

Pathways of patients with chronic haematological malignancies: a report from the UK's population-based HMRN

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Plain language summary

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Plain language summary

Around half of all blood cancers (leukaemias, lymphomas and myeloma) are chronic and incurable. Management often involves 'watch and wait', which begins with hospital-based monitoring and is followed by treatment if the cancer progresses. This typically leads to further observation and treatment in an ongoing process over time. Patients often experience anxiety and distress about not being treated at diagnosis and also because of uncertainty about 'if' and 'when' chemotherapy might be needed. Information is critical if patients are to (1) understand what may happen to them in the future and (2) be involved treatment decisions. However, evidence about the care pathways most patients follow is lacking. This programme was designed to fill this gap, tracking all patients with chronic blood cancers through their care pathways.

We collected information about diagnosis, treatment and outcome on approximately 8000 patients. These data were used to develop models that could be used to examine outcomes and costs. When compared with the general population, patients with blood cancer were confirmed to have more healthcare activity (e.g. hospital appointments and admissions). Computer programs were developed to electronically generate visual care-pathway 'maps' that revealed key similarities and differences between patient groups. Two questionnaires exploring quality of life and involvement in treatment decisions were developed and completed by 3153 patients in 14 hospitals. Thirty-five patients were interviewed about their preferences for information sharing and decision-making; needs were found to differ between patients and over time, and treatment recommendations from clinical staff were generally preferred. Emotional difficulties associated with uncertain trajectories were also clearly described.

Yielding new information about the pathways of patients with chronic haematological malignancies, findings from this programme can be built on to improve future care. Final information resources could not be developed or tested in practice due to COVID-19, which continues to impact how health care is delivered.

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This article

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