

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

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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Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DFE).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.

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# Executive Summary

## 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.

# 1. Introduction

## 1.1 Background

The work reported here 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. As this emphasis on coherence and proportionality suggests, 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. These changes mean that central government and local authority Children's Services Directorates are responsible for a very diverse range of services provided by a variety of providers in the private, voluntary and public sectors. The development of government guidance on the governance of research in children's services must address the potential challenges and complexities of work in these areas.

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 definition offered by the Department of Health's Research Governance Framework (RGF) offers a useful starting point for the discussions presented in this report. The implementation plan for the RGF in social care states that research governance:

*'sets out to encourage and sustain a research culture that promotes excellence in the conduct of research and reduces unacceptable variations in practice.'*

(Department of Health 2004: 2)

These objectives are achieved through a series of principles, requirements and key standards in five domains (ethics, science, information, health and safety, and finance), with mechanisms to deliver them, including monitoring and assessment arrangements.

### *The need for a new system?*

Governance frameworks for social research, including the RGF, already exist in government. The Government Social Research Unit has published guidance on ethical assurance of social research, which covers all social research conducted in and for government (HM Treasury 2006). And, as noted above, the Department of Health has implemented the Research Governance Framework (RGF) for Health and Social Care (Department of Health 2005), and most recently, has initiated the development of a Social Care Research Ethics Committee (SCREC), appointed by SCIE (the Social Care Institute for Excellence) and operating within the framework of the National Research Ethics Service (NRES). These existing frameworks raise the question of whether new governance arrangements are really necessary for research in children's services, or whether, for example, the RGF could (or should) inform the development of research governance arrangements for children's services?

Although the Research Governance Framework applies to research in health and social care, the impetus for the Framework reflects events in health care research, including previous adverse incidents within the NHS (Chief Medical Officer, 2000), and a European Community Directive on clinical trials involving medicines (Directive 2001/20/EC, Fontaine and Rosengren, 2001). This background raises some questions about its potential applicability to other forms of research. When the implementation plan for the Research Governance Framework in Social Care was being developed, it was noted that

social care research differs from health research in several key respects, including project timescales and the scope of the research, as well as the nature of risks involved in research participation. Equally, whilst there are some similarities, there are also substantive differences between research involving children's services and research in adult social care. Any recommendations for the development of research governance in children's services must take account of existing frameworks, but beyond that, new developments must be sensitive to the specific contexts in which research with children is conducted, as well as the ethical issues specific to research with children.

## 1.2 The integrated children's services agenda

The landscape of children's services has changed substantially since the Department of Health's Research Governance Framework was published in 2005. Notably, the formation of the former Department of Children, Schools and Families shifted responsibility for different aspects of child and family policy (including children's social care) from elsewhere in government (notably Department of Health and the Home Office) into a single department responsible for a diverse spectrum of policy and services for children and families.

This change reflected a fundamental shift, towards the development of integrated working in children's services, as set out in the *Every Child Matters* agenda published by DfES in 2004. This agenda continued to develop through policy frameworks such as the *Children's Plan* (DCSF 2007; DCSF 2009) and the statutory requirements for Children's Trusts (DCSF 2008).

Reflecting this national policy emphasis, local authorities integrated children's social care and education services within Children's Services Directorates. Integration was also evident in the development of multi-professional teams and of co-located services – notably through the Children's Centre programme and the development of extended services through schools. These developments have had two critical implications for research governance in children's services.

First, demarcations between education and child welfare services are less clear than used to be the case, and any development of research governance arrangements for children's services needs to take account of the growth and complexity of integrated working arrangements as well as the diversity of children's services<sup>1</sup>.

