



ACE Programme

Too Young to Get Cancer? – A Bristol Vague Symptoms project report

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1. Introduction to the project

1.1 Overview

“Too Young to Get Cancer?” is a Service Evaluation/Clinical Audit project to map the diagnostic pathway of 16-24 year olds referred to the South West TYA Multidisciplinary advisory Team (MDaT) in University Hospitals (UH) Bristol NHS Foundation Trust over an 18 month period between October 2014 and April 2016.

Our aim was to build an evidence base to inform future research and design of potential interventions, to improve time to diagnosis and the diagnostic experience for teenagers and young adults (TYA).

1.2 Context

Cancer is the most common cause of disease-related death in young people in the United Kingdom (accounting for 9% of all deaths in males and 15% of all deaths in females, aged 15–24), yet it is uncommon, accounting for less than 1% of cancers at all ages (CRUK, 2013). Despite the fact that there are limited data to link prolonged time to diagnosis with adverse outcome there is clear evidence that young people and their families highlight delay in achieving diagnosis as a major concern (Gibson et al, 2013).

Compared to work exploring time to diagnosis in adults with common cancer types, the small number of patients aged under 25 years affected by cancer, and their heterogeneous diagnoses, creates challenges in designing interventions which might readily be shown to influence the current situation (Dommett et al, 2013. Fern et al 2013).

Our proposal is that a better understanding of the referral pathways used by TYA patients across our regional network will help identify ways in which delays may be minimised in the future.

1.3 Aim and Objectives

- 1) To better understand the referral pathways used by TYA with cancer across the South West.
- 2) To define and inform the design of interventions to improve time to diagnosis in TYA cancer.
- 3) To disseminate findings within the primary and relevant secondary care communities in the South West and highlight the presentation and appropriate referral of TYA with suspected cancer.
- 4) To share lessons learned with other TYA services in England.

2. Method

2.1 Recruitment & Permissions

Permission was sought from the Caldicott Guardians of each trust in the South West, to extract and record data from within their trust.

Young people discussed by the South West TYA MDaT within the time frame for this study were identified. All demographic details and the current status of each young person was verified by their TYA Clinical Nurse Specialist (CNS) or other relevant healthcare professionals. Following verification, any young person who was deemed inappropriate to contact was removed from the database.

Permission was sought from all patients (or their next of kin if deceased) to access their records (prior to this, the patient information letter and permission form was shared with and commented on by young people). A process was implemented to follow up, with caution, patients from whom permission had not been received within 1 month. The relevant TYA CNS contacted the patient and then a second letter was sent if appropriate.

Upon receipt of the patient permission, the relevant named clinician in secondary care was informed of the project, and a letter was written to the GP Practice Manager requesting access to the young person's primary care records.

2.2 Bereaved Families

The inclusion of deceased patients was, if possible, important for the integrity of the project. An individual, case by case approach was taken when contacting the next of kin of a deceased young person. The healthcare professional identified to have a working relationship with the next of kin was contacted, and a personalised letter was sent if it was thought appropriate to do so.

2.3 Access to Records

Access to primary care records was usually arranged through the GP practice manager.

Access to secondary care records was coordinated by the cancer manager of each trust who provided access to the case notes and relevant online systems for information such as clinic letters, investigations and results, hospital admissions and discharges as well as the site specific MDT record/cancer registry.

2.4 Data Collection

Upon receipt of all relevant permissions, the Project Support Manager interrogated primary care and hospital records to extract information relating to:

- Symptom presentation and consultation frequency in primary care
- Source of referral and point of entry to secondary care for the symptoms that led to a cancer diagnosis

- Evidence of prior contact with secondary care (e.g. outpatient and A&E services) before the episode resulting in the diagnosis
- Time to start of treatment

A bespoke database was created to capture basic demographics alongside details of all healthcare contacts in both primary and secondary care.

In order to analyse events occurring in different healthcare settings, a standardised data collection tool was required. Event types that would encompass all health care contacts within both primary and secondary care were defined. It was agreed that all consultations, referrals, admissions, discharges, investigations, DNA's and MDT discussions would be captured. The instigating provider and event outcome was also recorded. In addition to this, symptoms at the time of presentation/event were also recorded. Information was recorded to enable further qualitative analysis. Comment sections and free text data were included to provide context to each event.

