The Big Society in an age of austerity: threats and opportunities for Health Consumer and Patients' Organizations in England

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Abstract

Background and Objective Health consumer and patients' organizations (HCPOs) seek to influence policy. But how are they affected by developments in the policy context and political environment?

Design The article draws on original research into HCPOs in the UK by the authors, including a major survey undertaken in 1999 and interviews with HCPOs and policymakers between 2000 and 2003 as well as a further survey in 2010. It also draws on a review of key government policies on health and the voluntary sector since 1997.

Results Developments in the political environment and policy context have created both opportunities and threats for HCPOs as they seek to influence policy. These include policies to promote choice and competition in public services; support for a greater role for the voluntary sector and civil society in health and welfare (including the current government's 'Big Society' idea); NHS reorganization; changes to the system of patient and public involvement; and austerity measures. Devolution of powers within the UK with regard to health policy and the rising profile of the EU in health matters have also had implications for HCPOs.

Discussion and Conclusion This analysis raises key issues for future research in the UK and elsewhere, such as how will HCPOs be able to maintain independence in an increasingly competitive environment? And how will they fare in an era of retrenchment? There are also challenges for HCPOs in relation to maintaining relationships in a new institutional setting characterized by multi-level governance.

Introduction

Academic interest in the role of health consumer and patients' organizations (HCPOs)

has grown in recent years. Defined as 'voluntary sector organizations that seek to promote and/or represent the interests of patients, users, carers and the wider public in the health policy

arena'(p. 530),¹ HCPOs have been the focus of studies in the UK and elsewhere.^{1–3} This literature indicates that HCPOs can be considered as both a response to, and a product of, the health, welfare and political systems in which they operate. This begs an important question: as the politics and policies of these systems change what are the implications for HCPOs?

This paper explores how UK HCPOs have been influenced by recent changes in policy and the political environment and looks ahead at the threats and opportunities they may encounter. This case is not unique, however. Key factors shaping the current policy context – health care reform; changes to the system of patient and public involvement; the increasing emphasis on self-help, voluntarism and individual responsibility (reflected in the 'Big Society' mantra of the current government and the Third Way approach of its predecessor); and pressures to cut public sector budgets in an era of economic crisis and austerity – are common to many countries at present. After setting out the background and context of the UK HCPO sector, we analyse the political context and policies of the 1997–2010 New Labour governments (headed by Tony Blair and subsequently Gordon Brown). This is followed by an analysis of the policies of the Conservative-Liberal Democrat Coalition government (led by David Cameron) which entered office in 2010. We recognize from the outset that the devolved governments in Scotland, Wales and Northern Ireland have adopted alternative reform programmes to those occurring in the English NHS, and the implications of this for HCPOs will also be examined.

This article draws on empirical research undertaken by the authors since the late 1990s, including an ESRC funded project during 1999–2003 and a more recent online survey exploring the campaigning role of HCPOs. The methods of the ESRC study, which included a 1999 survey of 123 organizations (out of 186, response rate 66%), and a series of interviews ($n = 70$) with HCPOs and policymakers, are fully outlined in our book, co-written with Judith Allsop.³ The second survey, of 122 organiza-

tions (of a total of 312, response rate 39%), funded by Leicester Business School, took place in the summer of 2010 and was hosted by speed survey. It should be noted that the sample in the later survey drew on slightly different inclusion criteria than the original. For example, the 2010 survey included research charities, which have become more overtly policy-oriented in recent years. The later survey also included groups from a broader range of health conditions. The way in which the sample was derived also differed. In 1999, printed directories were used to identify the sample; in 2010, this was achieved using membership lists from several national alliance organizations. There was, however, a degree of similarity between the two data sets, with the main types of organization identified in the ESRC study (formal alliances; population groups and condition-based groups, see p. 305)³ found in similar proportions in the 2010 survey.