Second, statutory guidance for Children's Trusts set out requirements for consultation with parents, carers, and children and young people, and for monitoring and evaluation of the Trust's work. For example, the guidance stated that the Trust's Governing Board must, '*have appropriate arrangements in place to ensure the voices of children, young people, parents and front line workers are heard*' and must also '*systematically and regularly monitor and evaluate results*' (DCSF 2008: 31). There was

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<sup>1</sup> This complexity is illustrated by an example from the authors' research. A recent study, commissioned by a local authority in inner-London, evaluated the pilot deployment of social workers based in state primary and secondary schools (Wigfall et al., 2008). The initiative was the result of collaboration between managers in education and social care within the local authority. Social workers in the pilot were employed, and line managed, in social services teams, but they and other study participants, including parents and teaching staff, were interviewed in or identified through the schools participating in the pilot. The study was reviewed by an Institute of Education Research Ethics Committee, and was not subject to local authority governance requirements, but it provides a useful illustration of the need for effective governance arrangements to account for the increasing integration of education and child welfare services.

therefore an expectation that Children's Trusts – and thus local authority children's services within those Trusts – should be engaged in the 'research-like' activities of consultation and evaluation.

These developments have had particular implications for the requirements of research governance in children's services, in terms of:

- (a) the volume and nature of research and research-like activity; and
- (b) the scope of research governance arrangements.

In particular, the integrated service context raises questions about how far it might be appropriate – or feasible – for systems designed for adult social care research governance to encompass the diversity of integrated children's services, and the volume of research-like activity ongoing in Children's Trusts.

### **1.3 The diversity of provision**

Reflecting the broad remit of the former Department for Children, Schools and Families, 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. Examples of this diversity include: childminders; private tutors; foster carers and foster care providing agencies; state and independent schools; early childhood education and care (ECEC) provision; out-of-school play and childcare settings for school-aged children; residential homes and secure units (and potentially also youth justice provision); mainstream and targeted parenting and family support provision; and children's social care services (e.g. for children in need; for disabled children). All these settings are potentially sites for research, and – in common with adult services – there is a mixed economy of provision, including private-for-profit, voluntary sector and public services.

An understanding of the complexity and diversity of children's services is central to any debate about the appropriate remit for research governance arrangements. For example, there is a question about how – and whether – research governance arrangements should (or could) apply to research in children's services that (a) is not funded by DfE and (b) is carried out in settings that are not wholly or directly sponsored by DfE. In practice, moreover, the picture is yet more complex. For example, if research takes place in a private nursery setting, run by an independent provider, would governance arrangements apply to research with any children in that setting, or only those children whose places are funded or subsidised by government (e.g. through the Nursery Education Grant)? Such specific examples serve to highlight the complexities of the task of developing governance arrangements in children's services. They indicate a particular need to consider the feasibility of research governance systems capturing research and research-like activity across this range of services.

### **1.4 What counts as 'research' in children's services**

In considering the appropriate scope and remit of research governance arrangements for children's services, it is necessary to consider the nature and range of research-like activity in children's settings. Whilst central government is a major funder of research in children's services, its role as a sponsor of research is distinct from – and small relative to – its role as a provider or funder of services that may host a wide range of research and research-like activity with children and their families, and with workers in children's services. Moreover, many other funders have invested in research in children's services – notably, local authority service providers, charitable funding bodies and the research councils, and other government departments.

An earlier mapping study of research activity in Councils with Social Services Responsibilities conducted by one of the authors of this report (see Boddy et al. 2006) revealed a wide variety of research-like activity in adult and children's social services departments. Most research reported in that study was not conducted by academic researchers – less than 10% of reported activity – and almost 20% was conducted by students, usually social services staff. Less than 20% of studies had external funding. While these findings are now out of date – based on research conducted in 2002-2003 – and do not address children's services directly, they nevertheless indicate issues that are likely to be relevant to the proposed project. Research in children's services is also likely to include a large proportion of student activity.

In addition, as noted earlier, the requirements of Children's Trust arrangements are a key driver for local authorities in conducting or commissioning service evaluations and consultation with service users (children, young people, parents and carers). This work is likely to utilise research methods, and so raise concomitant ethics concerns, but should it be 'counted' as research for the purposes of research governance?

