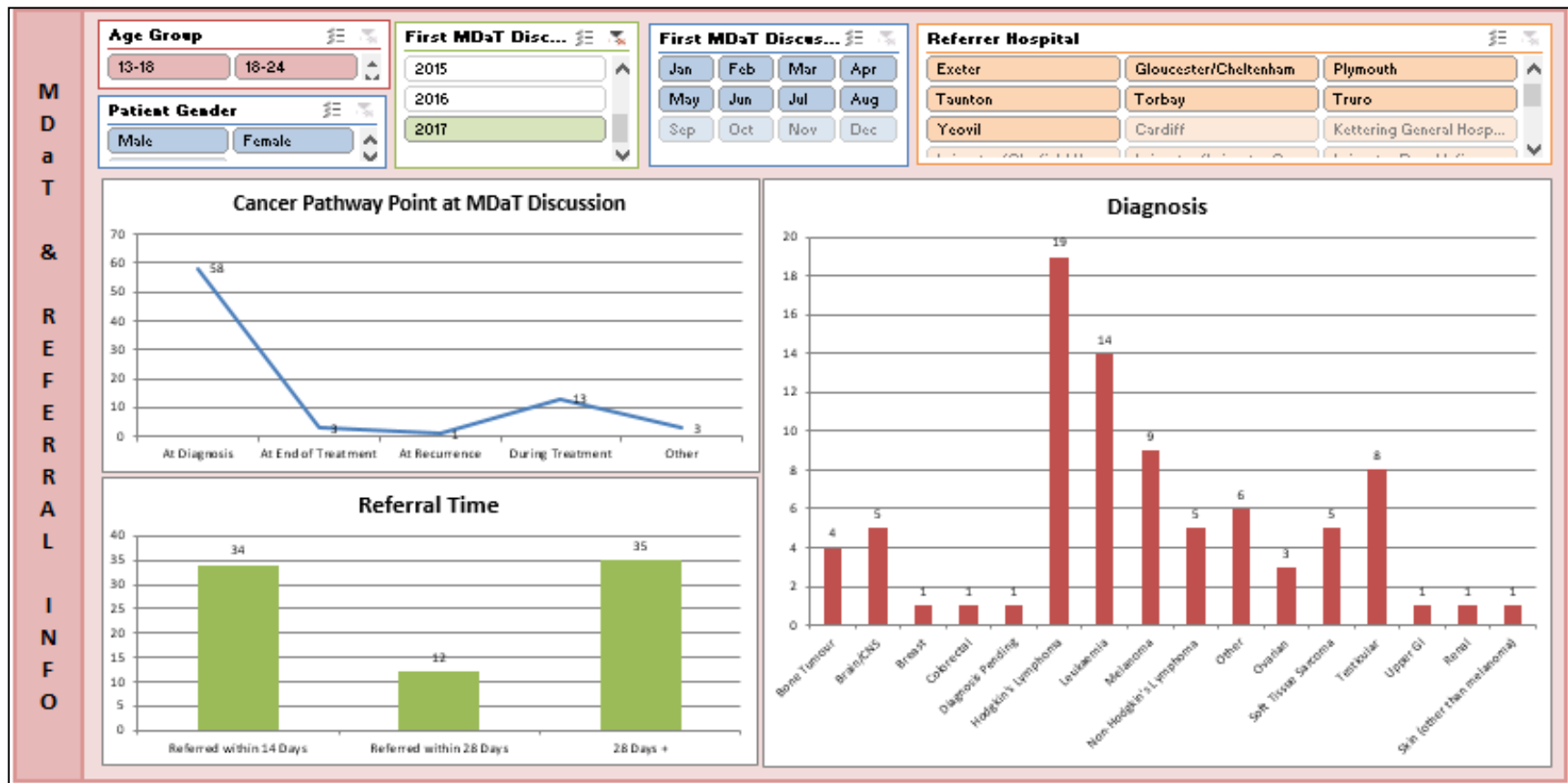
- Online system for registration, MDT management and data collection
- Comprehensive review of each patient
  - Birch cancer classification
  - Fertility status
  - Clinical trials recruitment
  - Holistic needs (IAM)
- Patient voice at the centre



