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The Limitations on Public Engagement in Healthcare Policy Co-Design in the United Kingdom and Pathways for Institutional Optimisation

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Abstract. Against the background of the transformation of the British medical system to patient-centred, public participatory policy co-design is regarded as the key path to improve the fairness, transparency and implementation efficiency of decision-making. Taking the joint design of British medical policy as the research theme, this paper systematically examines the development process and main modes of public participation (patient public voice mechanism, collaborative participation platform and system governance structure) and analyses the realistic dilemma from four dimensions: institutional defects, information failure, power imbalance and external resource constraints. It is found that the existing participation mechanism of the NHS has some core limitations, such as insufficient independence of supervision institutions, low openness of information, monopoly of decision-making power by professional authorities, and lack of funds and training support. Based on this, this paper puts forward the system optimisation path of rebuilding public trust, introducing innovative tools such as role prototype and policy prototype, increasing early resource investment and differentiated fund allocation. The research results can provide an improvement direction for multi-subject collaborative decision-making of British medical policy and also provide experience for other countries to build a medical governance model with deep public participation.

Keywords: Public engagement, healthcare policy co-design, institutional optimization.

1. Introduction

Co-design is generally defined as the act of collective creativity within a design process. In the administrative sense, adopting co-design strategies indicates the shared decision power between designers and people not trained in design across the whole span of a policymaking process. Participatory approaches admit the information gaps existing for all stakeholders for the effectiveness of the operation of a system, and that policy co-design processes could potentially bring better equity and transparency in decision-making, eventually leading to higher strategic efficiency [1].

The UK's history in a broader shift towards public participation in policymaking was reflected through a series of proposals and programmes, which committed to engagement with citizens with

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experience instead of solely expert-led [2]. Currently being mandatory, policies framed by the Cabinet Office's Policy Lab are rooted in end users' needs and experience, using methods including ethnography and prototyping to improve public involvement, empowering groups directly influenced by policies with decision-making rights.

However, theoretical positive effects of co-design are likely to be undermined when put into practice for multiple causes. For example, the failure of the scrapped Care.data scheme, an NHS England programme of work for amalgamating and sharing patient data from primary care for planning and research, has been proven false about the wide range of consultation it claimed to have by the 2016 Caldicott Report [3]. More than 90% of survey takers claimed they had never heard of the plan or did not understand its data-sharing terms, reflecting a failure in user-centred co-design of this programme. Furthermore, instrumental evidence shows frequent disconnections between public consultation and final judgment considerations, fostering imbalanced voice, ineffective implementations and weakened institutional trust.

Within the healthcare system, the shift to patient-centred healthcare services makes value-based medicine essential to the goal of creating value based on patients' needs, requiring ideas based on patients' perspectives and real-life experiences. The UK has been continuously promoting co-design programs for the past decade, actively developing extensive engagement with patients and staff through the amendment and implementation of the NHS Long Term Plan. Although previous research outlines the potentialities of co-design for the revision of healthcare services, few scholars discuss the practical factors that would or have caused the downfall of past co-design attempts.

Starting from these premises, the author discusses the features of past and current policy co-design strategies applied in the NHS England system and analyses their applicability critically under the complexity of the UK healthcare context. Suggestions on co-design tools which could be used in this area are given based on current frameworks, providing policymakers with potential pathways for future improvement.

2. The development and impacts of public engagement

2.1. History of public engagement

Since 1997, public participation in British medical policymaking has been continuously promoted, aiming at strengthening the voice of service users in policy planning and integrating patients' opinions into NHS governance [4]. In the early days, the Labour government promoted the reform with patients as the centre and set up a primary health care team to ensure public participation. In the 2000s, public participation was gradually institutionalised, and strategies such as the NHS Plan (2000), patient forums, and consultation support were established one after another, and then community participation was further expanded through legislation relying on local participation networks. In the 2010s, the concept of co-production entered the NHS system, and Health Watch standardised the channels for public opinion collection and feedback. In recent years, the comprehensive medical system (ICS) has integrated multiple subjects, promoted community and patients to participate in service planning and scheme formulation, and gained political and financial support [5]. Although the effectiveness is influenced by socio-economic factors, the joint design of British medical policy has developed from an initial participation to a mature joint production stage.