In total the Project Support Manager visited and extracted information from 66 GP surgeries. Other surgeries opted to post, fax or email records. We were unable to access the relevant GP records of 5 young people.

Data was also extracted from records at UH Bristol NHS Foundation Trust, Gloucestershire Hospitals NHS Foundation Trust, North Bristol NHS Trust, Plymouth Hospitals NHS Trust, Royal Cornwall Hospitals NHS Trust, Royal Devon And Exeter NHS Foundation Trust, Royal United Hospitals Bath NHS Foundation Trust, Taunton And Somerset NHS Foundation Trust and Weston Area Health NHS Trust.

2.5 Date and time period of intervention and data collection

The Project Support Manager came in to post July 6th 2015. Data collection was completed by Monday 5th September 2016. Analysis is ongoing and all key stakeholders and young people will be invited to our dissemination event on 17th November 2016.

3. Analysis

3.1 Mapping

All raw data collected by the Project Support Manager was used by the Project Operational Lead to construct individual pathway maps. (It is estimated that it took approximately 8 hours overall to collect all the necessary data for each young person, and that on average it took 60 minutes to map each pathway). These maps are a condensed version of all the data collected, showing transition between primary and secondary care displayed on a timeline.

3.2 Panel Discussions

All individual route maps were reviewed by a clinical panel.

The clinical panel was made up of a number of consultants from UH Bristol NHS Foundation Trust (including Paediatric Haematology and Oncology, TYA Haematology and Oncology, Clinical Oncology), a Macmillan GP, and the project team itself.

104 cases were discussed over 9 panel meetings, and each case took approximately 20-25 minutes to review, although some cases were more complex than others.

The aims of the panel discussions were to identify key events as well as:

1. Good practice
2. Missed opportunities for potential earlier diagnosis
3. Whether, and at which point, an intervention to effect earlier diagnosis might have been possible
4. Potential interventions that could affect the pathway and/or patient experience

As we progress through the analysis phase, we will also invite external specialists to contribute to panel outcomes.

We successfully structured the meetings, creating our own bespoke documentation, in order to record both the qualitative and quantitative data required for further analysis. During the panel process, key events were defined, as well as additional information relating to presentation, referrals, and routes to diagnosis, including the symptoms and specialities involved in each case. A qualitative data grid was used to capture general themes and suggestions, and at the end of the discussion the final outcome was agreed.

3.3 Defining Key Events/Intervals

In order to conduct quantitative analysis of the pathways, key events within all diagnostic pathways were identified. Key event definitions as described in the Aarhus Statement were used to support comparability with other research (Weller et al, 2012). Key events specific to the project were also defined, specifically the first presentation in relation to the cancer diagnosis from the perspective of the patient. This is a subjective date, which we are using to demonstrate a possible discrepancy between the perspective of the patient and the healthcare provider.

Key events for each young person were identified and agreed by the panel. These events have been used to quantify intervals along the diagnostic pathway. The intervals calculated are linked to “an illustration of the overall milestones and time intervals in the route from first symptom until start of treatment” (Olesen et al, 2009).

The date of diagnosis for the purpose of this project was defined as the date the specimen of first histological or cytological confirmation of malignancy was taken.

Clinical bottom line - each pathway was given an overall rating using a score similar to that used by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD

<http://www.ncepod.org.uk/grading.html>).

3.4 Feedback to professionals/young people/bereaved families

- Individual outcome reports summarising the case and detailing the panel comments for GP practice/secondary care.

- Key interval data will be disseminated to the healthcare providers involved in each specific case.
- All key stakeholders and young people will be invited to our dissemination event on 17th November 2016.
- Our abstract has been accepted for oral presentation at the Teenage Cancer Trust 9th International Conference and 1st Global AYA Cancer Congress, 5th – 7th December 2016, Edinburgh, UK.

4. Results

4.1 Results

166 TYA were approached to take part in the project. Permission was received from 105, giving an overall response rate of 63%. Response rate varied by diagnostic group and the time between diagnosis and recruitment.

Of responders 51% were male, 32% were aged 16-18 and 68% aged 19 and over. 92% were white British.

Lymphoma was the most common diagnosis (28%). The other diagnostic groups were carcinoma (19%), leukaemia (18%), brain/CNS (7%), germ cell tumour (10%), bone sarcoma (7%), soft tissue sarcoma (6%), malignant melanoma (5%) and other (3%). Brain/CNS tumours were under-represented and in part reflect low patient numbers observed in the region during the recruitment period. Leukaemia patients were over-represented, which likely reflects duration of treatment.

