Research governance in children’s services: the scope for new advice

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Background and aims

This project was commissioned by the former DCSF to inform the development of guidance on research governance in children’s services. The overarching aim was to contribute to the development of a more coherent and transparent system, that is proportionate to the governance needs and ethical risks in research with users of children’s services.

Research governance is fundamentally concerned with improving research, through the regulation and assurance of research quality and research ethics. Whilst different research governance models use their own definitions, the Department of Health’s Research Governance Framework (RGF) offers a useful definition of research governance, as aiming to encourage and sustain a research culture that promotes excellence in research conduct, and reduces unacceptable variations in practice (Department of Health 2004). These objectives are achieved through a series of principles, requirements and key standards.

The ethics and governance of research in children’s services raise particular issues. These include the governance of access to children, and ethical issues such as consent. In addition, since 2003, there have been major reforms in the way that children’s services are planned and delivered in central and local government. Children’s services in England comprise a very varied constituency, ranging from lone providers to institutional provision, and including private, voluntary and public sector provision. The integrated children’s services agenda, along with new frameworks such as statutory requirements for Children’s Trusts, also means that the boundaries between different areas of provision are increasingly blurred. The scope of research governance is also a particular consideration for children’s services, in a climate that emphasises service user consultation and service evaluation. The development of government guidance on the governance of research in children’s services must therefore address a complex series of challenges.

In 2009, following a period of informal consultation with key stakeholders, the former DCSF commissioned the work reported here, with the following overarching aims:

- to identify and evaluate existing arrangements for research governance and ethics review in children’s services in England; and
- to make recommendations for the future development of those governance arrangements, with the overall goal of ensuring a more coherent and transparent
system, that is proportionate to the governance needs and ethical risks in research with users of children’s services.

Methods

The first stage of the work involved thorough scoping reviews of relevant research literature on ethics issues in research with children and young people, and of initiatives relating to research governance and ethics review procedures. These reviews aimed to provide a context for subsequent data collection, and in particular, to identify key common themes and debates, across sources, to inform the development of recommendations. This first stage of scoping work also involved telephone or face-to-face interviews with national stakeholders, including representatives of funding bodies, independent and academic research organisations, and an organisation representing children and young people.

At the same time, an electronic survey was circulated by email to all 152 local authority Children’s Services Directorates. In total, 59 responses were received (39% response rate). The survey collected information about local authority governance arrangements and research activity, whilst also seeking respondents’ views on the development of governance arrangements for research with children in local authorities.

Subsequently, 30 interviews were conducted in eight local authority areas (face-to-face or by telephone), with a mixed case study approach designed to represent stakeholders in a range of authorities identified through the survey. These interviews provided qualitative data about research activity, existing research governance arrangements, and participants’ views or concerns about the governance of research in children’s services. Interviewees were recruited by a process of purposive and snowball sampling, with the survey respondent providing a starting point for sample recruitment. Across the eight local authorities, interviewees included the following perspectives: local authority managers with responsibility for different areas of children’s services (e.g. schools, early years, children’s social care, service user involvement) and for research governance in children’s services; representatives of service providers (e.g. schools); and representatives of academic and/or independent research organisations, or independent research consultants, who were involved in research in the local authority, including representatives of organisational research ethics committees.

Interview data and qualitative survey data were analysed thematically, using the constant comparative method, in relation to the study objectives and any issues or concerns (e.g. in relation to research ethics or quality, or proportionality) arising from national stakeholder interviews, the survey or scoping reviews.

Findings

In considering findings from the local authority survey and interviews, it is important to note three key caveats. First, local authorities with less well-developed research governance arrangements for children’s services, or with lower levels of research activity, might be less likely to have responded to the research. Consequently, the results may over-estimate both the preparedness of local authorities to develop research governance for children’s services, and the extent to which such developments might be seen as worthwhile or necessary. In addition, many survey respondents – including those in authorities with well-developed research governance systems – noted that their knowledge of research activity was likely to be incomplete, and their accounts of the nature of local authority research activity inevitably reflect this partial picture. Finally, there is a need to account for the positioning of different stakeholder interviewees. Interviewees were purposely sampled to bring a range of professional perspectives to the research – including researchers, local authority service
leads, and local authority staff responsible for research governance – but these different positions need to be acknowledged in interpreting respondents’ views.

**Local authority arrangements**

Most survey respondents had some systems in place for the governance of research in children’s services, but the nature of these arrangements varied considerably within and between local authorities. Few reported arrangements that spanned children’s services as a whole; even those that did have wide-ranging systems acknowledged that there were services (notably schools and Private, Voluntary and Independent sector services), or forms of research-like activity (e.g., consultation), which were not adequately captured by their systems.

