

# Clients or citizens? Some considerations for primary care organisations

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## SUMMARY

*Health services policy in the United Kingdom has given prominence to patient and public participation within a 'modernisation' agenda. The superficial consensus in support of lay participation masks a conflicting array of ideologies and theoretical perspectives that colour how this is interpreted. Both client-oriented perspectives and citizenship-oriented approaches are limited by the dynamics of power relationships and decision-making processes within National Health Service structures. Primary care organisations offer the possibility of developing structures for providing closer collaboration between citizens and services. In order to achieve this, however, vague processes of client representation need to be replaced by robust community-based participatory action research models.*

**Keywords:** *participatory action research; client-oriented perspective; citizenship-oriented perspective.*

## Introduction

LAY participation has recently become a prominent item on the health services planning agenda. The tidal wave of policy papers over the last decade has resulted in widespread activity purporting to consult or involve patients and the public in healthcare decision making across the National Health Service (NHS). In spite of widespread agreement about the virtues of 'participation', the various stakeholders involved can interpret this very differently.<sup>1</sup> Behind the superficial consensus lies a wide range of ideologies and approaches. This paper offers an overview of theories of participation in their historical context and discusses some of the issues raised by applying approaches in primary care organisations.

## Theoretical perspectives

Everyone participates in society, whether as an effective actor or as a passive victim.<sup>2</sup> Definitions of the term 'participation' in primary healthcare literature are many and varied. They range from 'being in a position to benefit from a project', through 'the capacity for influencing decision-making processes', to 'direct sharing in decision making' at the other end of the spectrum.<sup>3</sup>

One frequently quoted approach to making sense of these definitions has been Arnstein's 'ladder of citizen participation'. The term is used to cover a continuum of processes ranging from what is labelled as 'non-participation', such as manipulation and therapy, through degrees of tokenism, such as informing, consultation and placation, to degrees of citizen power, such as partnership, delegated power, and citizen control.<sup>4</sup> In the United Kingdom (UK) a similar distinction has been drawn between marginal participation, structural participation, and substantive participation.<sup>5</sup> The key distinction between these is the degree of control acquired by the community, with the underlying assumption that this is itself the ideal goal.

Participation takes place at a variety of levels, including the micro level of individual treatment at the point of service delivery; for example in a practice or primary care group, and the macro level; for example in a health board or national body. The nature and scope of participation; i.e. whether as 'clients' or 'citizens', depends on the context in which people are expected to participate and on the presence or absence of situational and structural constraints on their involvement. Lay participation can therefore be thought of as taking place along three dimensions: the degree of control, the decision-making domain, and the role adopted by the participant.<sup>6</sup>

The United Nations Development Programme (UNDP) distinguishes between participation as a means and as an end.<sup>7</sup> However, these processes are not mutually exclusive. Participation can be seen as a process whereby people

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cooperate with the implementation of an external programme to improve its effectiveness. On the other hand, it can be seen as an end in itself in which people acquire skills, knowledge, experience, and control over resources.<sup>8</sup> From this perspective, the role of professionals is to contribute expertise and resources to implement community decisions (Boxes 1 and 2).

### Community empowerment

Implicit in many of the definitions of participation is the theory of community empowerment. This has been defined as 'people (gaining) control in their own lives in the context of participating with each other to change their social and political realities'.<sup>9</sup> Community empowerment builds on the theory of social capital or social production of health. Health services are seen as simply one of a wide range of determinants shaping health in a community. Empowering communities to gain control over these factors is central to producing improved health. This perspective has a value base in the principle of self-determination as a human right.

This model, formalised in the World Health Organization (WHO) declaration of Alma-Ata in 1978, is built on historical experiences of community development. Its origins can be traced to early 20th-century rural economic development movements in the United States. The concept was popularised by the United Nations in the post-war period among former colonial countries as a means of rapidly expanding a modernisation programme. However, it was criticised for imposing 'democratic' values that failed to take into account the unequal distribution of power and wealth in communities.<sup>10</sup> From the 1960s onwards, the debate began to centre on the need for structural transformation in the social, economic, and power relationships between those who had material goods and opportunities to improve their life circumstances and those who did not. As community development became widespread in the UK, this debate was reflected in a tension between the promotion of community work as a means of developing the potential of individuals or groups and an emphasis on social activism to address issues of power and control.<sup>10</sup>

### Consumerism

The resurgence of neo-liberalism and conservative ideologies during the latter part of the 20th century, most notably during the 1980s, led to a shift in focus that re-emphasised individuals and their relationship with professionals. The 'paternalism' of health services was challenged, and debates about the most appropriate framework for developing the relationship between service providers and service users regained centre stage.

