Conference Abstract

Understanding patient and professional conceptions of "trust". Lessons from the PEBL project, an experiment in anonymous micro-blogging for the continuous assessment of patient experience

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Abstract

Introduction: Commissioners and service providers in Primary Care need reliable and regular information about how health services fit into the lives of the users. Indeed the requirement for this kind of information is becoming ever more pressing as the patient voice gains power, and responding to the priorities and perspectives of communities of service users climbs the healthcare agenda. It is also increasingly important for providers and commissioners to develop a dialogue with the communities they serve.

Aims: Building knowledge about patients' experiences of telehealth/telecare services and interacting with patient's and carer's concerns are crucial to the successful implementation and sustainability of NHS systems. The PEBL anonymous micro-blogging system presents an opportunity for establishing an on-going dialogue with patients and carers in a context which addresses the different risks perceived by NHS professionals and patients/carers in the field of narrative feedback

While statistical methods of gathering patient experience are widely applied both in the British NHS and around the world (Holzer and Minder 2011), the use of phenomenological approaches emphasizing first person story telling is relatively undeveloped (Coulter et al 2009). Here we report on a local micro-blogging project in Essex which has experimented with anonymous web-based feedback and dialogue as a method of permanent public/patient feedback to NHS service providers and commissioners.

Methods: This paper reports thematic analysis carried out on 30 semi-structures interview scripts. The interviews were recorded with a random selection of an equal number of patient/public bloggers and NHS managers/clinicians who had used the PEBL blogging website during 2011 and 2012. The blogs and responses appearing on the PEBL website (PEBL 2013) in 2011 and 2012 were also analysed as part of the research project.

Results: In this presentation, we describe how the notion of "trust" is central to the functioning of anonymous micro-blogging as a feedback method. From the patient side, "trust" involves the maintenance of anonymity as well as demonstrations that their stories are being heard. From the

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NHS manager/clinician perspective, the governance and moderation of free anonymous comment become salient issues, in the context of protection from malicious and potentially damaging material.

CONCLUSIONS: The PEBL project's work with gathering, analysing and feeding back patients' experiences presents a potentially useful opportunity for the commissioners and providers of telehealth/telecare services to develop a with patients.

Keywords:

microblogging, experience, narrative, feedback, dialogue

References

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