Background and context

In the UK, there is a rich and diverse voluntary sector. Although definitions of the sector have shifted over time (see⁴ and below), and the boundaries between the voluntary sector and the state and private sectors have blurred, there is a continuing belief in the distinctiveness of organizations that are not part of government and which are 'not for profit'. Using a broad measure of the voluntary sector, including charities, social enterprises, cooperatives and non-profit making bodies, it has been estimated that there are around 900 000 organizations in the UK, with a combined turnover of £157 billion and combined assets of £244 billion.⁵ Within this, the voluntary health sector is significant. It has been estimated that 28% of voluntary organizations work in the field of health and well-being.⁶ HCPOs form an important component of the voluntary health sector. They undertake a range of roles. From their perspective, the most important of these are linked to supporting patients and service users, providing information and raising awareness of health issues and medical conditions.^{1,3} In addition, many groups also rate highly their

policy advocacy role, recognizing their unique position of being able to codify and reflect the experience of those receiving healthcare services to providers and policymakers.³

Key factors in the political environment 1997–2010

The Labour government, headed by Tony Blair from 1997, and from 2007 by Gordon Brown, adopted policies which appeared to favour HCPOs and the voluntary sector more generally. Although claiming to be less ideological (and in particular less socialist) than previous Labour leaderships (and indeed less ideological than its Conservative party opponents, who had shifted to the right since the late 1990s), the incoming Labour government certainly had firm ideas about policy direction. These policies were articulated in relation to a concept to which Labour had become attracted while out of government: *The Third Way*.⁷ Labour (henceforth *New Labour*, a title it adopted to distinguish it from previous regimes) depicted itself as steering a middle way between the old 'statist' approach of previous Labour governments and the 'privatization and markets' approach favoured by the Conservatives. This overarching rhetoric emphasized two broad policy themes relevant to HCPOs: first, that citizens and service users should be able to influence public services and be given more choice and a stronger voice in the context of greater accountability; second, that citizens should take more responsibility for their own lives and not become dependent on the state and that the voluntary sector should have a greater role in public service provision.

The New Labour government therefore took a considerable interest in the voluntary health sector and in HCPOs. It also became actively involved in reforming structures of patient and public involvement. However, it did not begin with a blank page. The previous Conservative government (led by John Major) had considered these matters and identified a role for HCPOs in improving NHS policies and services through involvement in decision

making at local and national level.³ In 2001, in its Health and Social Care Act, the New Labour government introduced a statutory duty on NHS bodies to consult with patients and the public over proposed changes to services. It also established a system of health overview and scrutiny by local authorities (locally elected multipurpose public bodies covering a particular geographical area). Both these developments offered opportunities for HCPOs to get involved in local debates about health care services. However, it was increasingly believed that these measures did not go far enough in promoting the involvement of the public, patients and HCPOs. The statutory duty was too easy to evade in practice.⁸ It was clarified and narrowed in 2007, (curtailing involvement on issues where services were to be transferred to another provider – seen by some as stifling debate on privatization). In a move to strengthen involvement, however, a new duty was placed on primary care trusts (PCTs) and strategic health authorities to report on consultation processes and document their influence on decisions. Health scrutiny, meanwhile, had a questionable impact, with shortcomings such as insufficient resources, capacity and powers.^{9,10}

In 2003, the New Labour government reformed the system of patient and public involvement in the NHS, replacing local community health councils (on which voluntary organizations, including HCPOs, were represented) with patient and public involvement forums in each local NHS body. The councils' national body – the Association of Community Health Councils for England and Wales – was also abolished. The new patient and public involvement forums included HCPOs and voluntary organizations as representatives of patients, carers and the wider public. Some HCPOs also had a role in providing administrative support services for these new bodies. A national body was also established to promote patient and public involvement and to oversee the local forums (the Commission for Patient and Public Involvement in Health). However, the new arrangements were heavily criticized for

being fragmented, poorly resourced and ineffective.^{8,10} Consequently, the system was reformed again in 2008. The Commission was abolished. Local involvement networks (LINKs) were established, replacing patient and public involvement forums. HCPOs and other voluntary organizations were again involved as members of LINKs and, like the previous system, provided support services. The creation of foundation trusts, NHS hospitals with managerial and financial freedom, meanwhile entailed new involvement mechanisms to engage local people as members, with rights to vote in elections for, and become members of, the governing body. The effect of these various activities on HCPOs was mixed. In some respects, new opportunities to engage were created. However, the complexity and lack of coherence of the new structures undermined these opportunities. Moreover, tensions between different parts of the system arose, notably between patient and public involvement forums (and later LINKs) and foundation trusts, the latter operating a more individualized and narrow form of participation.