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2.2. Forms of public engagement

2.2.1. Patient and Public Voice (PPV) scheme

The PPV partner role allows people with lived experience to contribute to UK healthcare service development on an ongoing basis, being empowered with a significant level of responsibility and direct involvement in decision-making. PPV partners are invited to share their perspectives and experiences with the NHS to inform health services in a range of different ways, including areas of population health management, personalisation of care, addressing health inequalities, and improving accessibility to healthcare services. Consequently, the NHS aims to build positive and trusted relationships with communities to improve services, support, and outcomes for people whose problems are more precisely identified through real-life experience feedback from end users [4].

PPV partners include patients, people using services, carers, families, and other members of the public. The NHS aims to monitor and maximise the diversity of the PPV partners it works with while offering them an honorarium as encouragement. Total amount of directly recruited PPV partners remains at 350, collaborating with a larger public participation network reaching around 8,600 people so far, contributing to the evidence base for the 10-Year Health Plan. The 2022/23 PPV partners survey shows 60% agreement on the statement that the patient and public voice was valued by NHS England [6].

2.2.2. Collaborative engagement spaces

To better reflect individuals' and communities' needs and wants, NHS England adopts a bottom-up framework connected by Healthwatch. At the community level, citizens' panels consisting of representatives from local communities are funded and operated nationally by NHS England. When there is a need to survey public opinion on specific issues, members of the panels communicate directly with authorities for co-design. The division into regions and special features enables health authorities to form targeted focus groups for interviews.

The NHS promises to hold an extensive programme of community outreach, including 20-60 interactions with community groups per month, regular "collaborative space" meetings open to anyone, a lay partner programme, and social media engagement. The combination of offline and online strategies for community insight collection ensures that public views are considered in decision-making and that the issues people raise are addressed [6].

The exchange of communication between institutions and individuals also allows information about upcoming NHS-related events and important personal healthcare information to be provided to members. This builds public trust in health authorities and encourages wider and deeper interaction.

Healthwatch is regarded as part of the statutory system for Patient and Public Involvement (PPI) in England, operating throughout communities nationally and funded by local authorities. The system claims to function independently as a medium in the policy co-design process, collaborating with local governments as a major partner in monitoring the quality and design of health and social care. Seven years after their establishment, there are 150 local Healthwatch bodies across England [7]. Local Healthwatch organisations follow procedures to obtain public views on local social and healthcare services, organise reports based on these views, and submit them to decision-makers responsible for commissioning and scrutiny in care services, such as NHS Commissioning Groups.

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2.2.3. System governance

Directly belonging to the NHS, Clinical Reference Groups (CRGs) are responsible for advising on national policy for specialised healthcare services. CRGs include collaboration among Patient and Public Voice (PPV) representatives alongside clinical experts, emphasising the consideration of lived experience, professional knowledge, and carers' perspectives in developing clinical and humanised policies. These NHS policy co-design bodies iterate proposals through collaboration between staff and patients, shaping final solutions based on public requirements [8].

Policies on integration have been implemented for years and were formally legislated through the Health and Care Act 2022, which provided a statutory footing. The legal duties of Integrated Care Systems (ICSs) are to bring together different organisations and adopt cross-sector measures to satisfy the healthcare, public health, and social care needs of end users within the ICS framework [9]. With 42 integrated care boards operating at distinctive sizes, partnership structures, and incentive systems, ICS bodies operate according to the specific characteristics of each county to improve efficiency and effectiveness in information transmission and data collection [10]. The NHS seeks to promote internal integration in policy design processes by eliminating barriers to cooperation among primary authorities, communities, and other entities.