Patients were redefined as 'consumers'. Although consumers could be members of organisational groupings, individual priorities and interactions with health services were to define collective interests rather than ideas of community or wider determinants of health.

The consumer model of involvement has played and continues to play an influential role, in particular through its emphasis on information, access, choice, and redress.<sup>11</sup> The underlying principle is that the consumer is best placed to choose a pattern of consumption that maximises their welfare.

'The organised efforts to increase control over resources and regulative institutions, in given social situations, on the part of groups and movements hitherto excluded from such control.'

*Box 1. Working definition of the UNDP research programme into popular participation.<sup>2</sup>*

'A process whereby people ... exercise their right to play an active and direct role in the development of appropriate health services, in ensuring the conditions for sustained better health and in supporting the empowerment of communities for better health development.'

*Box 2. WHO definition of community involvement in health.<sup>4</sup>*

This has led to the adoption of client satisfaction as the primary outcome measure of consumerism.<sup>12</sup> Measurement of satisfaction remains the most widely used approach to incorporating lay views in evaluating health services. However, they have had little impact on quality improvement because of difficulties in interpreting findings, the variable effect of patient expectations, and the lack of bearing on clinical care.<sup>13</sup> The validity of the assumptions underpinning this approach have been increasingly questioned.<sup>13,14</sup>

Critics of consumerism have emphasised the illusory nature of choices presented to patients, their limited experience and expectations, the impossibility of explicit costing, the irrevocable nature of many medical interventions, and the difficulties in making comparisons.<sup>15</sup> Before choices can be made, the limits have already been set by a medical view of disease and treatment, with consumers often reliant on the supplier; for example healthcare professionals, drug companies, and government agencies, for interpretation of information. While the Internet has widened access to information, health is often presented in terms of products, such as treatments and services, or 'choices' about lifestyle and consumption of health products. Through failing to encourage reciprocal relationships and shared responsibility, consumerism may legitimise the avoidance of responsibility for difficult decisions by both consumers and professionals. An uninhibited market-led approach may therefore simply serve to increase expectations beyond the capacity of services to deliver.<sup>16,17</sup>

### Professional-patient partnership

In the UK, a reappraisal of earlier radical free-market ideologies in the 1990s was accompanied by promotion of the concept of a partnership between patients and professionals. This was given support by a joint NHS Executive/British Medical Association 'Doctor-Patient Partnership Initiative' in 1996.<sup>15</sup> Paternalism and consumerism were rejected, emphasising mutual responsibilities for difficult decisions within traditional professional-patient relationships. This approach explicitly sought to engage patients in issues raised by limited resources and imperfect knowledge.

Models of the professional-patient partnership have been developed on two levels: in individual relationships between healthcare professionals and patients, and through the involvement of users and the public at an organisational level. At the individual level, the emphasis has been on information and communication, shared decision making, and

professional attitudes.<sup>18</sup> The 'patient-centred' approach aims to enhance the capacity of patients to contribute to decision making in partnership with professionals.<sup>19,20</sup>

In a parallel process, the idea of partnership with patients has been applied at an organisational level. The objective of recent NHS reforms was described as 'a patient-centred health service'. Partnership in this context has been defined as 'shared information, shared decision making, shared evaluation, shared responsibility'.<sup>21</sup> There is an extensive and diverse literature promoting the involvement of patients and lay organisations as 'partners' in health services. The purported benefits of lay involvement in organisations are widely published (Box 3).

In recent years there has been a proliferation of patients', service users', and carers' organisations.<sup>22</sup> Involvement of lay 'partners' has been advocated in a variety of contexts, including needs assessment, shaping health policy, setting standards, and evaluating services and health-related research; for example through the Cochrane Collaboration.

