Pathways to diagnosis of haematological malignancies

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HMRN: What is it?

- Specialist population-based registry, set up in 2004
- Ascertains all people newly diagnosed with haematological malignancies in study area
- Around 2200 patients/year; over 22,000 registered so far
- Data collected and used for audit and research
- Section 251 support
HMRN: Where is it?

- Yorkshire and Humber
- Population ~4 million

- Similar socio-demographic structure to UK
  - age
  - sex
  - affluence/deprivation
  - urban/rural status
HMRN: Who is involved?

**Clinical care**
- Haematology clinical teams
- Yorkshire Cancer Network
- Humber & Yorkshire Coast Cancer Network

**Data management & analysis**
- Epidemiology & Cancer Statistics Group (ECSG)
  - Health Sciences
  - University of York

**Diagnostics**
- Haematological Malignancy Diagnostic Service (HMDS)
  - St James’s Institute of Oncology
  - Leeds Teaching Hospitals NHS Trust
HMRN: data

- Patient partnership
  - Focus groups
  - Health questionnaires
  - Quality-of-life (EQ-5D)
  - Cancer registrations
  - Death certificates
  - Hospital episode statistics
  - Area-based socio-demographics

- Diagnostic classification
  - Prognostic biomarkers
  - Treatment response
  - Progression and transformation

- Laboratory data

- Clinical data
  - Demographics
  - Prognostics
  - Treatment
  - Response

- National health data
Using HMRN data

Improving patient care through analysis of patient pathways
Symptoms and time to first help seeking and diagnosis of haematological malignancy

• Based on infrastructure of HMRN
• Questionnaire sent to patients diagnosed with a haematological malignancy, 2004-2011, who agreed we could contact them
• Around 6 weeks after diagnosis
• Asked to report symptoms experienced in time leading to diagnosis, date of onset of each symptom and date first sought medical help
• Returned by 3329 of those contacted (57%)

Distribution of symptoms reported by 2336 HMRN patients diagnosed 2004-2011 and UK Referral Guidelines; all diagnostic groups
Distribution of symptoms reported by 2336 HMRN patients diagnosed 2004-2011, by diagnostic group
Time from symptom onset to diagnosis in 2336 HMRN patients diagnosed 2004-2011
Duration (mean days) of the patient and diagnostic interval of HMRN patients diagnosed 2004-2011
National data on factors associated with delayed presentation (Kings College London)

- Included patients with acute leukaemia, lymphoma, CLL, CML and myeloma (200 of each)
- All had participated in the 2010 UK National Cancer Patient Experience Survey and agreed they would take part in further research
- Sent questionnaire (Nov 2011) about symptoms, time to presentation and reasons they may have delayed going to the doctors
- Response rate 79%
- 24% with CML delayed over 3 months, 9% with acute leukaemia
- Symptom profiles were broadly comparable with HMRN
- Risk factors for delay include sweating, thirst, itchiness, extreme fatigue and not realising symptoms were serious
Lymphoma and myeloma: understanding the patient pathway and promoting early diagnosis

• NAEDI funded study (2012-2015)
• HMRN infrastructure
• Appraisal interval > Help seeking (n=50)
• Primary care interval > Visit frequency and symptoms (population based)
• Secondary care interval > Referral pathway (population based)
  • All diagnoses July 2012-Dec 2013; ~3000
  • Type of referral
  • Referral specialities (from first referral to diagnosis)
  • Impact on referral type/speciality on time to diagnosis

• Routine HMRN information available for all patients – stage of disease, treatment pathways and survival outcomes etc.
Referral pathways and time to diagnosis: lymphoma patients diagnosed in 2000 (n=189)¹

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<thead>
<tr>
<th>Initial Referral (% of cases)</th>
<th>Time (median/range) between referral and diagnosis (months)</th>
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<td>General Surgery</td>
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<td>Others</td>
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Help seeking behaviour: Lymphoma, 2000

• Qualitative study including 32 patients¹
• Some key findings:
  • Few people had heard of lymphoma or knew of symptoms
  • Symptoms were variable by type and site of lymphoma
  • Symptoms mimic other illnesses/medical problems
  • Symptoms often vague, mild, intermittent, painless
  • Feeling well, other than a lump
  • Patients did not like to seek help for such symptoms
  • Patients ‘normalised’ symptoms, getting older, being busy etc.

Patient pathway: lymphoma

2009

“Went to the doctors at least 8 times. (Dr) kept telling me it would not be anything serious as I was too young.”

(Age 37; shoulder/chest pain, tired, breathless, cough, weight loss, coughing up blood; time to diagnosis 5 months)

2011

“A&E wasn’t productive. Went there four times and sent home with just other painkillers.”

(Age 52; pain/swelling in stomach, back pain, weight loss, not eating, drinking or sleeping; time to diagnosis 1 month)
Patient pathway: myeloma

2006
“Contacted my GP for severe back pain, x-rays revealed a fracture. I was referred to orthopaedics at hospital who supplied a brace and pain killers. Following 6 weeks and a further orthopaedic appointment, my GP asked me to supply a blood sample to check how severe my osteoarthritis was, as he thought this was the cause of the fracture. This revealed I was suffering from myeloma and had had it some time.”
(Age 78; back pain, breathless, lack of energy; time to diagnosis 22 months)

2011
“The backache just got worse and worse and still no referral was arranged to ortho until I had reached rock bottom physically and mentally. The ortho blood tests revealed high calcium levels and I was admitted as an emergency.”
(Age 70; backache, tired, poor skin and hair; symptoms to diagnosis 1 year)
Patient pathway: myeloma

2014

“I played golf... and found that the ball wasn’t going as far and... I had this pain in my shoulder blades and I was also getting tired more often, and this particular day I was struggling to get my breath, so that I knew something was wrong and I went to the walk-in clinic. And so... they examined me and said, oh, it’s a chest infection. So he gave me some antibiotics and a week later there was no improvement so I made an appointment, went to my own doctor’s surgery, saw (Dr) and.... he said, oh, it’s a chest infection, and he gave me some more antibiotics. Well, I went on (holiday) and everything went off quite well until we had to get into this coach and I got this really sharp, intense pain, only for maybe a few seconds, and then we came back and I went to the doctors again and this time I saw a stand-in doctor, and they said the same thing, oh yeah, it’s a chest infection, gave me some more antibiotics. Another week went past, no improvement, went back again, this time I still didn’t see my own doctor, I saw like, she’s not a doctor, but she was the next thing to a doctor. I saw her three times and she said more of the same thing, antibiotics, and then the last time she said, oh, we’ll try out some steroids. And they didn’t work so then she said, I’m sorry but we can’t do anything else for you, you’ll have to see a specialist... So I went to see this chest doctor. He did a lot of tests, and my white cells were high. He said... I want you to see a haematologist. So he wrote a letter to my doctors and they got me an appointment.”
Challenges:

• How to:

  • Improve knowledge of disease/symptoms among general public

  • Encourage **appropriate** help-seeking/presentation

  • Identify what would facilitate rapid identification of patients with potential haematological malignancies in primary care

  • Identify and address barriers to rapid and appropriate referral (between providers and specialities)
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