3. Limitations to current public engagement methods

3.1. Limitations from systemic flaws

Although the public participation mechanism of the NHS in Britain has been continuously improved, there are still some core defects, such as the dislocation of institutional incentives, the lack of independence of supervision institutions and the imbalance of decision-making power. As a key carrier of public participation, the local health observation organisation faces a prominent dilemma: its duty is to supervise local medical services, but it relies on local government funding, which leads to serious damage to its independence [11]. Research shows that only 48% of the public trusts the effectiveness of its participation and support, and the organisation is often regarded as an ordinary stakeholder, so it is difficult to play a core coordinating role [12]. At the same time, the positioning of social enterprises is vague, and the integrity of jurisdiction is limited [13]. Although the comprehensive medical team is required to carry out statutory consultation with the health observation organisation, it has no compulsory obligation to adopt the suggestions, which makes it difficult for its public opinion feedback to really influence the decision-making. On the whole, the defects in system design and the problem of interest correlation greatly weaken the actual effectiveness of health observation organisations and also reduce the effectiveness and credibility of public participation in the joint design of medical policies.

3.2. Limitations from information failure

NHS organisations have shown complex progress in improving openness and information transparency while integrating policy co-design into their organisational structures. Enabling wide access to information for patients is recognised as an ethical responsibility for healthcare systems, allowing suggestions to be raised and ensuring public involvement in healthcare development. However, engagement at this level is often criticised for maintaining authentic decision-making power and protecting system interests.

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The failure of the Accountable Care Organisations (ACO) proposal in 2018 reflects this conflict in several ways. The proposal aims to integrate health and social care services by awarding long-term contracts to manage local population health. However, it faced significant challenges from campaign groups due to its lack of clarity and transparency. The model involved limited information and data access for the public regarding the framework itself and its regulatory structure, and it appeared to be introduced based on limited public engagement through incomplete consultation [14]. This inadequate democratic legitimacy derived from restricting public access to relevant information caused public backlash and the collapse of engagement in healthcare policy co-design.

A series of NHS policies concerning the practical effects of openness and transparency in information access for the public have been evaluated, and the surveys of community healthcare users demonstrate negative perceptions based on their experiences [15]. In contrast, organisations and authority workers emphasise the importance of cautious intervention in promoting public engagement, highlighting perceived risks associated with sharing extensive information with the public. They argue that due to a lack of knowledge and professional expertise among ordinary citizens, limiting informational openness to exceptional circumstances may help avoid unnecessary anxiety or concern. The existence of behavioural standards frameworks therefore reinforces system efficiency at the cost of neglecting the needs and preferences of individuals involved. Tokenistic strategies for healthcare policy co-production may jeopardise eventual policy design, as problems experienced by end users may not be raised during the discovery phase.

3.3. Limitations to decision-making power imbalance

Previous research finds that the nature of the PPI model tends to be more theoretical than practical, with community participation emphasised primarily in implementation rather than genuine decision-making [16]. Co-production in the policy field is often regarded as risky, since approaches influenced by public voices may not necessarily align with methods traditionally recognised as optimal by academic or professional standards. The need to protect professional interests and academic authority within the UK healthcare system, therefore, encourages experts to retain primary decision-making power [17].

Under frequent redefinition of participation boundaries by professionals, co-design attempts do not necessarily produce broader inclusion in health policy development and may prevent policies from being shaped by the very public they are intended to serve. There has been insufficient attention paid to power imbalances during the co-design process, which undermines the possibility that public voices reach the decision-making stage. Structural power inequalities are therefore recognised as a major barrier to effective public involvement in healthcare policymaking.

This imbalance in decision-making power is also evident within current PPI models. Public engagement largely occurs through feedback and information delivery mechanisms rather than direct participation in policymaking. As described earlier, public views are typically collected through feedback from social service users and community-based surveys. This approach ignores bias in the selection process and in the pool of ideas, as access to healthcare services and feedback channels is itself unequal [18]. Consequently, controlled data collection provides only a limited influence from the public side in deeper decision-making processes. This arrangement maintains professional authority and decision-making power in healthcare development, creating the risk that co-design becomes symbolic rather than transformative.