Adult social care research governance arrangements, using the model of the Department of Health's Research Governance Framework (RGF) had been adapted for children’s services in some areas. The scope of these arrangements varied; in two case study authorities, the RGF was applied only to children’s social care, whereas RGF-based systems spanned children's services in the other four areas. Views were mixed on how well adult RGF arrangements applied to the needs of children’s services: concerns about a lack of ‘fit’ with children’s services were balanced against recognition that the system had provided a valuable framework in the absence of any alternative.

**The scope of guidance**

Survey and interview respondents generally welcomed the development of guidance on research governance in children’s services by government. Many local authority respondents expressed a desire for more consistency and greater rigour in existing systems, but interviewees also highlighted the potential for research governance guidance to promote ‘research-mindedness’ in local authority children’s services, by highlighting the potential value of good research.

In line with messages from the scoping reviews, almost all interviewees advocated an inclusive definition of research, to encompass research-like activities, such as consultation, audit or evaluation, which use research methods and thus may raise ethics or governance issues. Information sharing was highlighted as a key concern for research governance, suggesting that guidance also needs to address secondary use of data where identifiability may result.

**Quality**

The over-arching aim of research governance is to improve research, in part through checks on quality. The scoping review of governance arrangements highlighted the challenges – and subjectivity – inherent in judging quality. At the same time, interviewees and survey respondents highlighted a need for some external ‘check and challenge’ – not only to ensure quality, but also to help local authorities to determine which requests to for research involvement are worthwhile.

Discussions of quality were, however, also characterised by concern that research governance systems could adversely affect research quality, because of their impact on research timescales, and on the representativeness of research samples. This concern was, not surprisingly, highlighted by researchers in particular, but it was also raised by local authority stakeholders, including those responsible for service user involvement and consultation.

**Proportionality and flexibility**

The scoping review of research governance and ethics review systems indicated a shift in emphasis, over recent years, towards proportionate and principled-based approaches. Perhaps of particular relevance in the present context, most systems – including the National
Research Ethics Service pilot of proportionate ethics review, and the ESRC Framework for Research Ethics – do not automatically categorise research with children as high risk (and therefore research with children is eligible for proportionate or light touch review).

Survey and interview respondents commonly highlighted the need for guidance to ensure proportionate and flexible research governance arrangements. In part, this reflected concerns about the potential negative impacts of governance arrangements on research quality, as noted above. However, local authority concerns also related to the resourcing and capacity necessary to establish substantive systems, and to concern that the introduction of onerous systems would simply encourage people to find ways of avoiding the system, for example by classifying the activity as something other than research.

Children’s competence or vulnerability
The research highlighted debates about the extent to which children and young people should be seen as potentially vulnerable, or as capable of making decisions about whether or not to take part in research. These tensions were entwined with respondents’ professional positions and their perceived responsibilities – for example, to enable children’s voices to be heard or to protect children and parents’ rights. Linked to debates about children’s capacity to consent were considerations about the appropriate role of adult gatekeepers, and in particular, requirements for parental consent. Differences were apparent between the protective discourses of some local authority interviewees and the position of much of the academic literature, which recognises the particular ethics considerations in research with children, but which prioritises children’s rights and voices over those of adult gatekeepers. These debates highlight a particular need for clear guidance in relation to hierarchies of consent in research with children.

Ethics through the research process
The academic literature on research ethics also highlights a need to attend to considerations across the research process. Much of the discussion by interviewees was focused on ethics in relation to data collection – to consent in particular, but also in relation to the potential for a participant to disclose information that could raise safeguarding concerns, and the need for systems to address that possibility. However, there is also a need for guidance to address ethical practice in dissemination and reporting from research. This point was highlighted as a key need by a small number of interviewees, but it is noteworthy that those advocating attention to dissemination included respondents with particular expertise in consulting with children and young people, and supporting them in enabling their voices to be heard.

Conclusions and recommendations
The primary aim of the research reported here was to inform the development of guidance to ensure coherent and transparent research governance arrangements, which are proportionate to the governance needs and ethical needs of research in children’s services. The messages from the research aim to inform that over-arching goal.

Message 1. Variation across local authorities
Government guidance for research governance in children’s services needs to address variable practice across authorities, and to address many respondents’ desire for greater consistency in arrangements. However, it needs to strike a balance between these concerns and: (a) sensitivity to local contexts, and to the variety of existing established arrangements within local authorities; and (b) the risk that a highly prescriptive approach could duplicate existing arrangements or impose a substantial bureaucratic and financial burden for local authorities.
**Message 2. A role for the Department of Health Research Governance Framework?**

The Department of Health’s Research Governance Framework has evidently been a useful tool in some authorities, and has provided a valuable starting point for research governance in children’s services in some areas. However, the research suggests a lack of fit with the context of children’s services, particularly with regard to integrated services; statutory requirements for consultation with service users; and the development of evidence based services, and the role of research and of service evaluation within that agenda in children’s services.