A related consideration is who does the research – whose work would be subject to any newly developed research governance arrangements? This question is critical in terms of the potential impact of any new requirements on the commissioning of research. The publication of the ESRC Research Ethics Framework (ESRC 2005) prompted many academic institutions to develop ethics review and research governance arrangements (Tinker and Coomber 2004). However, much government-commissioned research is carried out by independent research organisations<sup>2</sup>, which may not have access to institutional arrangements for research governance and/or ethics review, and this may be true for local authority research activity too.

Another question that needs to be addressed concerns the levels of scrutiny and independence that would be acceptable for any newly developed systems. Most non-government funders, such as the major charitable foundations, have followed the principles of the ESRC Framework for Research Ethics in their research governance requirements. By contrast, one driver for the newly established Social Care Research Ethics Committee was the definition of an 'appropriate body' for ethics review within the 2005 Mental Capacity Act (Department of Health 2007): university ethics committees do not meet the Act's requirements for independence (from the researcher). This emphasis on independence reflects concerns about the vulnerability of research participants. The Mental Capacity Act does not apply to children, but discussion of the ethics of research with children has also often focused on their potential vulnerability.

## 1.5 Aims and objectives

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

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<sup>2</sup> For example, of the 45 most recently contracted projects listed on the DCSF Research Gateway, 31 projects were being conducted by independent research organisations, compared to 12 conducted by academic institutions (and two not specified). Information accessed 1 March 2010:  
<http://www.dcsf.gov.uk/research/programmeofresearch/index.cfm?resultspage=41&type=3>

- 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.

The specific objectives of the work were to:

- i. identify initiatives relating to research governance and ethics review procedures, across central and local government; the research councils and other funding bodies; the university sector; research-related organisations (including research organisations in the private and voluntary sector); professional associations (e.g. BPS, BERA, BSA); and ethics regulatory bodies and other related professional bodies (e.g. NRES, SCREC, AREC);
- ii. clarify relationships between these initiatives;
- iii. assess the significance of these initiatives to the future of research governance and ethics review in children's services;
- iv. organise a forum for debate about the risks or benefits to participants in children's research in order to inform the future development of proportionate research governance systems and ethical review procedures;
- v. assess the nature and extent of research in children's services which is not currently covered by existing research governance systems and ethics review procedures;
- vi. explore ways in which research governance systems and ethical review procedures could be extended to include work that is not currently subject to research governance scrutiny, and thus to identify an appropriate remit for a proportionate research governance system, taking account of the range of research-like activity in children's services; and
- vii. examine the differences in interpretation and implementation of research governance frameworks and guidance between different local authorities.

## 1.6 Structure of the report

The report is structured to provide a cohesive overview of the key considerations in development of research governance arrangements in children's services. Following this introductory chapter and an overview of the project's methods in Chapter Two, the key themes emerging from the work will be presented in two chapters, which draw together findings from:

- scoping reviews of relevant frameworks for research governance and research ethics reviews and of relevant academic literature on ethics considerations in research with children and young people;
- interviews with national stakeholders;
- a survey of local authority Directors of Children's Services; and
- interviews with key stakeholders linked to eight local authorities.

Chapter Three will address research governance arrangements in children's services, considering current arrangements in the local authorities studied, along with key messages from the scoping reviews, and a thematic analysis of respondents' views. Chapter Four is focused specifically on ethics considerations. Whilst research ethics comprise just one element of research governance, there is a critical question for the proposed study about the applicability of existing systems (such as the Department of Health's Research Governance Framework) to children's services, and that depends in part on the extent to which research with children and young people should be seen as inherently high risk because of their potential vulnerability. This fundamental issue will be considered in Chapter Four, through a discussion of respondents' views and key messages from the scoping reviews.

Finally, the implications for the development of research governance arrangements in children's services will be addressed in Chapter Five, along with recommendations about ways forward.

