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Diagnostic journeys in myeloma: How long does it take to diagnose? Methodological issues and progress to date

North Wales Centre for Primary Care Research
Canolfan Gogledd Cymru ar gyfer Ymchwil Gofal Cychwynnol

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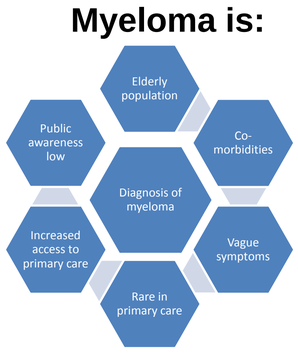
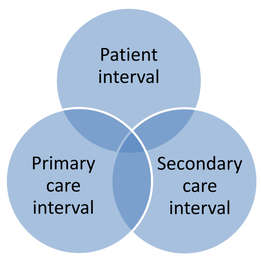
Background

Myeloma is a mature B cell malignancy with no set pattern of presentation. It is acknowledged as 'hard to diagnose' with multiple complexities contributing to time-to-diagnosis. There is limited literature to describe these pathways. Journey time intervals may be influenced in multiple domains:

Myeloma is:



Domains of potential delay:



Studies in clinical settings rely on retrospective analysis of historically collected data; with biomedical or scientific paradigms underpinning analysis. Emphasis is on 'objective' measurements; the subjective and socially situated experiences and interactions within the journey is not considered.

Aims

- Quantify and describe how diagnostic journeys occur in myeloma patients across Wales
- Determine factors, interactions and experiences influencing the pathway to individual diagnosis
- Determine factors which facilitate timely diagnosis

Methods

Phase 1 Quantitative study:
Designed disease specific questionnaires to patient, GP and diagnosing specialist collect complexities of the journey; triangulation and interpretation of data determining influences and exact time to diagnosis. Recruitment direct from diagnosing MDT allows collection of real time data on:
- Pre-diagnosis symptomology and duration
- Routes of presentation in PC and SC
- Frequency of health care access
- Demographics
- Comorbidities

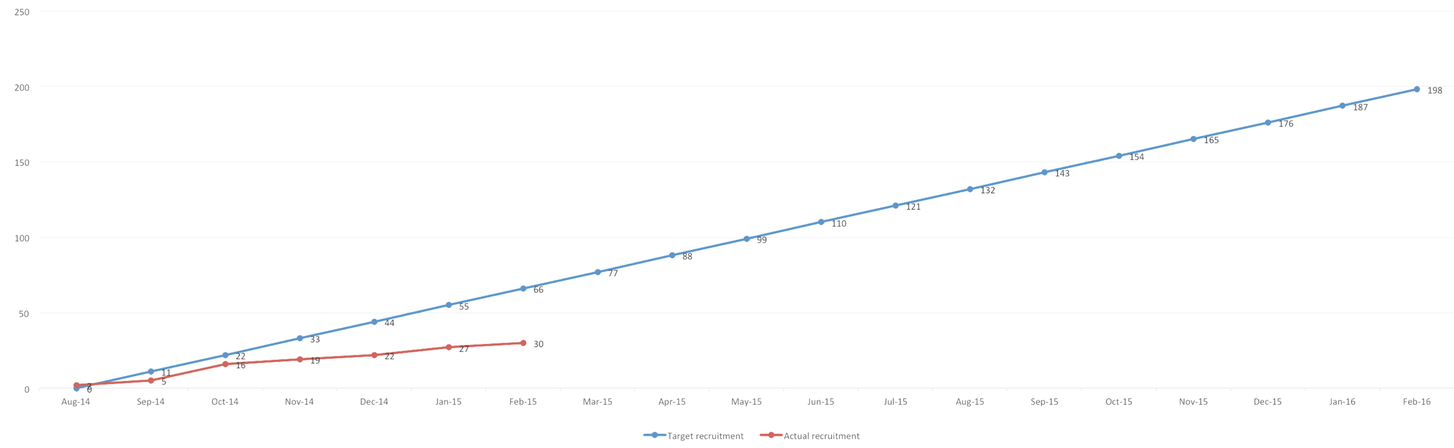
Free text questions in all participant questionnaires help identify information-rich participants for interview

Phase 2 Qualitative study:
Semi-structured interviews with patients and their GPs
- Evolving interview guide informed from Phase I data
- Personal social and contextual experience captured
- Sampled from prompt, longer and asymptomatic
- Determines what works well and what doesn't work so well

Analysis:
- Phase I and II data - independent reporting and publication
- Synthesis of two datasets – unique view and report of factors promoting timely diagnosis help influence policy and practice

Recruitment to date

Recruitment Phase I



Questionnaire Return Phase I

Patient questionnaires returned vs screened	Primary Care questionnaires Returned	Secondary Care questionnaires returned	Full 3 dimensional profile available	No consent to clinicians questionnaire
30/43 70%	13/30 43%	22/30 73%	13/30 43%	1/30 3%

Early findings: results from first 30 patients

Time to diagnosis	Appraisal interval	Diagnostic interval
Interval –median days (interquartile range)		
144 (32-258)	43 (4-227)	62.5 (16-171)
Range 0-825	Range 0-714	Range 0-253

Presentation Symptoms

- **29/30 patients report symptoms pre-diagnosis**
- **17/30 patients experience 3 or more symptoms pre-diagnosis (range 0-7)**
- **Bone pain 19/30**
- **Musculoskeletal pain 17/30**
- **Fatigue 14/30**
- **Repeated or recurring infections 8/30**
- **22/30 patients require pain relieving therapy for symptom management with 13/30 requiring opioids**
- **10/30 patients c/o cluster symptomology- bone pain/musculoskeletal pain/fatigue**

Presentation Route

- **28/30 patients report having had consultations with their GP prior to diagnosis of myeloma**
- **19/30 had 3 or more consultations with GPs (range 0- 11)**
- **10/22 patients received direct referral to haematology**
- **13/30 patients went on to present as an emergency to secondary care**
- **3/30 patients were being monitored for MGUS within PC**
- **2/30 patients being monitored for MGUS within SC**
- **1/30 being monitored for previous plasmacytoma within a SC**
- **2 patients in a monitoring program for MGUS in PC went onto present as an emergency to SC**

Conclusions

Study feasibility:
- Full engagement in Wales – demonstrates interest of patient and professionals
- Methods operationally viable - successful uptake of 70% •Complexity of the pathway collected successfully
- Disease specific questionnaire gives first opportunity to study in depth the patient pathway and interactions
- Data rich and informative
- Phase I successfully identifying Phase II participants and informing interview guide

Early findings:
- Primary care – problematic referral pathways onto SC
- Symptom attribution – patient – poor recognition of seriousness
- Symptoms attribution GP – misattribution of recognised myeloma related symptoms Symptom signature – "bone, musculoskeletal pain and fatigue
- Associations of variables will provide greater insight
- Qualitative interviews will add to the richness of data giving a unique context to the results.

For further information about this project please contact Tania Seale: Email t.d.seale@bangor.ac.uk