Response to NHS Chief Executive’s Open Call for Evidence and Ideas

Respondent ID: 16

Organisation name: Commissioning and System Management Directorate Department of Health

Type of response: Email
Dear Ian (and Review)

Some thoughts:

I'd argue that one of the most neglected sources of innovation spread is those who use the service.

Whilst they don't see themselves as 'diffusers' patient organisations are one of the leading agents.

From my time at Diabetes UK I can think of two very specific examples - there must be thousands.

- the first was the role of patients in ensuring Doctors took their socks off to prick their feet to check for neuropathy at annual review. The tool - a short leaflet detailing what to expect at your annual review, produced in plain English and routed in good evidence. The agent - simple patients armed with the tool and asking questions. I can't remember the stats it was 10 years ago! but it was pretty convincing that it had increased take up significantly. With a direct link to incidence of lower limb amputation.

- the second if the spread of the DAPNE programme for patient education (and its many sisters DESMOND, XPERT etc). Funded initially with a £30k grant by Diabetes UK, loved by patients because it focused on what mattered to them (hence the title 'like what you eat, eat what you like'). Now wide spread, but sadly still not universal for all people with diabetes, but driven a great deal because patients asked for it. Outcome - virtuous circle: patients quality of life, better adherence, reduced HbA1C, lower long term complications.

These are just two I am aware of. There must be thousands - the broad focus on patient education is a good one.

Lesson.

- Low tech can be best.
- If patients know what will work them they can be significant drivers of spread.
- Whilst we shouldn't discount spreading new innovation the primary task is to spread what we already know works - if we focused only on that we'd see huge improvement, even if new innovation stopped tomorrow.

What we would need to do:
- focus determinedly on ensuring that patients know what the evidence tells us works (explicit service promises?);
- but ensure that what needs to work is defined on benefit to patients, not what HCPs and Managers assume they want (though the two are often related we should not assume this);
- publish data which demonstrates who gets this right and who doesn't in a language which is focused on patients (not clinicians and managers);
- work through and enable trusted third parties as agents (patient groups could be key);
- build an expectation from patients and the service that patients should have a right to be demanding;
- listen to what patients think is important and focus on spreading that (why is it that all patients with LTCs don't get access to decent education as of right and actively
commissioned, when the evidence base is so strong - answer? perhaps because patients rate it more highly than many professionals?)

Hope this is helpful.

Paul Streets
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Commissioning and System Management Directorate
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