

'Just one thing' – what would myeloma patients change about their treatment and care?



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Myeloma UK is the only organisation in the UK dealing exclusively with the incurable blood cancer myeloma and related conditions. We are committed to working with healthcare professionals to improve the lives of myeloma patients at every stage of their journey, from detection and diagnosis to end of life.

Background

Ensuring patients with cancer have the best possible experience throughout their treatment and care has long been central to National Health Service (NHS) strategy.^{1,2} The Clinical Service Excellence Programme (CSEP) is a Myeloma UK best-practice initiative, designed to support hospitals in delivering services that are patient-focused and responsive to individual need. An integral component of the CSEP assessment process is feedback from patients on their experience of care.

Aims

Seeking feedback from patients enables clinicians to:

- Evaluate the standard of care they provide
- Identify positive aspects of the service
- Highlight any areas of improvement that would positively impact patients
- Inform service development and resource planning

Method

Patients from hospitals undergoing CSEP accreditation are invited to complete an anonymous patient survey comprising 26 questions about their experience of care.

The survey ends with the optional question:

'If you could change one thing about your myeloma treatment and care, what would it be?'

Between 2015 and 2021, this question was answered by 664 patients from 41 hospitals. Of these patients, 268 answered with constructive or negative comments. These comments were thematically organised into eight categories: communication with healthcare professionals (HCPs), continuity of care, coordination of care, holistic needs, hospital facilities, travel, treatment options, and waiting times.

The majority of comments were positive; these are not included in the results presented.



Results

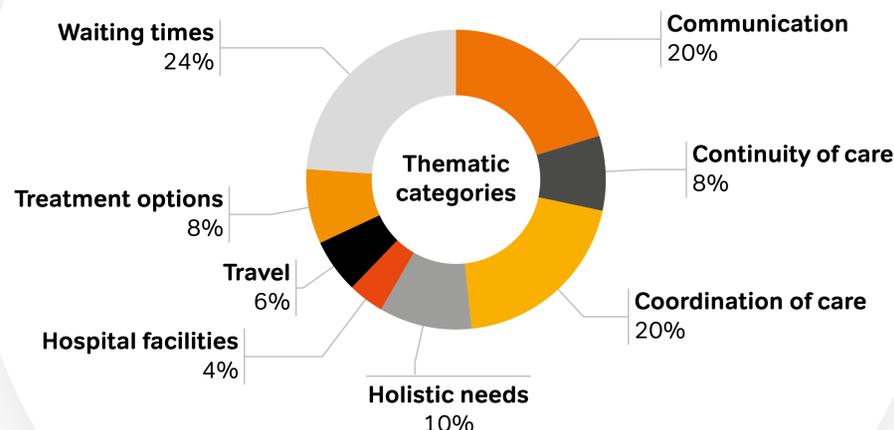
Thematic categories of patient responses (n=268)



24% of patients said length of waiting time is the one thing they would change



20% of patients felt communication with HCPs is an area that could be improved



20% of patients would like to see better coordination of care



10% of patients would like a more holistic approach to their needs



Discussion

The eight themes indicate the key areas of improvement which are important to patients. Some of these themes highlight systemic logistical problems within the NHS: waiting times, hospital facilities, treatment options and travel to hospital. Other themes underline the importance of good communication, continuity of care, and having holistic needs

met; all of which have significance in myeloma. An overarching theme is continuity of care between departments and with primary care. Waiting times in clinic and pharmacy were the key concern. This may reflect the greater numbers of myeloma patients being monitored, as treatment options and survival rates improve. It should be noted that most of the

comments analysed pre-date the coronavirus pandemic. Now that telephone clinics have become widespread, it will be of future interest to gauge how this affects concerns about waiting times.

Hospitals undergo CSEP re-accreditation every four years, enabling them to measure the impact of any service changes.

Conclusion

Individually, the results from the survey facilitate a feedback process that is dynamically responsive to patients' concerns. Collectively, the results contribute to a wider understanding of myeloma patients' experience and what matters most in their treatment and care. This data is being used to facilitate improvements in clinical practice and outcomes via CSEP.

References: 1. The NHS Cancer Plan, 2000 2. The NHS Long Term Plan, 2019

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Clinical Service Excellence Programme

Recognising best practice in myeloma care