### Participatory citizenship

These developments in the NHS have taken place within the context of broader debates about democracy and citizenship in the UK, in particular from a growing interest in participatory democracy. Citizen participation has been proposed as a necessary supplement to what are seen as the inadequacies of representative democracy.<sup>23</sup> Political participation thus becomes a source of identity for otherwise excluded groups.<sup>1</sup>

Passive citizenship is a status that guarantees formal rights. Such rights provide protection; for example, of private property, but do not confer active right; for example, to a decent standard of living. From this perspective, consumerism has been criticised<sup>13</sup> as substituting market exchange for active political engagement between members of society. Active citizenship, in this sense, emphasises reciprocity and interdependence, founded on individual beliefs, interests, and aspirations. Citizens participate in the political arena of power in which conflicting interests and values are resolved.

Public services seek to guarantee positive 'substantive' rights; for example the right to a basic income and the right to healthcare, and emphasise social rights and social citizenship. However, such concepts can also reinforce passivity. Citizens become dependent recipients of public services managed by a professional bureaucracy. The development within the NHS of user and public involvement has emerged partly in response to such critiques of the welfare state. As well as promoting active citizenship, this may be motivated partly by a desire to mobilise public opinion in support of a nationalised health service that is facing widespread criticism.<sup>1</sup>

### Critical evaluation

#### Client-oriented approaches

Observational studies in general practice suggest that a 'patient-centred' approach leads to greater satisfaction, higher 'enablement' scores, a lower symptom burden, and reduced referral rates.<sup>24</sup> The desire for information appears to be universal and independent of social factors, with a strong link between better health outcomes and better

#### Benefits to patients

- Better outcomes of treatment and care
- An enhanced sense of self-esteem and capacity to control their own lives
- A more satisfying experience of using health services
- More accessible, sensitive, and responsive health services

#### Benefits to the NHS

- Restoration of public confidence
- Improved outcomes
- More appropriate use of health services
- Potential for greater cost effectiveness
- Sharing responsibilities for health care with the public

#### Benefits to public health

- Reduction in health inequalities
- Improved health
- Greater understanding of the links between health and the circumstances in which people live
- More healthy environmental, social, and economic policies

#### Benefits to communities

- Improved social cohesion
- Healthier democracy

Box 3. Purported benefits of public involvement.<sup>41</sup>

doctor-patient communication.<sup>25</sup> A desire for more information does not imply a wish to assume responsibility for decisions.<sup>26</sup> The effect of shared decision making on health outcomes remains uncertain.<sup>27</sup> These correlate more strongly to the level of information received than to the degree of involvement in decision making.<sup>28</sup> Little is known about the impact of shared knowledge (and uncertainty) on professional-patient relationships, on resources, and the effect on patient expectations of information intended to influence self-care and patient knowledge. The extent to which patients wish to be involved in decision making varies between individuals and depends on the specific context.<sup>29</sup>

The empirical evidence base for a 'patient-centred' approach in health services management is less well developed, although patient participation groups have an established tradition in general practice. A review of the experiences of 25 such groups suggested that, despite doctors being sceptical, concrete objectives could, nevertheless, be achieved. It highlighted the problem of transferability of experiences, given the fact that such groups tend to have been set up by enthusiasts. Concerns about whether participants are representative of 'patients' as a whole were frequently raised.<sup>30</sup> Such concerns highlighted a degree of defensiveness in doctors in relation to lay 'voices', who derive their legitimacy from personal experience rather than expertise or democratic process.

Studies evaluating user involvement in health services have identified a number of constraints. In spite of health organisations listing community opinion as a high priority, systems for obtaining community views tend to be weak. Most public consultation remains on an *ad hoc* basis, and tends to focus around controversial decisions, such as the closure of services.<sup>31</sup> Constraints include the complexity of healthcare systems, professional attitudes, a lack of political will, and pressures of time and resources.<sup>32</sup> User organisations in the UK are exceptionally heterogeneous. Their disparate

and often conflicting interests give them a weak position in terms of health policy making. This is in contrast to the Netherlands and Australia, where well organised patient bodies on a statutory footing provide a 'balance of power' alongside the government, professional bodies, and the pharmaceutical industry.<sup>15</sup>