## 2. Methods<sup>3</sup>

### 2.1 Scoping review and consultation with key stakeholders

The first stage of the work involved thorough scoping reviews of:

- (a) the research literature on ethics issues in research with children and young people; and
- (b) initiatives relating to research governance and ethics review procedures, across central and local government; the research councils and other funding bodies; the university sector; research and research-related organisations (including research organisations in the private and voluntary sector); professional associations; and ethics regulatory bodies and other related professional bodies.

Relevant material was identified through online searches (e.g. using Google, Google Scholar, and searching content in relevant journals and in websites of relevant organisations)<sup>4</sup>.

Six interviews were carried out with stakeholders representing national or key expert perspectives:

- two telephone interviews with representatives of independent research organisations that conduct research (including government-funded research) in children's services;
- one face-to-face interview with a senior university researcher who conducts research (including government-funded research) in children's services;
- one face-to-face interview with a representative of a major funding body other than the former DCSF;
- one telephone interview with a representative of the Association of Directors of Children's Services; and
- one telephone interview with an organisation that represents children and young people.

Interviews with key stakeholders followed a topic-guide that was adapted depending on their professional role and expertise, to address issues in relation to the study objectives, including: relevant initiatives in relation to research governance and ethics review; key ethical issues and risks involved in research with children or based in children's services; gatekeeping and barriers to research in children's services; recommendations for the development of research governance arrangements in children's services. A detailed note was made of each interview, and interviews were analysed thematically in conjunction with interview data from local authority case studies, using the constant comparative method (see below).

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<sup>3</sup> The work reported here was approved by an Institute of Education Faculty Research Ethics Committee before any fieldwork commenced. The project also had approval from the ADCS Research Committee.

<sup>4</sup> Examples of key words included the following (used in combination where appropriate): research; governance; consent; child\*; ethics; ethical; permission; review; approval; family; parent\*; Fraser Guidelines; Gillick; opt in; opt out; sampl\*

## 2.2 Local authority survey

An electronic survey was circulated by email to all 152 local authority Children's Services Directorates. To encourage responding, the survey was jointly badged as a DCSF and IOE exercise and initial information about the survey was sent in the DCSF local authority email bulletin (as was) followed by direct emails to Directors of Children's Services, and with at least two reminders sent to named contacts. In total, 59 responses were received (39% response rate).

For ease of completion, the survey was hosted on a secure website (Survey Monkey), and was also made available to respondents as an MS Word document on request. The survey collected factual information about local authority research (and research-like activity); existing systems of research governance and research ethics review; it also asked respondents for their views on the development of governance arrangements for research involving local authority children's services, including development needs, strengths, barriers, and ways forward (see Appendix 1 for a copy of the questionnaire).

The aims of conducting this survey were twofold. First, it was intended to raise awareness of the planned development of governance arrangements for children's services, and act as a forum for consultation in that regard. Second, the survey aimed to inform subsequent local authority case studies (see below). The survey asked specifically if the local authority would be willing to take part in follow up interviews, and asked for a key contact to be identified in relation to further work.

## 2.3 Local authority case studies

In total, 30 interviews were conducted in eight local authority areas, selected to represent a range of research governance arrangements on the basis of survey responses, and using a mixed case study approach. Originally, it had been intended that four local authority case studies would be conducted, but it was agreed with the project commissioners that one supplementary interview would be carried out in each of four additional authorities to enable the research better to capture the variety of systems in place. These stakeholder interviews aimed to complement survey data by providing qualitative data about research activity, existing research governance arrangements, and participants' views or concerns about the governance of research in children's services. To ensure the case studies include a range of perspectives, the eight local authorities were purposively sampled on the basis of survey data to include:

- local authorities with a variety of research governance arrangements for children's services, in terms of how well established or standardised arrangements were, and the extent to which systems had been developed from the Department of Health RGF for adult social care; and
- local authorities with high, medium and low volumes of research activity in children's services, including research involving external researchers.

