

1. What we knew

- When NHS organisations consider changes to health services, they need to involve patients and the public.¹
- **BUT** little is known about the impact of involving patients, carers, and the public in change, or how best to involve people.
- In 2010, stroke services in London and Greater Manchester were centralised into a small number of specialist 'Hyper Acute Stroke Units'. In both regions, leaders of the changes used different methods to involve local people in planning and carrying out the changes.^{1, 2, 3}

3. What we found

- Patients and the public were involved in a number of ways:
 - **Consultation exercises** (e.g. surveys, public meetings);
 - Patients, carers, and people from stroke patient organisations as members of **governance structures** (e.g. project boards);
 - Getting **patient and carer views** once changes were put in place.
- Depending on their personal perspective, people's opinions reflected many different views of how things had gone.
- Patient and public involvement was mostly seen as facilitating the process rather than influencing what the changes might look like.
- We argue that involvement was seen to have value in three ways -
 - Pre-empting or helping **manage agitation**, e.g. objections to changes
 - Providing **verification** of patients' perspectives and desires
 - **Substantiation** – bringing the patient 'into the room' where discussions were held and where, sometimes, disagreements between professionals were aired.

2. What we did

- In this paper we looked at how patients, carers, and the public were involved in these changes and what effect involvement had.
- We analysed **45 interviews** with the people leading the service changes together with **project documents** to examine:
 - What involvement patients and public had in the changes.
 - What difference involvement made to all concerned.

4. What this means

- Professionals found it hard to say what impact involvement had.
- They felt it had **strategic value** by supporting implementation of a service model to deliver evidence-based care to people with stroke.
- They also felt it had **intrinsic value**, allowing participation of citizens in health service change.
- We argue the concept of '**value**' might be more useful than '**impact**' when we try to understand the involvement of citizens in health service development.



References

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2. **Fulop NJ et al.** Innovations in major system reconfiguration in England: a study of the effectiveness, acceptability and processes of implementation of two models of stroke care. *Implementation Science* 2013. doi:10.1186/1748-5908-8-5
3. **Turner S et al.** Lessons for major system change: centralization of stroke services in two metropolitan areas in England. *Journal of Health Services Research & Policy* 2016. doi:10.1177/1355819615626189

[Find out more:](#)

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Our website

<https://www.ucl.ac.uk/dahr/research-pages/strokestudy>

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