An editorial reviewing the experiences of lay representatives and patient liaison groups concluded that effective partnership in this setting was possible, and cited a number of examples in which patient input had significantly influenced the outcome of decisions. Discussion between professionals and patients can alter the way in which doctors perceive issues and strengthen positions that protect patients' interests. The editorial also highlighted the time required to develop trust, and the importance of the proportion of lay people compared with healthcare professionals on committees (Box 4).<sup>33</sup>

Partnership implies a sharing of risks, and substantial common interests that can be negotiated. The emphasis on consensus ignores the possibility that the interests of professionals and patients are often genuinely in conflict. Unequal access to funding, resources, information, and decision-making power and status, means that the possibilities for genuine debate and negotiation are limited.<sup>15</sup> The health of the patient is itself in play and may become dependent on the services of the doctor. The unequal risks taken by a patient in trusting a doctor suggest a fundamental imbalance of power implicit in the nature of their relationship (Box 5).

Assumptions about transfer of power in the 'partnership' model are oversimplified, although older, more coercive forms of power, may be less prominent.<sup>15</sup> Power shapes relationships through language and institutional practices, combining to produce 'discourses' controlling how something is experienced and thought about. Promoting informed decision making does not in itself result in empowerment. While 'well-informed' patients may be under an illusion of autonomy, their choices are, nevertheless, shaped by dominant expert medical knowledge.<sup>34</sup> This gives prominence to a world view of disease and treatment constructed by the medical profession.<sup>35</sup> Traditional forms of knowledge, lay belief systems, alternative approaches to health, social determinants of health, and the capacity of communities to use their own resources for improved health remain devalued in practice and largely on the periphery of health systems. Despite a rejection of consumerism, market-driven research continues to be a dominant force shaping primary care in the UK.

### *Citizen- and community-oriented models*

Community support through social networks has been postulated to be protective of people's health. High levels of trust and density of group membership are associated with reduced morbidity. Lack of control, lack of self-esteem, poor social support, and social fragmentation are associated with increased morbidity.<sup>36</sup>

Based on this theory of 'social capital', it has been claimed that community participation can improve health status and reduce inequalities. There is evidence that community development approaches to needs assessment are more likely to result in changes that are adapted to the needs of the community. They can result in a reduction in exclusion from ser-

- The patient liaison group of the Royal College of General Practitioners is a doctor-patient group. It aims to listen to different viewpoints and reach consensus on difficult issues
- Patient information leaflets produced by the group sometimes tackle issues not usually addressed in leaflets written by doctors; for example, giving explicit advice about choices of treatment or how to decline having a medical student present during a consultation
- At other times the consensus reached does not change professional standards for practice as much as some patient groups would like. For example, guidance on removing patients from general practitioners' lists does not state that patients should never be removed against their wishes, but restricts the number of reasons that may justify removal

Box 4. One patient-partnership group.<sup>33</sup>

- Case studies of user involvement in the fields of mental health services and services for people with physical disabilities have identified an emerging 'consultation industry'
- 'Participation entrepreneurs' can develop their careers around championing public involvement, attending a popular conference and workshop circuit
- The studies found no examples of an advance commitment to taking action on the basis of consultation. Users remained simply one of many competing interests that were balanced by local managers
- Managers expressed criticism of user groups as unrepresentative and poorly organised. These criticisms allowed managers to ignore their views
- User groups could be used, however, to legitimise decisions and strengthen the manager's position vis-à-vis other interest groups<sup>1</sup>

Box 5. User involvement in mental health services.

vices; for example, an increased uptake of screening services by women from ethnic minority groups. They are more likely to lead to interagency collaboration in resolving problems appropriately.<sup>37</sup> A survey of 100 projects on poverty and health in the UK gave examples of increased income for communities, improved services, identification of previously unrecognised issues, and raised awareness of poverty and ill health.<sup>4</sup> However, systematic reviews evaluating community participation programmes are lacking, although several approaches have been proposed.<sup>10</sup>

A central issue remains the control of resources. Many projects have remained at the level of community mobilisation to improve the effectiveness of externally controlled programmes. An extensive international programme of research into popular participation in the 1970s concluded that community development would continue to be limited unless the question of redistribution of power was addressed.<sup>2</sup> Significantly, there were no examples of communities being able to carry out sustainable development without external political and technocratic support. Where there were examples of increased control of resources, this had taken place in a favourable political context. In many circumstances, community participation resulted, in effect, in decreased control, with communities being given responsibility for vanishing external resources in the expectation that they would be able to find internal mechanisms for financing;



for example through the introduction of user fees. At the very least, participation was found to be a process that unleashed unexpected demands, requiring both the willingness and the ability to respond to these.