4.2 Route to Diagnosis

93% of TYA had contact with primary care in the period prior to diagnosis. First presentation relating to the cancer diagnosis was to primary care in 89% of evaluable pathways, compared to 7% presenting to A&E and 4% presenting to other healthcare professionals.

The panel evaluated whether cancer was suspected at first presentation, evidenced by medical note documentation or actions. Of those presenting to primary care, cancer was suspected in 34% of cases. This varied by diagnostic group with evidence of cancer suspicion highest in germ cell tumours (i.e. young adults presenting with testicular symptoms) at 67%. Cancer was not suspected at first presentation in any of the bone sarcoma patients.

Using established definitions (Elliss-Brookes et al, 2012), 45% of patients were referred via Two Week Wait (2WW) pathways, 38% presented as an emergency, 11% via GP referrals, 6% other outpatient routes and 1 patient was detected via screening. Of the patients presenting via an emergency route 37% were deemed 'potentially avoidable' (i.e. that the referral could have been made earlier) and 63% 'unavoidable'. Route to diagnosis varied by diagnostic group. All malignant melanoma patients were referred via 2WW, compared to only one of the bone sarcoma patients and none of the brain tumour patients.

4.3 Key Event Interval Analysis

Quantitative analysis of all pathways is ongoing. The longest median diagnostic interval (from first presentation relating to the cancer diagnosis to date of diagnosis) was observed in bone sarcoma patients (81 days, range 45-169 days). The shortest diagnostic intervals were observed in leukaemia patients, followed by germ cell tumour patients. Ongoing analysis and interrogation of specific pathways is required.

4.4 Clinical Bottom Line

95 pathways were evaluated. The panel agreed that there was insufficient data available to evaluate the clinical bottom line in 9 cases. Of the evaluable pathways, 42% were deemed to represent good or best practice. 43% of pathways were evaluated as requiring room for improvement i.e. aspects of clinical and/or organisational care could have been better. 15% of pathways were considered less than satisfactory. This varied between diagnostic groups. All bone tumour pathways were deemed either room for improvement (43%) or less than satisfactory (57%). Of the lymphoma pathways evaluated, 60% were room for improvement and 12% less than satisfactory. In comparison, 78% of leukaemia pathways were deemed to represent good practice followed by 67% of germ cell tumour pathways.

Qualitative analysis including adherence to and use of cancer referral guidance and symptomatology is ongoing.

At this stage of analysis early themes are emerging relating to:

- Accountability for/effective management of patients within secondary care pathways
- Radiology reporting and response to positive investigations
- Application of NICE referral guidance in TYA
- Patient experience

5. Impacts and Benefits

5.1 Impact

On completion of our analysis we will aim to propose potential interventions. This will include the need to further interrogate specific diagnostic pathways within site specific teams.

5.2 Resources

The database and bespoke analysis documentation could be used in other studies analysing the entire patient pathway.

6. Barriers

- Geography was a potential barrier to this project. However due to the largely positive response from the various trusts and GP surgeries, visits were coordinated effectively and visits to each area were grouped and condensed.

- Concern from one trust that the project could be seen to 'open a can of worms'. This was resolved through management of expectations and using feedback to make amendments to correspondence.
- For a small number of young people, additional verbal permission was sought by GP practice. This prevented us from accessing the GP records of one young person.
- We encountered gaps in information in a small number of pathways as a result of the unsuccessful transfer of GP records from one surgery to another.
- The relatively small number of patients in the TYA age group, and the large range of different diagnoses, might have prevented clear conclusions. In the event, important themes have emerged.

7. Enablers

- Without the willingness of TYA to participate this project would not be possible.
- Liaison with TYA CNS's was also integral to this project. Without them it would have been difficult to confirm the current status of a number of young people and whether it would be appropriate to approach them in the first instance. It also enabled us to follow up on some outstanding permission forms.
- The majority of all professionals, from GP's to lead clinicians, were very helpful and keen to participate in the project. Working with the cancer managers streamlined the data collection process and enabled us to gain access to as much information as possible, in order to construct detailed individual pathways through the diagnostic journeys of the young people involved.

8. Outcome

Analysis is ongoing and will inform our overall conclusions and proposed interventions.

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