

*use MY data

My Data

Is it complete ?

Is it accurate ?

What does it show about my diagnosis and treatment ?

Why can't we all see our own data ?

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Individual level cancer data compiled from many sources

- Cancer Waiting Times
- Pathology Reports
- Multi Disciplinary Team Reports
- Cancer Outcome Services Data (COSD)
- Hospital Admission Data
- Treatment Records (Surgery, Chemo, Radio)
- Screening
- Clinical Audits
- Death Certificates..... not yet part of My Data!



Summary cancer registration record is created by National Cancer Registration Service

The screenshot shows a web browser window with the URL 'Tumour EXTERNAL ENVR...'. The page header includes 'encore' and navigation links for Search, Inbox (0), Reports, ESources (4474), Utilities, and Account. The user 'Andy Smith' is logged in. The main content area displays patient details for Andrew Smith (ID: 271989539) and a tumour record (ID: 0301-14-37828). The tumour details include registration status (Final), diagnosis date (30.12.2013), and primary site (ICD-O-3 (2011) C494: Connective, Subcutaneous And Other Soft Tissues Of Abdomen). The staging information is displayed in a table.

Andrew **Smith** 271989539 Patient details

Tumour number 1. Centre/Year/Serial: 0301-14-37828

Tumour details Edit Stage Audit Timeline

Status of registration **Final**

Pre-COSD Mode

Diagnosis date 30.12.2013

Postcode at diagnosis S17 3PT TRENT CANCER REGISTRY (Y0301)

Primary site **ICD-O-3 (2011) C494: Connective, Subcutaneous And Other Soft Tissues Of Abdomen**

Histology 9880/3: Malignant lymphoma, large B-cell, diffuse, NOS

Grade X

Laterality Not Applicable (8)

Tumour size

Nodes Involved Excised

Excision margin

Multifocal

No scans found false

Staging

Registry	Date
T N M	edition
TNM Stage Insufficient Info	

Basis of diagnosis Histology Of Primary (7)

Screened ('diagnostic route')

No treatment reason

Lab number* PH054273S/13

Further information

Bypass all validation

Delete Reference Audits [None]

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Screened
("diagnostic route")
No treatment reason
Lab number* PH054273S/13
Further information
Bypass all validation

Submorphologys [None]

Recurrences [None]

Original Scans [None]

Events
Add to this tumour: Pathology Notification Referral Imaging Drug Therapy Radiotherapy Surgery Event Other Treatment

Event	Provider	Hosp #	Practitioner	Date	Source type	
Pathology [Diagnostic]	Sheffield Te...	WR2992	Morley N	30.12.2013	Pathology On Disk	Details
Drug therapy	Royal Hallam...		Morley N	16.01.2014	Cosd Xml	Details
→ Anti Cancer Drug Regimen (Cytotoxic Chemotherapy)						

Registration actions Add

Action initiated	Action date	Place	User	Dt closed		
SEARCH	Search Outstanding Information	30.12.2013	Sheffield T...	suejackson	10.09.2014	Details
COMPLETE	Complete Registration Complete	10.09.2014 08:08	suejackson	10.09.2014	Details	
→ Autogenerated at finalising tumour						

Other tumours
[None]