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3.4. Limitations from external factors

Several studies identify resource constraints as a primary reason for failure in NHS policy co-design initiatives. At the community level, insufficient funding restricts the ability to organise engagement activities and support data collection, while insufficient training for patient representatives undermines meaningful participation.

An example of failure is the abolished Clinical Commissioning Groups (CCGs), GP-dominated bodies responsible for commissioning social and healthcare services. Operating under a tight budget allocated through weighted capitation, CCGs left limited funding for public engagement with priorities of providing Personal Health Budgets to certain groups. Till October 2025, the NHS's operating budgets for ICBs have been cut down by 50%, further constraining collaboration in strategic commissioning. Insufficient budget for staffing that could potentially be available for public engagement support would restrict the co-design activities in both frequency and scale aspects [6]. As a result, residents' voices are less likely to reach higher-level decision makers.

Patient Participation Groups (PPGs) are struggling with a lack of institutional support. Patients as participants usually have limited professional knowledge, preventing them from gaining a deep understanding of clinical and systemic issues, especially when they also lack access to relevant information. For small-scale community clinics without sufficient experience and expertise, they may encounter difficulties in holding such PPG activities consistently in the long term. These constraints undermine the development of effective collaboration and communication between patients and healthcare authorities, stagnating the progress in policy co-design.

4. Potential pathways for policy co-design optimisation

4.1. Building public trust in authorities

A common phenomenon among the participants during the co-design process is a lack of a sense of belonging to the design panel, which may be due to their insufficient institutional trust. Without seeing themselves as one of the policy co-creators, patients are less likely to trust authorities in improving the healthcare services based on suggestions from them. Their real-life medical experiences and ideas are usually not considered essential in policymaking. Because of such negativity, health authorities face the dilemma that fewer patients are willing to provide valuable information and suggestions. Participants in practice often have more negative perceptions of design activities and outcomes, while senior managers in authorities tend to maintain overly positive attitudes toward these programmes [19]. This difference reflects a gap in the perception of the co-design framework between different social roles within health authorities.

Personal experience and feelings about co-design activities can largely influence participants' general trust in institutions. To build a sense of ownership of policy design, institutions should adopt more user-friendly methods that value the patients' ideas more in policymaking. Communities can potentially use 3D printing technology to create a local hospital model and simulate the patient's experience after the implementation of the policy through role-play activities. This may remind participants that they are directly contributing to policies that could benefit themselves. To make service changes more significant, the authorities could potentially design the simulation programmes to calculate and demonstrate real-time quantitative impacts on the healthcare system following systemic changes. This would allow participants to feel more immersed in the designer roles. Moreover, instead of simply guiding participants throughout all phases, staff supporting the workshops should adopt a collaborative attitude. The local authorities and healthcare organisations

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should release a monthly report on progress in public participation in healthcare policy co-design based on data collected through surveys and workshops, providing suggestions and future development potentials for the NHS accordingly. Meanwhile, the public should have full access to these relevant documents through official websites or workshop brochures. Together, these measures could improve public trust in institutional co-design activities and encourage more positive participation.

Another strategy focuses on improving information openness to the public. Hierarchies in professional policymaking skills often make experts consider co-design and collaboration with end-users simply as one-way consultation, providing only the information they think is necessary. This kind of knowledge confinement may make participants feel inferior in this process and erode their confidence in institutional commitments. Restricting participants' access to certain information may prevent valuable suggestions from emerging due to participants' knowledge gaps. Institutions could strengthen information provision channels by continuously updating participants on new healthcare proposals and upcoming engagement activities. This could be achieved through notices on community bulletin boards and the distribution of free informational brochures via mail or email. Greater information transparency may encourage participants to provide more ideas and engage more actively, while also building better empathy between staff members and participants within co-design projects.