Other health issues and policies created a mixture of opportunities and threats. The New Labour Government pursued initiatives to extend patient choice and local commissioning by PCTs. On the one hand, these initiatives were seen as reducing the role of HCPOs, as they were based on an individualized model of patient and public involvement. On the other, they created opportunities for HCPOs, as commissioners and providers sought out the views of these organizations and used them as a conduit to engage with patients, users and carers. There is little evidence on which of these forces was the stronger. Some found that local HCPOs had little impact on commissioning, while others suggested that commissioning created opportunities for dialogue with NHS commissioners.^{11,12} In addition, government increasingly emphasized the prevention of illness, and it appears that HCPOs responded to some degree to this agenda creating fresh opportunities for some HCPOs to engage with government and seek to influence policy in areas such as cancer prevention.¹

A further factor affecting HCPOs relates to changes in the wider voluntary sector. Government encouraged voluntary organizations, including HCPOs, to become more involved in service provision. Bidding for contracts and providing services offered these organizations greater status and legitimacy. But it also threatened to weaken their advocacy function. It is widely recognized that greater financial dependency of groups on government and public authorities can undermine their independence.³ Of course, voluntary organizations providing public services are not always in a weak position. It is possible that public authorities may become dependent on highly specialized providers for both service provision and engagement of users.¹² In this period, the government acknowledged voluntary organizations as legitimate representatives of service users and citizens (and in the case of HCPOs, patients, users and carers as well as the wider public). A national compact was established¹³ which has since been revised,¹⁴ setting out the parameters for the relationship between central government and the voluntary sector. In addition, local compacts were also established. New funding schemes ('Futurebuilders' and 'Change Up/Capacity Builders') were introduced to build capacity within the sector.

Furthermore, a strategic partnership agreement was drawn up by the Department of Health (DH) specifically for the voluntary health sector, which emphasized the latter's involvement in needs assessment, planning and service provision. In addition, a national strategic partnership forum was established to implement this agreement, drawing members from voluntary health organizations and HCPOs. Later, in 2009, the DH established a strategic partners programme, funding a number of voluntary health organizations to act as a channel of communication between itself and the sector. Voluntary health organizations (including HCPOs) were also represented on the Department of Health (DH) National Stakeholder Forum alongside representatives of NHS organizations, trade unions and professional associations.

Developments within the HCPO sector itself were also relevant. In 2008, National Voices was launched as a formal alliance covering the health and social care sector in England. It is a coalition of over 200 organizations and has been important in establishing a coherent voice, for example, on recent health legislation.¹⁵ However, tensions remained, given the distinctive and condition-specific nature of many groups. Individual groups have also undergone significant changes. Of the 39 HCPOs that were selected for interview for the initial ESRC study, only 22 were still operating under the same name in autumn 2010. In some cases, groups had merged with others to form stronger organizations with greater capacity to support members, provide services and influence policy. However, flux in the sector can also be destabilizing, undermining continuity and momentum.

As suggested earlier, changes in the policy process arising from multilevel governance have also been important. Devolution of health policy responsibilities within the UK to governments in Scotland, Wales and Northern Ireland has created the potential for further policy divergence¹⁶ and additional opportunities for HCPOs to influence policy. Interestingly, our 2010 survey found that a significant proportion (42%) of respondents stated that influencing policy in Wales, Scotland and Northern Ireland was 'very important'. Devolution may also place additional burdens on groups, however, draining resources and undermining capacity. The strain of dealing with four separate administrations may also create tensions within HCPOs, particularly if the organizations adopt a devolved structure.

The focus on Europe, as a result of the EU extending its activities in this field, is also noteworthy.¹⁷ Even though health services remain a national competency under EU rules, there has been an increased role for EU institutions in fostering cooperation on health matters, especially public health issues, medical products and cross-border patient rights. The 2010 survey found that influencing policy at the EU level was a priority for a minority of UK

HCPOs (16%). A slightly higher proportion reported at least quarterly contact with EU institutions (see Table 1). However, levels of interaction with Europe may be underestimated as a result of UK HCPOs operating through pan-European groups rather than by direct representation. EU-wide alliances have already developed around particular conditions and population groups.³ Notably, pan-European groups seem to be increasing: over half those listed in a 2008 directory of EU-level HCPOs were formed since 2000.¹⁸

In summary, the New Labour era was a mixed blessing for HCPOs. The surveys undertaken by the authors showed that national bodies were keen to have a policy role. In both the 1999 and 2010 surveys, a majority of HCPOs stated that influencing national policy was 'very important' to them (61% in 1999 and 55% in 2010). The importance of local policy was also acknowledged with 64% of the 2010 survey respondents stating that this was either 'very important' or 'fairly important' to them. The two surveys also revealed that HCPOs reported substantial levels of contact with policymakers (see Table 1).