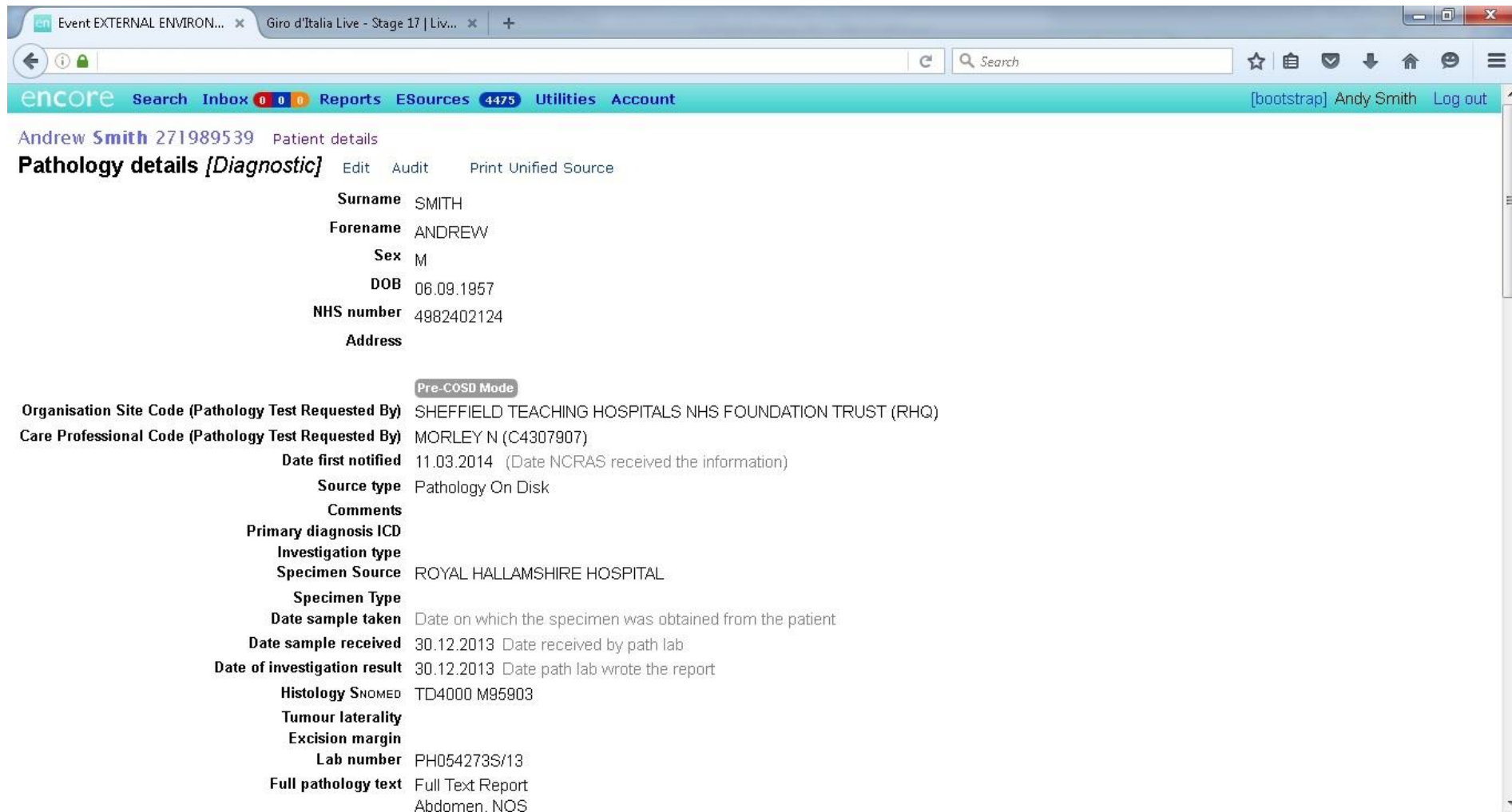
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My Cancer Registration Summary Record

- What is there is accurate
- Incomplete – no Stage. I'm sure I had radio
- Doesn't tell the story of my diagnostic pathway

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A lot of data still comes from pathology reports



The screenshot shows a web browser window with a patient record page. The browser tabs include 'Event EXTERNAL ENVIRON...' and 'Giro d'Italia Live - Stage 17 | Liv...'. The address bar contains a search field. The page header is 'encore' with navigation links for Search, Inbox (0), Reports, ESources (4475), Utilities, and Account. The user is identified as 'Andy Smith' with a 'Log out' link.