The 'tyranny' of participation has been criticised as a technical solution to what are political issues, such that participative processes merely reproduce their political context. Individuals and organisations create a veneer of participation to promote careers and success, while existing power dynamics reproduce themselves unchanged.<sup>38</sup> In a resource deficient environment, mistaken assumptions about the innate resourcefulness of communities, coupled with substantial costs in time and money, can result in considerable investment, with little gain from participation. Economic restructuring and competitive or individualistic values undermine the cultural and structural influences necessary for sustainable participation.<sup>39</sup>

It has been questioned whether moves toward community and citizen participation will have any significant impact in producing participatory democratic changes in the NHS.<sup>23</sup> Although professional bureaucratic management is giving way to new forms of public management, the direct exercise of power is being replaced by central influence through rules, regulatory frameworks, and the distribution of finances. These focus on internal organisational issues, in particular, performance measures.

Despite the rhetoric, performance measures largely ignore the importance of social capital: the role of health service users as co-producers of health, and the role of social exclusion. Professional forms of knowledge predominate. Decision making is treated as a function of technical expertise, rather than 'multivalued choices between irreconcilable alternatives'.<sup>23</sup> Responsiveness to communities remains within a tightly defined framework of control. Participation is therefore likely to be severely limited by the problems in finding points of leverage.<sup>23</sup>

### Primary care organisations: bringing together clients and citizens

With NHS structures leaving little room for communities to exert influence, community development approaches in promoting participation in health have remained peripheral to conventional health services. One explanation for this may be the modest impact of community-oriented approaches when applied at a lower operational level (for example, practice level) rather than at a population level or the level where defining decisions are made.

Primary care organisations offer a new institutional framework for developing a closer collaboration between citizens and services. They have the potential to enhance accountability to communities through locality development planning processes, commissioning locally relevant research, developing relationships with community bodies, and providing an infrastructure to support dialogue between managers, staff and patients. Indeed, the policy context in which primary care organisations have been established prioritises their role in engaging with local communities.<sup>40,41</sup>

Despite these potential strengths, unless primary care organisations address the issues raised by participation, they run the risk of failing to meet their potential for engaging with

- The Dumbiedykes Health Study used rapid appraisal to define the health and social needs of a community and to formulate joint action plans between the residents and local service providers
- As a result, a health forum of professionals and local residents has been set up to seek to action changes. It has continued for more than 4 years with strong social work, community education, housing, and voluntary sector involvement
- The priorities that have been addressed include improving bus services and play areas, attracting supermarkets into the area, and improving organisational aspects of local general practices and the care of people with mental illness

Box 6. An experience of 'rapid appraisal' in primary care.<sup>43</sup>

communities. The widespread use of 'patients' forums', promoted by government policy, illustrates this. While lay people are apparently empowered by their involvement in the process, it has been demonstrated that their views are usually placed in a weak position relative to other technical and professional 'voices'.<sup>42</sup> For communities to exert any substantial influence on primary care organisations, approaches must be adopted that explicitly address issues of voice and power.

Two applications have been widely used in the health field to translate the theory of empowerment into practice. Both have evolved in the developing world and relate closely to primary healthcare principles.<sup>10</sup> With a strong theoretical and evidence base, they are well suited to bringing together community-orientated participatory approaches and client-focused primary care services. They have been called 'rapid appraisal' and 'participatory action research'.

### Rapid appraisal

Rapid appraisal methods share the characteristics of being quick, relatively inexpensive, aimed at communities rather than individuals, and directed towards action rather than documentation. Rapid appraisals have been used to guide expanded primary care teams, to assess mental health needs in a community, to orientate new staff, and to introduce students to health and social needs in a community (Box 6).<sup>43</sup>

The strengths of rapid appraisals include the low use of resources, reliance on participation, and focus on communities.<sup>43</sup> Members of the local community are involved in the planning process. The approach is oriented towards producing action, although it does not include a specific focus on action as an integral part of the participatory process; neither does it set out specifically to generate learning from the effect of the action being realised.<sup>10</sup> These are integral to the model that has been labelled participatory action research.