In some respects, this reflects a broadly positive political environment and favourable policy agenda during this period. However, when looking beneath the surface, there were aspects of both which undermined HCPOs, and patient and public involvement more widely, in

Table 1 Percentage of groups reporting 'at least quarterly' contact with policymakers on health policy issues in the previous 3 years

	1999 %	2010 %
Central Government		
Department of Health Civil Servants	48	39
Department of Health Ministers	30	34
Prime Minister's Office	8	5
Parliament		
MPs	*	49
Peers	*	32
European Union Institutions	19	19

*In the 1999 survey, 45% of the groups reported contact with parliament at least quarterly. Source: Questionnaire data sets 1999, 2010.

particular the flawed reform of patient and public involvement systems; continuing difficulties with resources and capacity of HCPOs; challenges to the independence of HCPOs as they became more heavily involved in service provision; and the challenges of multilevel governance which not only stretched the resources of HCPOs but created internal organizational issues discussed above.

Coalition government and the future for HCPOs

In May 2010, following an inconclusive general election, the Conservative party and the Liberal democrats formed a coalition government under the leadership of David Cameron (the Conservative leader). Despite initially ruling out a top-down reorganization of the NHS, within months the new government decided to launch a comprehensive restructuring [in a White Paper, *Equity and Excellence: Liberating the NHS* (Cm 7881, 2010)].¹⁹ This led to the Health and Social Care Act 2012, which is likely to have a substantial impact on HCPOs. This legislation is currently being implemented. The key elements of this new framework are as follows:

An increased emphasis on personalization, patient choice and competition: new providers (voluntary and private sector) are encouraged to provide health services within a regulated market. Providers must meet a quality threshold. Anticompetitive behaviour against the interests of patients is prohibited. Service commissioners have a duty to promote patient choice. In addition, government is extending the personalization of care from social care (where people already have personal budgets) to health care.²⁰

Devolution of powers and responsibilities for planning and commissioning health services: The Secretary of State for Health sets out a mandate (setting out key objectives for the NHS) and a resources framework. A new NHS Commissioning Board (since renamed NHS England) is responsible for the delivery of these objectives and accountable for the NHS budget. NHS England commissions

primary care services (and some hospital and public health services), but the majority of secondary care is commissioned by local clinical commissioning groups led by GPs. The previous lower-tier commissioning bodies, PCTs, have now been abolished, as have upper-tier NHS authorities, the strategic health authorities. The creation of a larger number of local commissioning bodies (over 200 compared to 152 PCTs) linked to general practice reflects a key theme of government policy: to localize decision making. Notably the NHS is now under a duty to promote local autonomy, subject to this being in the interests of the service as a whole.

A new system of public health governance: Most local public health services are now the responsibility of those local authorities with social services responsibilities (that is county councils, unitary authorities and London boroughs). They receive a ring-fenced budget for this purpose. Public health teams, including Directors of Public Health (DPHs), have been transferred from PCTs to these bodies. These local authorities are also required to establish health and well-being boards (including DPHs, councillors, directors of children's services and adult social services, clinical commissioning group representatives, and local Healthwatch – see below). Health and well-being boards lead local health needs assessment and develop a joint health and well-being strategy for their area. In addition, a new national body for public health expertise (Public Health England) has been created as a non-departmental public body.

Requirements to improve service quality, reduce health inequalities and integrate services: NHS bodies now have an explicit duty to improve the quality of services. In addition, they have duties to reduce inequalities in access to health care and to promote service integration. Health and well-being boards are also expected to lead and promote integration between public health and social care and health services via their joint strategies and by encouraging the pooling of resources across health and social care services.