Andrew Smith 271989539 Patient details

Pathology details [Diagnostic] Edit Audit Print Unified Source

Surname	SMITH
Forename	ANDREW
Sex	M
DOB	06.09.1957
NHS number	4982402124
Address	

Pre-COSD Mode

Organisation Site Code (Pathology Test Requested By)	SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST (RHQ)
Care Professional Code (Pathology Test Requested By)	MORLEY N (C4307907)
Date first notified	11.03.2014 (Date NCRAS received the information)
Source type	Pathology On Disk
Comments	
Primary diagnosis ICD	
Investigation type	
Specimen Source	ROYAL HALLAMSHIRE HOSPITAL
Specimen Type	
Date sample taken	Date on which the specimen was obtained from the patient
Date sample received	30.12.2013 Date received by path lab
Date of investigation result	30.12.2013 Date path lab wrote the report
Histology SNOMED	TD4000 M95903
Tumour laterality	
Excision margin	
Lab number	PH054273S/13
Full pathology text	Full Text Report Abdomen. NOS



Full pathology text

Full Text Report
Abdomen, NOS

Malignant lymphoma, NOS

Andrew SMITH - WR2992 HODS 27346

SPECIMEN

Needle core biopsy from abdominal mass

CLINICAL DETAILS

? Lymphoma. Previous biopsy not diagnostic.

MACROSCOPY

A single core of white tissue measuring 12 mm in length plus an additional fragment.

MICROSCOPY

These are needle core biopsies of largely necrotic abnormal lymphoid tissue consisting of a mixed population of small and large lymphoid cells. Both populations appear to be morphologically abnormal, although morphological interpretation is extensively compromised by necrosis. These cells have the following immunophenotype:

CD10, CD20, bcl2 - Positive

CD3, CD5, CD23, CD30, Cyclin D1, bcl6, MUM1 - Negative

The screenshot shows a web browser window with two tabs: "Event EXTERNAL ENVIRON..." and "Giro d'Italia Live - Stage 17 | Liv...". The address bar contains a search field with the text "Search". The main content area displays a report with the following text:

CD10, CD20, bcl2 - Positive

CD3, CD5, CD23, CD30, Cyclin D1, bcl6, MUM1 - Negative

It is possible that some of the negative staining results are false negatives because of the low level of viability of this tissue. Similarly, Ki67 is difficult to interpret but the proliferation fraction of the neoplastic population appears to be high. CD3 and CD5 demonstrate a bi-stander T-cell population. No follicular dendritic cell population is detected by CD23.

This is interpreted as being an aggressive B-cell lymphoma showing germinal centre differentiation. The expression of bcl2 indicates that this is not Burkitt lymphoma. The immunophenotype and growth pattern are most in keeping with this being diffuse large B-cell lymphoma, not otherwise specified, showing germinal centre differentiation. The cellular morphology is, however, unusual for this condition given the presence of an unusually small population of cells, some of which have bi-lobed nuclei. It is recommended that this is managed as a diffuse large B-cell lymphoma.

Conclusion: Needle core biopsy, abdominal mass - Aggressive B-cell lymphoma, probably diffuse large B-cell lymphoma, NOS.

Ref: NS

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My Chemo details in the summary record

Unified eSources Transfer

Provider: Royal Hallamshire Hospital
Hospital Number: WR2992 NHS No: 4982402124
Name:
Previous Surname: Date of Birth: 06.09.1957
Sex: Ethnicity:
Address: GP Practice Code
GP Code: GP Practice Code

Core Linkage Diagnosis
Primary Diagnosis: C833 Large Cell (Diffuse)
Laterality:

Cancertreatmentmodality02
Organisationsitecode RHQHH
Providertreatmentstartdate
te Cancer
Treatmentstartdate 2014-01-16
Cancer
Cancertreatmenteventtyp01
e
Consultantcode C4307907

LPI Provider Code RHQ
NHS No. Status Ind. 01
Code
COSD XML Record ID 7941432D-2305-403A-8220-5A5484347847

Andrew Smith 271989539
Born on 06.09.1957 Alive on 06.03.2015 NHS number: 4982402124 White Brit **F2** Bookmark

0. Summary 1. Active Monitoring (COSD) 2. Path

2. Treatments, Imaging and Pathology

Pre-COSD Mode

Diagnosis date 30.12.2013
Postcode at diagnosis S17 3PT TRENT CANCER REGISTRY (Y0301)
Primary site ICD-O-3 (2011) C494: Connective, Subcutaneous And Other Soft Tissues Of Abc
Histology 9680/3: Malignant lymphoma, large B-cell, diffuse, NOS
clear icd10rev4o2
 C833 DIFFUSE LARGE B-CELL LYMPHOMA
 C825 DIFFUSE FOLLICLE CENTRE LYMPHOMA

Grade X
Laterality 8 : Not applicable (B)
Nodes Involved Excised
Excision margin
Lymph node information
Multifocal
Bone marrow involvement
No scans found

Staging Registry (REGISTRY) Date
T N M edition
TNM Stage Insufficient info (?) Revised Ann Arbor
Basis of diagnosis 7 : Histology of primary (7)
No treatment reason
Further information

<https://yubikey.encore.nhs.uk/stagings/281677522/edit#>

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So what about all those amazing reports that come out?

