

POSTER ABSTRACT

Towards Active Integrated Waiting Lists: The Patient Lived Experience

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Background: Specialist healthcare providers internationally face challenges managing elective care waiting lists. There is an increase focus on how we can provide integrated care solutions to achieve active rather than passive waiting. This requires potentially complex interactions across care boundaries and care providers alongside novel digital solutions. Crucially however we must also understand the lived patient experience of people on those waiting lists. Little research has considered the lived experience of people on waiting lists for specialist care.

Methods: 46,000 individual patients on waiting lists at a major tertiary referral centre in the West Midlands, United Kingdom were sent a survey to understand their experiences of waiting for specialist care whilst remaining in the community context. Patients were contacted via SMS initially with a link to a web-portal with follow up contact via letter for those who did not complete the initial survey. This work is linked to/informed by extensive, commissioned, independent deliberative patient and public involvement work looking at waiting list management previously completed for this organization. This was approved locally as a service evaluation.

Results: 20,741 responses were received, representing a 45% response rate. 62% of response were received via the website, with 38% via letter. 1,633 patients (7.9%) wished to be removed form the waiting list. 18.5% felt that being on the waiting list was severely stopping them from carrying out normal tasks, 17.7% reported that being on the waiting list was severely impacting their ability to work and 14.0% reported that being on the waiting list severely impacted their ability to care for others. 20.7% felt their condition had got severely worse whilst on the list. Impact of being on the waiting list was most notable for those in the most deprived population groups, with 25% of patients in the most deprived areas having been severely impacted by the wait time, compared with 14% in the least deprived areas. There was additional variation on the impact of waiting based on ethnicity, age and work status.

Discussion: High healthcare demands result in an inevitability of patients waiting for specialist services. This work demonstrates the diversity of lived experiences for patients on elective care waiting lists, stressing differences between key population groups including those with protected

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characteristics. Patient cohorts within specialist waiting lists must be seen as diverse and dynamic. Much promised prioritisation and active waiting initiatives must be individualised to meet the diverse needs of the people on the waiting lists and recognise further work is needed to better understand how to engage with these groups.

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