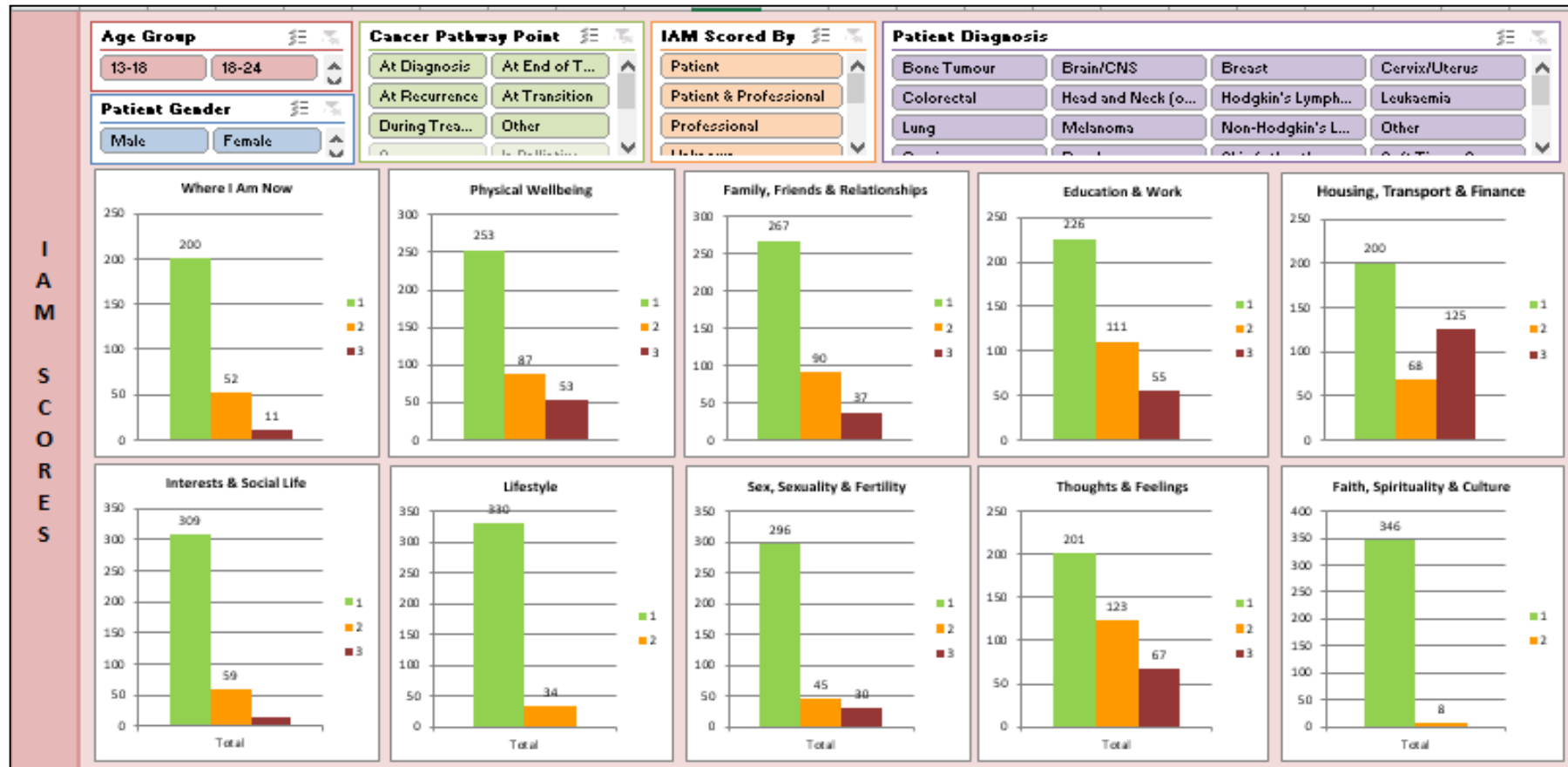
# IAM Portal quality dashboard



# IAM Portal quality dashboard



# IAM Portal quality dashboard



# Feedback







“I liked it because it is just for young people to give their thoughts and ideas. It gave me time to think, everyone should have a go.....it’s really useful.”  
(Young person)

“It is a great concept and will be a huge benefit for both patients and clinical teams... The data from SWIMMS will be fantastic and powerful particularly as it will be consistent across the UK.”  
(Professional)