### Participatory action research

Participatory action research links research with action to address problems identified by the participants.<sup>10</sup> This is a style of research rather than a method. Its three defining elements are its participatory character, its democratic impulse, and its simultaneous contribution to social science and social change.<sup>44</sup> It is associated most prominently with the work of the Brazilian educationalist, Paulo Freire.<sup>45</sup> Freire emphasised the ideological character of knowledge. Knowledge developed by external experts becomes a sort of 'monologue'. The

'voice' of the expert transforms human subjects into passive objects of knowledge, alienating them from their lived experiences and reinforcing existing social structures. Freire contrasted this with 'dialogical' research, in which both experts and community are co-learners in a dynamic cycle of action and reflection. Community members become central to the process of knowing and creating knowledge in order to act on that knowledge for change (Box 7).<sup>46</sup>

Power relationships become a legitimate focus for dialogue. Participants construct a language to explain the problems they face. Through joint action to bring about change, participants gain confidence in their 'voice'. More importantly, by shared reflection on their action, participants robustly examine their original perceptions to arrive at a position that more authentically explains their situation and gives grounds for more effective action.

Through this process, the 'authenticity' of the 'lay' voice, with a unique and tested knowledge of the problems being addressed, comes to occupy a privileged position relative to 'expert' knowledge that often struggles to fill the gap between theory and practice. The traditional boundaries between expert and lay become blurred. The perceptions of participants become indispensable to providing a greater 'fit' with the unique features of their situation (Box 8).

There have been several reviews of health-related participatory research. One Canadian review of the literature identified more than 400 health-related studies involving participatory research aimed at education and taking action or effecting social change.<sup>10</sup> A recent review of participatory approaches in health-related research highlighted collaboration, respectful relationships, mutual education, and action derived from research questions of relevance to participants as positive outcomes from this approach.<sup>47</sup> A review of community-orientated primary care supported a cyclical model of change, grounded in participatory action research theory, as key to community participation in introducing innovation.<sup>4</sup> This approach has been found to enthuse professionals, engage with patients, and produce innovative services tailored to local needs.<sup>48</sup>

A number of issues have been identified<sup>10</sup> that are relevant to implementing such approaches in primary care organisations. The impact on attitudes and behaviours of professionals and officials is uncertain and may be destabilising. Success depends on facilitators who are able to act as negotiators and interlocutors in a process which, by its very nature, is unpredictable and will give rise to conflicting interests. Anthropological and sociological researchers, as well as community educators, have important skills to offer primary care organisations in this regard. Second, the process of developing community knowledge cannot be seen simply as a means of extracting information that is of use to the organisation. The participatory process results in challenges to the priorities and use of resources within the organisation. Third, the long-term nature of the process must be acknowledged. Many projects have faced issues of sustainability that need to be addressed from the outset. Finally, the process engages with creative methods of research and analysis, such as storytelling, and the use of visual as well as oral or written information. These pose a cultural challenge to the bureaucracy of decision making in the NHS.

'Dialogue with the people is neither a concession nor a gift, much less a tactic to be used for domination. Dialogue, as the encounter between men and women to "name" the world, is a fundamental precondition for true humanisation.'

Box 7. *Dialogue*.<sup>47</sup>

- A women's health project was implemented by Social Action for Rural and Tribal Inhabitants of India using a participatory action research approach
- The programme was instigated at the request of the women, who were involved at all stages of planning and implementation
- Women shared their stories and talked about their bodies, exploring not only their experiences but their subordinated social position. This enabled them to recognise their individual and collective strengths
- The women's own knowledge of traditional medicine and non-drug therapies was validated through field exercises and workshops in which they learnt the basics of gynaecology through self-examination
- Increased politicisation in relation to social rights led to demands for change. Some of the women who attended the original workshops are now involved in the training of new health workers

Box 8. *An example of 'empowering' action research*.<sup>10</sup>

## Conclusion

It is no longer acceptable for participation in health to remain dominated by marginal, poorly defined, and unevaluated processes of 'user' representation. Health planners need to engage with solid mechanisms that integrate community participation into health service development through robust research processes. There is an urgent need for a programme to support and evaluate the application of participatory research models in primary care organisations.

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