**Message 3. A broad definition of research**

Guidance on research governance for children’s services should adopt a broad definition of research which explicitly highlights the value of good quality research as a resource for policy and service development, in order to give a clear message that research governance should not act as a barrier to research, and to support local authorities’ efforts to develop research-mindedness among their staff. Guidance should encompass ‘research-like’ activities that use research methods, including consultation and evaluation, and data review or audit where individuals may be identifiable, and the definition of research should be broad to ensure that it does not privilege any specific research methods or methodological approaches.

**Message 4: Quality assurance**

There is a need to embed appropriate levels of scrutiny across the research process, from commissioning to dissemination, to recognise the ethics and governance considerations that apply at all stages of the process. Such oversight would also serve to ensure that studies which have the necessary research governance approval are able to proceed as agreed. Concerns about quality must also accommodate the potential negative sequelae of disproportionate governance (e.g. for samples or research timescales).

**Message 5: A flexible and proportionate approach**

Flexibility and proportionality should be key principles of guidance on research governance systems, such that arrangements should (a) be based on key minimum standards, which can be implemented flexibly, depending on local needs and contexts; (b) avoid duplication of review, by clarifying which forms of independent scrutiny should be accepted for the purposes of research governance in children’s services; (c) be responsive to differences in likely levels of risk, and in resources and timescales for the work; and (d) allow that, whilst the same systems may not be applicable across all sectors of children’s services, minimum standards should apply across research involving children’s services.

**Message 6. Hierarchies of consent**

Government guidance for research governance in children’s services should attend specifically to the issue of children and young people’s consent. Guidance should not be age specific, but it should specify the following:

(a) valid (freely given and fully informed) consent, not assent, should be secured from all participants, including children, regardless of age, in all but exceptional circumstances;

(b) consent for participation should be sought using enabling methods that are appropriate to the levels of understanding of potential participants;

(c) adult gatekeepers (including parents, carers, or professionals with a duty of care) should normally always be informed if a child is going to be approached as a potential participant, with the proviso that this may not be appropriate in exceptional circumstances;

(d) adult gatekeepers should have the opportunity to consent or assent for a child to be approached as a potential participant, or to refuse permission for the child to be approached, with the proviso that it may not be appropriate to seek adult permission for research with children in some circumstances;
(e) adult gatekeepers cannot give valid consent on behalf of children, although in exceptional circumstances children’s assent may be a justifiable alternative. When consent from child participants is not going to be secured, this must be justified by the researchers, and should include an explanation of how the researchers will ensure that participants have assented to their participation and continue to do so (e.g. researchers should attend to signs of boredom or distress in children too young to express verbally their consent, or their refusal to give consent).

**Message 7. A principles-based approach**
Research governance in children’s services should be based on clear underpinning principles, to guide decision-making at all stages of the research process. This approach should be flexible enough to accommodate the variety of disciplinary and methodological approaches and of stakeholders (including local authorities, settings, and researchers and research organisations) involved in research in children’s services. It should also allow that the specifics of how principles should be applied may vary, whilst principles and minimum standards remain constant across domains. Avoidance of duplication of review is a key tenet of proportionate systems, and so guidance should stipulate arrangements for ‘passporting’ ethics and research governance approvals by other scrutiny bodies.

**Message 8. A system of passporting**
Government guidance for research governance in children’s services should advocate a staged and proportionate system, which ensures independent scrutiny whilst avoiding duplication of review. Such a system should allow ‘passporting’ of other forms of scrutiny, based on established guidance, and specifying accepted systems for external ethics review and for independent scrutiny of research quality and competence. Guidance should also specify minimum standards for independent scrutiny of research governance and ethics, for research activity which cannot be passported following external scrutiny.

**In conclusion**
The development of research governance for children’s services is undeniably a complex task – complicated by the diversity inherent in the integrated children’s service agenda, as well as by emotive debates about the potential vulnerability of children and young people, and the protective responsibilities of local authority staff, with regard to their duty of care to their service users. However, the main conclusions from this work are clear. To develop a coherent and transparent system of research governance – a system that can be applied across the diverse, and increasingly integrated climate of children’s services – necessitates a simple, and flexible, approach. This approach must be based on clear principles, whilst being flexible in its implementation around key minimum standards. New guidance may not capture every form of research-like activity involving children’s services, and it is likely to take some time for systems to develop. Nonetheless, such guidance has tremendous potential as a tool for raising awareness and raising standards. It is a beginning, not an end-point.
Additional Information
The full report can be accessed at http://publications.education.gov.uk/
Further information about this research can be obtained from
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This research report was commissioned before the new UK Government took office on 11 May 2010. As a result the content may not reflect current Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DFE).

The views expressed in this report are the authors’ and do not necessarily reflect those of the Department for Education.