A new system of patient and public involvement: At national level, Healthwatch England has been established as a subcommittee of the health care regulator, the Care Quality Commission. Healthwatch England will be consulted on national health policy priorities and will be expected to act on local reports about problems in health and social care. At local level, LINKs (see above) have been replaced by local Healthwatch, commissioned by local authorities with social service responsibilities. Local Healthwatch is required to be representative of local people. It will be able to inspect premises used for the delivery of health and social care services and highlight problems by alerting Healthwatch England and local authority health scrutiny bodies. Local Healthwatch is also expected to facilitate patient choice by signposting local services and may be commissioned by local authorities to assist with complaints about health and social care. In addition, health scrutiny has been reformed. Councils have more freedom to organize scrutiny in ways best suited to their local circumstances (and are no longer required to have a specific health scrutiny committee).

These policies and reforms represent significant continuities with the previous Labour government, which also emphasized choice and markets, reformed patient and public involvement, and had started to move to a more decentralized system of decision making in its latter years. Even so, the changes introduced by the Coalition government are likely to have a number of main implications. The abolition of key NHS bodies is likely to disrupt existing relationships between the voluntary sector (including HCPOs) and the NHS. It will take time for the new commissioning bodies to re-establish relationships previously developed between HCPOs and PCTs. Moreover, an increase in the number of local commissioners may add to the burden on HCPOs as they seek to influence commissioning decisions. The replacement of LINKs with local Healthwatch may also be similarly

disruptive to relationships between statutory bodies and the voluntary sector.

Given the intended localization of commissioning responsibilities, it is likely that local bodies (clinical commissioning groups, health and well-being boards and local Healthwatch) will increasingly be the target of HCPOs. Notably, clinical commissioning groups, as the key budget-holding and commissioning bodies for local health care services, are expected to involve patients, users and carers and the wider public in their decision-making processes and plans. This will create incentives and opportunities for HCPOs to engage with them (directly or via the health and well-being board or local Healthwatch). However, there is some scepticism about how and to what extent this will happen in practice.²¹ It will take time to build trusting relationships. In addition, there are concerns that as larger HCPOs become directly involved in commissioning at local level, this may pit them against formal involvement structures, weakening the latter. Health and well-being boards are likely to be a focal point for HCPOs given their roles mentioned above. In addition, local authorities' new powers and duties in public health will encourage HCPOs interested in prevention to engage with them. A consequence of these changes taken together is that if planning and commissioning decisions are taken at a more local level, HCPOs will have to respond by strengthening their local structures and provide sufficient capacity and support for engagement with local decision makers in health care, social care and public health.

Notwithstanding this, there will be a continued need for a strong national presence. HCPOs will need to maintain contact with national health policymakers, for example, to influence the Secretary of State's mandate and NHS England, as well as other bodies such as Healthwatch, the Care Quality Commission, Public Health England and also NICE (now renamed the National Institute for Health and Care Excellence – which now has an extended role in relation to health care quality standards). This will be particularly true for groups

dealing with rare conditions which will continue to be commissioned at national level. Finally, the integrated care agenda, with its drive to ensure that health care, social care and public health services meet the many and complex needs of individual patients, offers opportunities for HCPOs. For many years, those representing people with chronic conditions have campaigned for a more collaborative approach where the range of services provided are more effectively integrated.

Austerity and the Big Society

The Coalition's government's broader economic and social policies, in the context of austerity, also have implications for HCPOs. The NHS budget has effectively been cut, despite the Cameron government's commitment to slightly increase it in real terms.²² Budgetary pressures have increased due to several factors: the government's efficiency savings programme (£20 billion over 4 years); the costs of NHS reorganization (£1.7 billion); and the continued rising demand for health care due to demographics and medical technology. Meanwhile, social care funding has been reduced, due to public expenditure cuts in local government. While public health budgets have been ring-fenced, there is concern that funds are insufficient to meet the huge challenge of problems such as alcohol misuse, tobacco-related disease and obesity.

The austerity approach of the Coalition government presents many problems for HCPOs. As the capacity of health and social care systems is reduced, unmet needs are likely to increase and standards of care may fall. This is likely to increase demands on HCPOs for advice, information and assistance. Meanwhile, HCPOs that are funded by the state for services, advocacy and policy advice are being affected by budget cuts in the NHS and local government.²³ Indeed across the voluntary sector, capacity is being adversely affected by the austerity programme.²⁴ More positively, HCPOs may derive opportunities from the conditions created by austerity in the public

finances. They may recruit more members as people adopt self-help approaches to managing illness. They may also attract more support from patients, and perhaps the wider public as well, by contesting budget cuts and highlighting the consequences of retrenchment on services.