4.2. Innovative co-design tools used in multiple stages

As mentioned earlier, the UK healthcare system is often criticised as "tokenistic" in its co-design attempts. The current PPI model relies largely on traditional frameworks that mostly adopt professional-led approaches. By considering user feedback at multiple stages, rather than limiting engagement to one-way consultation, healthcare development could become more democratic while addressing healthcare inequalities.

To narrow the gap between experts and patients, the personas method could be used during the definition stage. Due to institutional biases and top-down policy design traditions, it may be hard for senior policymakers and other powerful stakeholders to value patients' perspectives [20]. By bringing multiple stakeholders together in workshops, including individuals and social organisation representatives, staff members could randomly assign personas to participants for role-playing activities. This approach allows stakeholders to engage in deeper communication and develop an empathetic understanding of each other's perspectives. When final decisions are made with full consideration for patients, healthcare institutions could combine professional expertise and human-centred deliberation, which helps them better identify potential problems embedded in theoretical frameworks for future policies and actively seek improvement pathways. This process eventually reduces the public resistance to policy implementation.

Introducing a prototyping stage before formal policy implementation may also build a sense of co-ownership among patients. Representatives from the target population could be divided into two groups and asked to test two potential strategies designed to address the same issue. After the testing phase, participants would provide feedback based on their simulated feelings of each strategy. This preliminary testing allows comments based on real-life experiences while integrating end users more deeply into the design process.

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4.3. More inputs in co-design preparations

The latest NHS financial framework proposes a gradual reduction in running cost allowances, with financial deficits likely to further restrict the institutional support for individual ICBs, reflecting remaining limitations in preparatory input. Meanwhile, funding distribution based largely on population size, as the current distribution framework, may overlook regional inequalities in healthcare access. These risks worsen inequalities and further marginalise disadvantaged groups in healthcare policy co-design.

Allocating funding while considering regional quality of life and healthcare development levels could help address fairness concerns. For example, a region with a smaller population should not necessarily receive less funding for co-design activities. The healthcare authority should establish two distinctive distribution models for budget distribution based on population scale and regional development differences in healthcare and economic aspects and divide funding into two phases based on each individual region's score in each direction. If a region faces low healthcare quality, poor patient satisfaction, and weaker economic conditions, the national healthcare system should consider providing greater financial support. Increased financial and professional resources would enable more comprehensive co-design activities that better include marginalised groups.

To further optimise the co-design system, the national healthcare system should also increase investment in training programmes for both staff members and participating end users in research and engagement skills. The failure to generate valuable insights in smaller practices often results from a lack of experienced personnel capable of managing co-design processes effectively. Greater financial and academic investment in expanding expertise within healthcare policymaking could help these organisations overcome such challenges and make co-design practices more efficient. In the long term, trained staff could contribute to more systematic co-design processes and improved regional health service development. For participating end users, receiving training may help them analyse problems from multiple perspectives and strengthen their ability to engage in policymaking discussions. This could help reduce decision-making power imbalances in healthcare policy and strengthen the overall intention of policy co-design.

5. Conclusion

After investigating the framework of joint design of British medical policy, this paper finds that joint design has significant value in enhancing public participation, absorbing the opinions of vulnerable groups, enhancing policy recognition and institutional trust. However, its effect is highly dependent on the independence of supervision institutions, the balance of power distribution, the transparency of information and the stable resource guarantee. At present, the NHS in Britain has obvious shortcomings in these aspects, which leads to limited overall efficiency.

To advance co-design within the healthcare system, the UK must adopt strategies that are better aligned with its specific context. Ensuring equality between authorities and public participants is crucial, as it fosters mutual respect and strengthens trust within multi-stakeholder environments. The integration of innovative co-design tools throughout all stages could transform the tokenistic consultation process into a more substantive policy development mechanism. Furthermore, empowering participants through greater informational openness and more collaborative attitudes can increase engagement among target groups. Given constrained resources, authorities should prioritise funding and training allocation strategies that address multiple dimensions of inequality, ultimately contributing to improved equity in healthcare access.

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