Delivering Healthy Ambitions
Better for Less

Overview.

Introducing a community monitoring approach can improve patient experience and clinical outcomes whilst significantly reducing costs.

This approach describes a community based specialist service for patients diagnosed with haematological conditions but has the potential for wider application.

Why specialist monitoring in the community?

Population studies demonstrate MGUS/early CLL* in approximately 3-5% of adults. Greater use of blood testing in routine health screening/investigation is increasingly producing diagnoses of these diseases where previously they may have gone undetected until symptoms appeared.

The crude incidence rate for MGUS and early CLL is around 11 per 100,000 per year, with median survival of 10 years. Prevalence is in excess of 50,000 patients in the UK, around 5,000 of which are in Yorkshire and the Humber.

Current treatment is not targeted and damages normal tissue once the malignant cells are in the minority. Early stage patients by definition have low disease bulk. Treatment at an early stage leads to little or no benefit and can be detrimental to health, particularly in elderly patients.

The risk of disease progression to a stage requiring treatment is low: around 5-10% per year for Stage A CLL and around 1% per year for MBL and MGUS. Most patients will die of natural causes. So why propose systematic monitoring?

The reason is that irreversible damage such as bone lesions or renal failure can occur before the patient feels symptoms. In other cases disease progression may be so gradual that the patient may be unaware of worsening symptoms such as anaemia, thrombocytopenia or dehydration.

With the existing system patients are sometimes not diagnosed or not informed of the diagnosis to avoid unnecessary anxiety. Monitoring is not standardised leading to differential levels of care. In many cases patients are referred back to their GP and/or monitored for symptoms only or not at all. Alternatively, large numbers of patients not requiring treatment are monitored through regular attendance at hospital out patient clinics. This diverts specialist expertise away from patients with progressive disease, is not cost effective, and can create a culture of 'illness' around people who could be getting on with their lives.

What is the challenge?

Currently patients who require routine ongoing monitoring are seen, typically twice a year, by specialist teams in secondary care clinics. Monitoring in these clinics can be slow due to pressure on limited specialist teams, inconvenient for patients, and costly, (£260 for a first outpatient appointment, and £114 per follow up, required twice annually) when compare to community based alternatives.

*** MGUS is a pre-cancerous blood disorder/ CLL is chronic lymphocytic leukemia.**

How could we provide better care for less?

The development of a community-based monitoring service for people with haematological cancers has been an initiative led by the Haematological Malignancy Diagnosis Service (HMDS) at Leeds Teaching Hospitals NHS Trust in collaboration with the Yorkshire Cancer Network. The idea was to provide more patient–centred, systematic monitoring for patients diagnosed with the haematological conditions MGUS and early CLL, although the approach has potential for much wider application. The following pages describe the approach in detail.

Benefits

Negotiation is required between commissioner and provider(s) to establish a community specialist monitoring system with dialogue between GPs and secondary care consultants. The focus of negotiation should be on the clear benefits to implementing this approach:

Patient benefits

Reduction in hospital visits and consultations. Results are returned promptly to the GP who then communicates them to the patient and appropriate action is taken. If hospital visits reduce there may be additional benefits for family members and carers, who no longer need to take leave from their own place of work to transport or accompany their relative to / from clinic.

Quality benefits

GPs have rapid one to one access to specialist opinion and advice. Decisions can be easily and effectively made on borderline or difficult cases. Community monitoring can ensure more appropriate use is made of specialist opinion and resources.

Financial benefits

As well as the quality benefits, there are also potentially significant financial benefits to be generated from keeping people out of hospital for routine testing.

The HMDS initiative has been running for three years, in each year, the scheme has demonstrated a saving when compared with clinic based monitoring. In 2010/11, the tariff price for an adult haematology follow up is £114, compared to the £78 cost of the outreach scheme. In addition there are opportunities for further savings from the outreach scheme through recognised economies of scale. At a cost of £78, the savings relative to the 2010/11 tariff are over 30%.

Savings to an average PCT are relatively conservative at just under £30,000 annually; however the difference in cost of the outreach service compared to clinic based monitoring remains significant at 31% in 2010/11. The potential to extend the service to additional patient groups would generate further savings both through the lesser cost relative to tariff and where economies of scale can be generated.

The savings identified only cover the reduction in outpatient appointments; additional savings from across the patient pathway will be significant. Additional benefits of specialist monitoring lie in the avoidance of costs associated with bone lesions and renal failure that patients may develop without appropriate monitoring. Tariff prices for HRGs associated with the treatment of these conditions range from £312 (chronic renal failure with length of stay 1 day or less) to £4,288 (chronic renal failure with major CC) under the 2010/11 tariff. Further potential savings accrue from reduced ambulance journeys and demand upon specialist clinicians' time.