- Routes to Diagnosis
- Comparative treatment reports
- Analyses of survival against treatments

There is a lot more in addition to the summary record

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Cancer

Cancer patients to get faster diagnosis, says Jeremy Hunt

Health experts believe new measure diagnosing patients within 28 days could save up to 11,000 lives a year

Press Association

Sunday 13 September 2015 10.57 BST



This article is 1 year old

0 152



i Health secretary Jeremy Hunt: 'Those who sadly have cancer will get treatment much quicker and we will save thousands of lives as a result.' Photograph: Neil Hall/PA

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Cancer Waiting Times and Hospital Episode Statistics

- Tell the story of my diagnostic pathway
- Fill in a lot of detail
- Allow derivation of key metrics

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Systemic Anti Cancer Therapy (SACT) data

- Chemo
- Very detailed, very thorough
- Exact dose of each individual drug
- **R-CHOP** (cyclophosphamide, doxorubicin, vincristine, and prednisone), plus the monoclonal antibody rituximab
- No Prednisone – but it is in the regimen

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The screenshot shows a web browser displaying a Daily Mail article. The URL is www.dailymail.co.uk/health/article-3766382/Nineteen-NHS-trusts-review-chemotherapy-high-death-rates.html. The page features the MailOnline logo and a 'health' sub-brand with a green leaf graphic. Navigation links include Home, News, U.S., Sport, TV&Showbiz, Australia, Femail, Health (selected), Science, Money, Video, Travel, and Fashion Finder. A search bar is located on the right side of the page. The main headline reads: **Hundreds of NHS cancer patients have been 'killed by chemotherapy': 19 hospital trusts with high death rates are told to improve**. Below the headline is a bulleted list of key findings:

- Public Health England reviewed chemotherapy mortality across country
- Study looked at 30,000 patients who received cancer treatment
- Found 19 trusts had mortality rates in excess of the 95% control limits
- Cancer charities said it was vital patients were made aware of the risks

 The article is attributed to 'By KATE PICKLES FOR MAILONLINE'. On the right side, there are social media sharing options for Facebook, Twitter, and Google+, along with a 'DON'T MISS' section featuring a photo of a woman and a child, with a caption: 'I'm just not ready to believe it': Carol McGiffin reveals her younger sister Tracy has died just four months after being diagnosed with cancer.

I am a doctor caring for cancer patients. the authors have done an incomplete study without even verifying with the physicians if the data is correct. The hospitals do not have the required resources to send the data and check their accuracy, and the doctors have no idea about the data sent, not do they have chance to verify it. In my practice itself, patients with stage IV disease, who have received palliative chemotherapy have been coded as having received curative treatment. With unreliable data, the authors have performed a disservice to the patients and treating physicians by producing results which are spurious at best. The only purposes the study has served is to create a culture of victimisation among patients and has created an air of fear among doctors. Rather than improving care, it has demoralised many doctors and has put off patients from receiving valuable chemotherapy treatment.

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...style/health/651155/targeted-radiotherapy-breast-cancer-effective-research

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Home > Life & Style > Health > Targeted radiotherapy could be as effective as treating whole breast for cancer patients



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Targeted radiotherapy could be as effective as treating whole breast for cancer patients



www.express.co.uk/news/uk/E43143/Cancer-patients-NHS-radiotherapy-machines-CT-scanners-out-of-date

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REVEALED: Cancer patients put at serious risk by OUT-OF-DATE machines

CANCER patients are being put at serious risk of debilitating side effects as they are treated on OUT OF DATE machines and scanners.