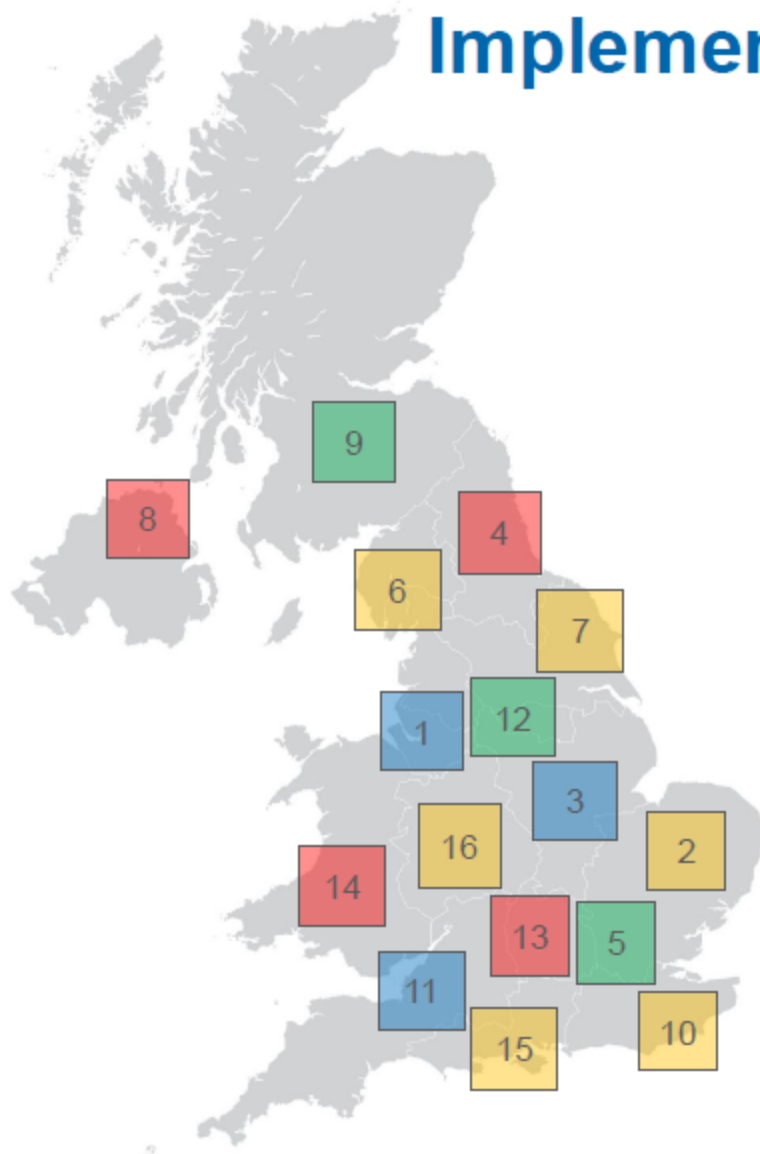


# What have we done so far: Implementation



-  IAM Portal live (3)
-  Process started (3)
-  Preparations started (6)
-  Plan being established (4)

1. Cheshire & Merseyside
2. East Anglia
3. East Midlands
4. North East
5. North East & North Central London, Hertfordshire & Essex
6. North West
7. North Yorkshire, West Yorkshire & Humberside
8. Northern Ireland
9. Scotland
10. South East
11. South West
12. South Yorkshire
13. Thames Valley
14. Wales
15. Wessex
16. West Midlands



# What next...



- On going Macmillan partnership – close synergy with Macmillan eHNA programme/LWBC strategy
- Macmillan endorsement as the HNA of choice for TYAs
- Potential for use by young people in other health settings
  - Young adult aftercare programmes
  - Other serious chronic health conditions

# The IAM Portal



- Support the delivery of a patient focused regional service
- Access to age-appropriate resources
- Promote patient self-management
- Provide structured processes to the TYA MDaT
- Deliver robust data about patient needs & service delivery

# IAM Portal



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- Access to age-appropriate resources
- Promote patient self-management
- Provide structured processes to the TYA MDaT
- Deliver robust data about patient needs & service delivery

**‘A digital platform supporting TYA with cancer across a regional service**

# With thanks to....



.....everyone who helped ensure that the development and pilot were successful.

In particular:

- Our partners **Macmillan Cancer Care, Teenage Cancer Trust & Sitekit**
- The TYA South West Clinical Service Team
- CLIC Sargent social workers in the South West
- The site specific clinical nurse specialists involved in the care of TYA patients during the pilot
- Everybody who helped with the content development

# Thank you



## Jamie Cargill

Teenage Cancer Trust Nurse Consultant South West TYA Cancer Service

[www.tyaiaam.co.uk](http://www.tyaiaam.co.uk)

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/publications/>

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