On top of this there are savings to the patient in terms of time and expense in making a hospital visits.

A new approach – HMDS case study

Newly diagnosed patients are initially assessed by a specialist in a Haematology clinic. Patients meeting the criteria for community monitoring are offered the option to be monitored via their GP practice. Patients who decline will have ongoing clinic review.

Those patients who take up the community monitoring will be registered with the HMDS service. HMDS then liaise with the patient's GP to organise the patient monitoring. Patients are monitored at twice yearly intervals. HMDS send a monitoring pack to the patient 2 weeks prior to the follow up date asking the patient to make an appointment with the Practice Nurse/ phlebotomist as appropriate. Packs contain covering letter with instructions for return of the pack, patient information sheet, symptom questionnaire and nurse/ phlebotomist information sheet.

There is a failsafe mechanism so that if the pack is not returned to HMDS within 4 weeks the GP and/or patient are contacted to identify the reason.

Patients whose biological tests give cause for concern are re-appointed to the haematology clinic. For patients whose biological tests are OK but whose questionnaire is suggestive of progression, HMDS contact the GP/patient for further exploration of the symptoms of concern.

Patients with no sign of progression on either biological test or symptom questionnaire receive a report (copied to GP) indicating their condition is stable and the date for the next pack to be sent out.

The revised pathway was developed by a core group of clinical and scientific staff from HMDS, Yorkshire Cancer Network Service Improvement Team, Haematology Consultants and GP Cancer Leads from the organisations in the pilot areas. The joint Haematology Group covering both the Yorkshire Cancer Network and the Humber and Yorkshire Coast Cancer Network was used as an overall reference groups for the development of the new service. This is a multi-professional group that also includes patient and carer representation from the YCN User Partnership Group. In addition, during the early stages of redesign the service concept and supporting patient information was explored in detail with a patient/carer reference group to ensure a reasonable balance between encouraging diagnosed individuals to comply with the monitoring protocol without creating unnecessary alarm about the significance of their condition.

To support the new pathway, HMDS have developed an IT platform to undertake the flow cytometry analysis. This is a secure web-based application accessed via nhs.net. It produces a fully integrated report with cumulative results for the individual patient. It tracks and manages sample processing and manages follow up and despatch of samples.

Evaluation

Over the course of the pilot study, 284 patients from three hospitals have accepted the opportunity for community monitoring over a 15 month period. Five hundred and forty-five samples have been taken and processed.

The new approach delivers a high level of patient satisfaction: 84% of patients attending clinic said they would prefer the community based service, and 88% of those using the community based approach said they preferred it to clinic attendance. Patients attending clinic reported average wait in clinic of 60 minutes, compared with average wait of 5 minutes on the outreach scheme.

As a pilot it has proved acceptable to primary care, with 212 practitioners in 116 practices managing patients on the scheme. Just 4 practitioners rejected the scheme when approached, mainly voicing concerns about shifting work from primary to secondary care. Most problems should be resolved by mainstream commissioning of the service rather than running as a pilot.

The approach has proved a safe, effective approach to disease monitoring. Over the pilot period only 16 of the 284 patients have required a clinic referral, 8 of which had turned out to be ineligible for community monitoring on closer assessment; 5 required specialist re-assessment (one of which showed disease progression) and 3 decided they preferred clinic-based monitoring.

The robustness of the approach also lends itself to expansion to other patient groups and possibly healthcare providers beyond the area currently covered by HMDS.

Key benefits of an outreach service are:

- Greater patient choice. 88% prefer the service to conventional monitoring with less travel, less waiting and more control over timing of appointments
- High quality monitoring in a local setting. It provides integrated information management tools and advanced diagnostics with consultant review for every patient
- Improved support for primary care to manage patients with complex health issues. In some areas primary care currently manages theses patients with no direct support from secondary care
- Benefits to the local health economy; reduced clinic appointments and patient transport.

Implications for providers need to be fully discussed and properly managed – including changing clinical working practices.

Other applications

Specialist community based monitoring has been applied to MGUS and CLL but the same approach could potentially be applied to a variety of other conditions requiring specialist monitoring.

One patient group to which there could be benefit in including in the service are those patients being monitored post treatment. These could include ‘cured’ patients such as Hodgkin lymphoma with more than 5 years in remission (who may only need a systematic questionnaire type approach), or CLL and myeloma patients whose long term monitoring is similar to untreated indolent disease, although all patients will relapse. For the latter group there is potential to expand the outreach service to provide some or all the monitoring.

Key contacts

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Better for Less briefings

All NHS Yorkshire and the Humber Better for Less briefings are available from:

www.healthyambitions.co.uk/betterforless