How do managers and leaders in the National Health Service and social care respond to service user involvement in mental health services in both its traditional and emergent forms? The ENSUE study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Plain English summary

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User involvement in mental health services was established before involvement in most other medical specialties and could be said to have taken the form of a ‘new social movement’. Early literature suggested that, when it came to involvement in the UK NHS and social care, service users (SUs) and their organisations struggled to have a real impact on decision-making at either individual or strategic levels. The aim of the present study was to find out how user involvement is faring currently. We discovered that ‘ordinary’ SUs do have some involvement in service planning and delivery; they regard this as having a positive impact; and they are supported by both front-line and senior staff. In studying user-led organisations, we found that they are working in a climate of organisational change and complexity that has forced them to adapt and change, such that ‘traditional’ styles of confrontation and campaigning have given way to the adoption of more corporate and professional modes. However, this posed many challenges for the organisations we studied. In addition, new opportunities and forums have opened up for user involvement, including the possibilities of becoming members and governors of NHS foundation trusts. When we looked at these, similar issues of appropriate styles of behaviour and negotiation arose. Personalisation is another way in which SUs may control their own care, but we found little evidence that this is happening. We therefore recommend that more research be carried out on the applicability of personalisation to the field of mental health.
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