The other broad policy influence potentially shaping the political environment of HCPOs is Cameron's commitment to the 'Big Society'.^{25,26} Although vague and ambiguous, the Big Society implies a shift in power from the state to civil society. Voluntary organizations such as HCPOs are seen as important to this vision in a number of ways. They harness voluntarism and social action; they can provide services that are highly responsive to needs; they can represent people's views and engage with local people. They can support co-production and promote social responsibility by increasing self-reliance and the realization of a community's potential. On these grounds, the Big Society can strengthen the legitimacy of HCPOs and their role in service provision and advocacy. However, the Big Society has been criticized for cloaking budget cuts. Voluntary organizations have been expected to step into the breach left by a reduction in statutory services. Meanwhile cuts in voluntary sector funding, as already noted, reduce their capacity to provide services. In addition, a greater role in service provision could add to the existing tensions between service provision and advocacy. Indeed, the independence and legitimacy of HCPOs and other voluntary organizations could be undermined by an extended role in service provision, especially where they undertake a rationing role on behalf of the state. A further issue is that the Big Society could create winners and losers within the voluntary sector and among HCPOs specifically. Organizations that 'dance to the government's tune' or adopt its ideological position with regard to health and welfare, could benefit, while those that refuse to comply could be disadvantaged. This could lead to widening inequalities within the HCPO sector between those that support government policy and those that oppose it.

Other factors

Finally, it is possible that other factors will impact on HCPOs in the future. First, despite anti-European rhetoric, Europe is likely to continue to become more important in health policy.¹⁷ If so, HCPOs will have to respond, either by direct lobbying or via European-wide groups and networks. Participating in such networks could stretch even further the resources of national organizations. However, it may also offer additional opportunities; for example, EU funding for research into neurological conditions has acted as an incentive to improve cooperation among HCPOs and professional organizations.²⁷ In addition, devolution remains a key challenge for HCPOs. The NHS Reforms discussed above only apply to England; other governments in the UK have placed much less emphasis on choice, markets and competition. Moreover, Scotland, Wales and Northern Ireland are developing their own approaches to policymaking, which will require groups to stretch their resources even further. This may, however, afford the opportunity to develop local-level solutions to policy problems.

Conclusion

We have shown how the policy and political environment is a major factor in shaping the activities of HCPOs and their success and influence. By exploring key factors in the current environment, we have identified important questions about how HCPOs will fare in the future. The first question relates to the independence of HCPOs vs. government and public bodies (and other policy actors such as commercial and professional interests). How and to what extent will HCPOs be able to maintain independence in an increasingly competitive environment, where they are expected to bid for service contracts? Second, and related to this, competition between HCPOs may lead to 'winners and losers' and undermine collaboration between them. How will groups overcome a 'divide and rule' situation

and maintain coherence as a sector? Third, both public and private sectors (and individuals) face economic problems and funding sources are threatened. How will HCPOs ensure their survival in an era of falling donations and budget cuts? A fourth question concerns the tensions between individual patient/citizen involvement and collective representation via HCPOs. The latter can support the former (for example in making choices about health care) and active patients/citizens can increase the capacity of the latter. But the two forms are also in competition with each other. Too strong a focus on individuals can undermine the role of HCPOs. How will HCPOs be able to manage the conflicts and tensions between these aspects of representation? Furthermore, it will be interesting to see how HCPOs, particularly those with limited resources, maintain and extend their influence over policy, particularly in an era of multilevel governance when decisions affecting health and social care are made at various levels of government. It is not just about resources; however, organizations will have to arrange and adapt their functions to meet the demands of an increasingly differentiated policy system.

The final key question is about policy influence. All too often it has been assumed that because HCPOs have gained access to decision makers and been accorded legitimacy, they have some influence over policy. This is in fact an empirical question and one that is rarely investigated systematically. It is also a strategically relevant question for HCPOs themselves. Evidence of influence may affect the future willingness of HCPOs to engage in the policy process. Any future work into HCPOs must explore their impact on policy and the extent to which they influence policy both as independent entities and in conjunction with other policy actors. Indeed, this is a key element of our continuing programme of work in this field.

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None.

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