

Service User Engagement – What is to be done?

1. The key to the successful engagement of service users in the improvement of health services is to ask service users questions which only they can answer. Service users are uniquely positioned in the healthcare system to provide information about their own personal experience and expectations of healthcare.
2. The information in stories that service users have to tell about their own experience of being unwell, and the care that was provided to them can only be unlocked if these stories are listened to and attended to. These are the stories that service users tell to their friends and family and to anyone who asks, “How are you?”, along with the stories of those who provide care they form the very substance of the healthcare system.
3. The only thing that really counts when considering the quality and effectiveness of any healthcare system is what happens when a patient receives care from someone qualified and able to give that care. No amount of carefully collected and collated information can be a substitute for the first hand accounts of what it is like to be a patient or a provider of healthcare.
4. This means that we must return to the first hand experience of service users and those who care for them and to the stories they tell, this becomes the beginning and the end of good care. We can quantify the tests done, the treatments administered, and the prognosis offered, but this can never convey the anguish and fear of the person who is ill, to understand this we must listen to the stories that they have to tell.
5. Any approach which asks service users to contribute to or to comment on detailed proposals for changes in services will tend to fail for two reasons.
 - a. Most service users do not have the detailed knowledge and understanding of the sheer complexity of healthcare provision to be able to contribute or comment effectively on even quite small proposals for service change and improvement.
 - i. Service users are too often presented with in depth and jargon filled documents and asked to comment. Their inability to even understand what is being presented to them produces bewilderment at best and resentment at worst.
 - ii. This kind of consultative process has little or no value beyond giving a formal stamp of patient approval to proposals which may or may not affect how patients experience the system and may or may not improve this experience.

- b. Managers and others who arrange and provide services are presented with the demand that people who do not understand the mechanisms and systems through which healthcare is provided (service users) are to be asked to comment and advise on work in which they have invested time, effort and expertise.
 - i. At worst this can provoke a resentment which leads to resistance to service user involvement.
 - ii. At best, there is a genuine attempt to explain the intricacies of what is proposed and to engage the service user in these intricacies of service delivery but even this is rarely useful and leaves both service user and provider with a sense of futility.
- 6. The mistake inherent in this conventional approach to engagement is that service users are asked to contribute to, and comment on things which they do not understand and have very little hope of understanding in the time available. Moreover, their views are much less likely to be informed by an expert knowledge and understanding of the systems under consideration.
- 7. The alternative is to ask service users the questions to which *only they have the answers* and to use this information to inform the detailed proposals for change and improvement. Patients do not really care how the service they receive is delivered, they do not wish, or need, to know about, or understand the complex systems and mechanisms operating behind the services which they receive.
- 8. Patients are interested in outcomes, the service that they actually receive. Their experience of this is encapsulated in the stories that they tell, and it is to these stories that everyone involved in the provision of healthcare must look if they are to improve the quality of the care that is delivered.

The Importance of Storytelling

- 9. The stories that service users have to tell, the accounts of their episodes of illness and the treatment that they receive, will tell us more about any hospital doctor or nurse than the wealth of information that is now published. The importance of these narratives, their sheer everydayness, cannot be underestimated.
- 10. The current practice of feeding back quantitative information (waiting lists and waiting times, re-admission and death rates) as a means of promoting improvements in practice lacks this common humanity, and because it does not predominantly emanate from the stories told by service users, the kinds of changes that it provokes do little to change these stories. In

fact this kind of feedback more often distorts performance in ways that do not necessarily benefit service users.

11. By listening to stories told by those who use the service and taking actions which will improve the experience of the other patients who follow them through the system, the experience of ill health could be made at least more tolerable for all of those involved.
12. Anecdotal evidence has long been denigrated and disregarded as a lever of change but if the experience of real service users is to be improved it is to the stories they tell that we must return, both as a source of information and for assurance that the changes that are made have been effective.
13. The information gained from the stories that patients tell may be messy and not easily formed into neat packages, but there is already robust and well researched methodology to support qualitative data collection. The unevenness of this kind of information simply reflects the unique nature of each person's experience and the unique nature of every encounter between a patient and those who care for them, and this is precisely why they must be attended to.
14. Asking service users for their stories will lead to a wealth of rich data which will require some work to develop into a thematic analysis. While this is more time intensive than the analysis of quantitative data, it has the potential to lead to a better informed data set with which to begin the process of service redesign.
15. To do otherwise is to create a situation in which those who are cared for increasingly distrust the measures that are in place to re-assure them that they are safe, and that they will receive good quality care. The divergence between our personal experience of healthcare and the measured and advertised excellence of that care will be fatal to the trust we all need to place in the institutions and people who provide the care.
16. If our own experience of healthcare, and the experience of our friends and family, is at odds with the widely publicised and closely measured excellence of our local hospital, it will be the stories, not the league table that will decide how we judge our hospital.
17. On the other side, as it were, those who provide care will inevitably become increasingly preoccupied with measures that do not make any significant impact on the first hand lived experience of their patients. As good professionals they will be aware of this disconnection and its effect will be most discouraging.

18. The morale of professional staff who know that the measures that they are judged by do not meet the primary aims of their profession will be put in extreme peril. As their efforts become increasingly alienated from their ultimate professional goal of improving the lives of their patients, the quality of the care they provide will diminish.
19. Service users can be an asset to good practice but only if their engagement is seen positively and this can only be achieved if service users are asked questions about things that they understand and which no-one else can answer.

Service User Agendas

20. Service User agendas are the means through which the expectations of patients can be captured.
21. Individual service users will have different agendas, but it will be possible to create agendas for different groups of service users, for example; all those using the same service, or all of those suffering from the same condition. The agenda of a single patient will never provide the basis for the re-design of a service, this must always be based on the collection of stories from a group of service users
22. Agendas must only represent the expectations of service users, and the information which makes up the agenda will only be gained from the service users themselves.
23. The answers to questions like; “As a patient, what should you expect from this service?” “What happened to you when you came to this hospital/clinic?” and “How could your experience have been made better?” will provide all of information needed on which to base a Service user Agenda.
24. Service User Agendas encapsulate the stories of each individual patient and they can be used to propose and support changes to the ways that services are delivered to patients, safe in the knowledge that any changes will automatically be aimed towards improving the experience of service users. The improvements will be witnessed by the subsequent stories that future patients have to tell.
25. Service User agendas are not a means by which the agendas of those who provide care are to be supported or promoted. Service user agendas, as the summary expression of the stories patient have to tell, are at the *very beginning* of the kind of option appraisal which leads to service changes. Any proposal for service change or development which does not originate from a service user agenda is unlikely to be successful.

26. It will not always be the case that Service User Agendas can be fully met however by referring back to the agenda in the presentation of any proposed changes, an explanation as to why not all of the elements of the agenda will be met, can be clearly given. While this is not as satisfactory as the fulfilment of all items on the agenda it is much more satisfactory than not listening in the first place.
27. All clinical professionals need their patients to trust them, without trust the therapeutic relationship between clinician and patient cannot be sustained.
28. By listening to the stories patients tell, and by responding to these stories with proposals for improvement, trust is built and re-inforced. Without this form of engagement service users will always be left outside the process through which decisions about services are made, and their trust in the safety and quality of these services will be diminished.

Author: Derek Mitchell