

## THE CASE FOR A COMMUNITY-BASED APPROACH TO PATIENT EMPOWERMENT

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This discussion piece arose out of a roundtable event on patient empowerment hosted by the Centre for Empowering Patients and Communities (CEmPaC) in June 2022 and a roundtable on shared-decision making December 2023. The participants highlighted the need to look beyond the individual and widen to include the role and power of communities in improving health outcomes and reducing health inequalities.

NHS policy in the UK has increasingly focused on self-management and the role of the individual in managing their own health and becoming an equal partner in their care. Unfortunately, there remains a tendency to equate empowerment with health information and the use of health APPs. Furthermore, there is a focus on treatment location choice or access to health records rather than the mechanisms and processes by which people develop the capabilities and motivation to manage their health.

Over the last twenty years a wide range of concepts and approaches have evolved, beginning with the idea of the 'Expert Patient' in the late 1990s<sup>1-2</sup>, to Personalized care in the 2020s<sup>3</sup>. All of these at their core have the theoretical concept that if people are given the right support and opportunities to manage their health and care in partnership with clinicians, then they will have better health outcomes and use health and care resources more effectively.

The concepts draw upon a biopsychosocial model of health described by George Engel in the 1970s which suggests that health is an interplay of not just the biological causes and pathologies but an interplay between the person's emotional and psychological wellbeing, their environment and the pathology of the disease.

This has also been a key focus of self-management courses which give equal importance to managing the emotional impact of a health condition as well as day to day life, employment, family etc., alongside managing the condition itself, through lifestyle modification, treatment adherence etc.

More recently Health and Wellbeing coaches in the UK are now directly employed in primary care settings where they provide one to one and group support on changing and managing health behaviours.

Providing opportunities for people to maintain health is equally important, hence we have seen the introduction of social prescribing where people are connected to activities such as gardening, walking groups or debt and housing support and ideas like community connectors (discussed below).

All of these approaches have various degrees of success in improving health and wellbeing. However there has been a shift in demographics and health as seen in the rise in work inactivity due to mental health problems in the 18-34 year-old age group. This may indicate that a modification of existing approaches may be needed for a generation who have shifted more to the 'I' narrative in society which is amplified by social media in particular, and impacts on how mental health is experienced and portrayed<sup>4</sup>.

In older people issues such as social isolation and loneliness are recognised as being strongly correlated with poor health outcomes, quality of life and premature death<sup>5</sup>. COVID 19 drove a fundamental shift of people to being online more and in some cases less connected to communities and wary of group situations.

With this perspective, perhaps now is the time to shift from a focus on individual empowerment and efficacy to that of collective efficacy and community empowerment.

Collective efficacy was first proposed by Bandura<sup>6</sup> who defined it as 'a group's shared belief in its conjoint capabilities to organize and execute the courses of action required to produce given levels of attainments'. Importantly, collective efficacy is not just the sum of its individuals but an emergent property of the group.

Combining these two concepts and approaches may significantly improve the long term sustainability of outcomes from self-management programs and other approaches that focus on the individual and individual responsibility.

Collective efficacy has tended to be used in relation to reducing crime but the same process could be used to improve the overall health of communities and in particular begin to impact on entrenched health inequalities and on those communities that have had higher levels of conditions such as heart disease, mental health problems and diabetes.

However, as in ways to support individuals to be more in control of their health and care the evidence is often mixed and hard to navigate. Concepts such as community empowerment are even more problematic and often viewed as fluffy and lacking a clear theoretical framework.

Collective efficacy or community empowerment are often combined with concepts such as 'co-production'. The aim of co-production is to drive change within services and traditional state-citizen relationships through 'an equal and reciprocal relationship between professionals, people using services, their families and their neighbours'<sup>7</sup>.

We can infer from this definition that just as the individual needs the confidence, knowledge and skills to manage their health, so communities themselves need to feel empowered and have the mechanisms to engage in co-production of services and shaping their communities.

Policy makers have set out ambitions to reduce health inequalities and improve the number and quality of life years but it is clear that this needs to be done not just on the individual level but on the community level as well. This means going beyond health and thinking much more deeply, widely and long term about how do we empower people in communities to come together and envision how they want their community to be and feel able to achieve that? As in health care overall, people are often overwhelmed and feel helpless.

It is clear that we need to move towards community policies that place wellbeing at their heart; this may need a shift from seeing economic growth as the main way of achieving prosperity to shifting towards community cohesion and an economy based on achieving wellbeing as a primary goal.

Some communities have started in this direction, often characterised by a shift away from local councils run on political party lines to those genuinely run by communities for communities as championed by Peter Macfadyen and the flat pack democracy in Frome (where community connectors play a key part) as covered by a national Newspaper in 2015<sup>8</sup>.

In conclusion, we have seen a range of policy initiatives and approaches all running parallel to each other and often seen to be competing against each other for scarce resources and funding. Work by organisations such as the Centre for empowering people and communities ([www.cempac.org](http://www.cempac.org)) and the European health futures forum ([www.ehff.eu](http://www.ehff.eu)) show that a radical rethink of health and community policies is needed. This will require political leaders to act with vision and potentially be politically agnostic to gain the consensus for change needed. The rise of initiatives such as flatpack democracy, wellbeing communities and compassionate cities show that there is an appetite for such a change.

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