By REBECCA PERRING
PUBLISHED: 10:43, Thu, Feb 11, 2016 | UPDATED: 11:04, Thu, Feb 11, 2016

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4

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Have I got better

- No Death certificate
- No recurrence – scare November 2016
- No Patient Recorded Outcomes
- But there is social media!

Your Activities

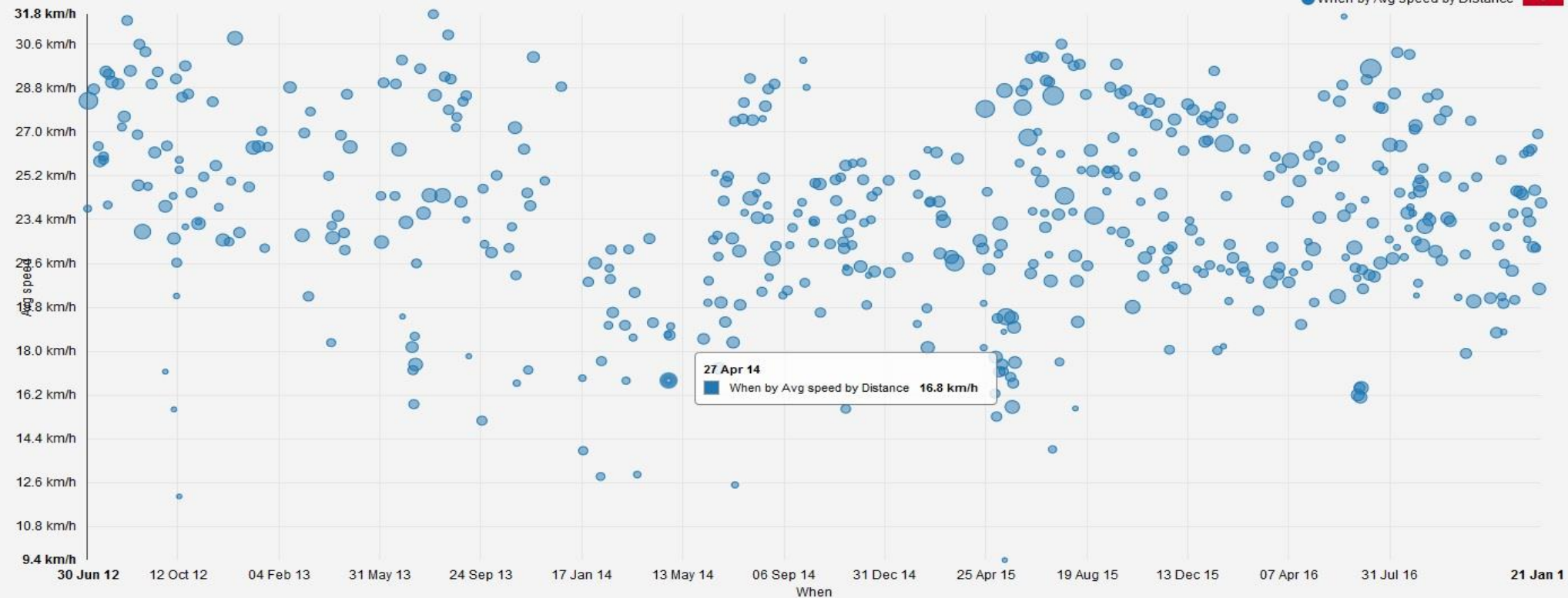
Your data is private...

Summary Activities Segments Efforts Routes Challenges Wheel Infographic Signature Image Rivals Update

Show Filters Add filter Activity Id + Config All ?

List Map Chart

When by Avg speed by Distance ⚙️



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What did I find

- My data is generally accurate
- Incomplete – Stage, Prednisone, Outcomes
- Secure
- I trust the people who handle it
- Doesn't tell anyone much about me

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Why should **WE** be able to see **OUR** data

- Check it is accurate and complete
- Patients can confirm the accuracy of the data
- Counter 'false facts' and sensationalist BS
- Know how and where our data are being used
- Informed opinion about risks and benefits
- Active and involved patients will have better outcomes – Can we prove this