People powered health “as profound a social change as women’s liberation”

- Many patients find health services frustrating, disempowering and difficult to navigate
- The BMJ’s Patient Partnership Editor says systems must change to become more centred around patient needs and priorities

Empowered patients are driving a social movement and spearheading a shift in roles “as profound as women’s liberation, racial equality, gay rights, and disability rights” says a leading patient advocate in a new series published by The BMJ today.

They are capable and motivated to help themselves and other patients to get better care and work with health professionals to redesign and improve services which are not well geared to meet the challenge of demographic change and the rise in number of people living with long term conditions where it’s important that people take on a greater role in self managing their health and medical conditions.

These are just some of the views expressed in a ‘Spotlight’ on patient centred care that explores how doctors and patients can work collaboratively together to improve the way health care is designed and delivered so that it better meets the needs and priorities of patients.
The series is another step in the development of the journal’s Patient Partnership strategy and brings together analysis and comment from doctors, patients, carers, and community representatives to help inform, inspire and spur change.

It includes a call to accelerate the process of opening the medical record to patients and the rate at which this is happening in the US, UK and mainland Europe is flagged. But the movement to share notes with patient comes with a warning from Victor Montori at the Mayo clinic that giving patients “viewing rights” is not enough. Currently medical notes tend to be bulky and “indigestible” and they need to be made easier to read and used to foster better conversations between patients and doctors – not substitute for them.

There is also a call to routinely enlist patient and carers help to redesign health delivery systems to make them more responsive to patients needs; and a message sent about how both doctors and patients need to get to grips with new technologies and critically assess their pros and cons.

Medical futurist, Betalan Mesko, says we need to be better prepared for a technological future that is “set to tear down the ivory tower of medicine.” He argues that doctors and patients “all need to acquire digital literacy skills, get to grips with new technologies, and use new channels of communication.”

Measuring and incentivising person centred care gets wide support, and the merits of introducing legislation to embed it are discussed. The familiar message that strong leaders, who ensure that all staff are responsible for patient partnership and person centred care, can transform failing services fast, is also a key theme.

There are also calls for a radical redesign of care for the rising number of people living with long term conditions, based on evidence that tailored support helps patients better understand and self manage their condition.
Another issue the series underlines is that in an unequal world, the issue for billions of people – and not only those in low and middle income countries, is not whether care is patient centred but whether its available at all, its poor quality, and high cost.

Anger at health inequity and disillusionment in public services is spurring change, in many countries and Anita Jain, Assistant Editor for The BMJ India provides illuminating examples of patients mobilising to safeguard their right to health, and local communities holding health officials to account.

“It’s time to get real about delivering person centred care,” says The BMJ’s Patient Partnership Editor, Tessa Richards in an editorial to accompany the series. “It’s not a panacea for all of medicine ills, but we should not underestimate its contribution to tackling them.”

Many experts who have contributed to the series echo her views that working collaboratively and sharing decisions about care, services and systems “is challenging and requires a sea change in mindset among health professionals and patients alike. But the rewards are rich and reaped mutually.”

Contact:
Emma Dickinson, BMJ Media Relations, London, UK
Tel: +44 (0)20 7383 6529
Email: edickinson@bmj.com

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