The case study authorities were chosen to reflect variation in local authority type, although this was not a primary selection criterion. The authorities also encompassed some geographical spread, from the north of England to London and the south.

Interviewees were recruited by a process of purposive and snowball sampling, with the key respondent from the local authority providing a starting point for sample recruitment. In each of the four 'core' case study areas, sampling aimed to include the following stakeholder perspectives across the local authorities:

- the key respondent from the local authority, nominated on the survey questionnaire;
- local authority managers with responsibility for schools, early years provision, children's social care, or parenting and family support;
- representatives of service providers from schools, early years provision, children's social care, or parenting and family support; and
- representatives of academic and/or independent research organisations, or independent research consultants, including representatives of organisational research ethics committees.

Interviewees were purposively sampled, on the basis of recommendations from key contacts and other interviewees, in line with the general framework outlined above<sup>5</sup>. In the remaining four case study areas, it was intended that one interview would be conducted, with the nominated key contact who had returned the questionnaire. However, in Case Study Area 8, this initial interview highlighted a range of issues very relevant to the research aims, and the respondent proposed two additional stakeholders for inclusion in the research. Given that the overarching aim of the research was to learn from key experiences that could inform the development of future arrangements, it was judged that these stakeholder perspectives would be relevant to the study, and so these additional interviews were carried out.

Interviews were conducted face to face or by telephone, and were open-ended, following a broad topic-guide, which was adapted as appropriate for their professional role and organisation. The areas addressed in interviews included: interviewees' role and responsibilities; research governance arrangements and their application across children's services (if appropriate); examples of projects; key issues in research with children, young people and families; advice to government on the development of research governance; any other issues (see Appendix 2). A detailed note was made of each interview, and interviews were analysed thematically in relation to the study objectives and issues or concerns (e.g. in relation to research ethics or quality, or proportionality) arising from national stakeholder interviews, the survey or scoping reviews. Quotes from interviews presented in the results section are extracted from detailed interviewer notes.

Details of interviews conducted in each local authority are summarised in Table 2.1.

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<sup>5</sup> In local authority 3 it was not possible to interview an external researcher within the study timeframe, but additional researchers were interviewed for Case Studies 2 and 4, who gave accounts of experiences of work across a range of local authorities.

**Table 2.1 Local authority stakeholder interviews**

LA	Authority type	Research Governance	Interviews conducted
1	Metropolitan Borough Council	Adult social care arrangements applied to children's social care; otherwise arrangements are specific to the service involved in the research.	<p><b>Children's Services Directorate/Children's Trust:</b></p> <ul style="list-style-type: none"> <li>• Senior manager (commissioning)</li> <li>• Head of Children's Social Care</li> <li>• Assistant Executive Director, Family Well-being</li> <li>• Participation and inclusion manager</li> <li>• Service lead (CAMHS)</li> <li>• Service lead (MST)</li> </ul> <p><b>Researchers:</b></p> <ul style="list-style-type: none"> <li>• Academic: senior lecturer, runs MAs taken by LA staff.</li> </ul>
2	Metropolitan Borough Council	Arrangements are specific to the service involved in the research	<p><b>Children's Services Directorate:</b></p> <ul style="list-style-type: none"> <li>• Director of Children's Services</li> <li>• Former School Improvement Lead</li> <li>• Extended Services Manager (former head of children's centre)/university research ethics committee</li> </ul> <p><b>Service providers:</b></p> <ul style="list-style-type: none"> <li>• Head of primary school that hosted research</li> </ul> <p><b>Researchers:</b></p> <ul style="list-style-type: none"> <li>• Independent research consultant</li> <li>• Academic: senior researcher</li> <li>• Academic: senior researcher /research ethics committee.</li> </ul>
3	London Borough	DoH RGF for adults adapted into a Children's Services specific Research Governance Framework (RGF)	<p><b>Children's Services Directorate:</b></p> <ul style="list-style-type: none"> <li>• Research and performance manager for strategy team</li> <li>• Research and performance officer for strategy team</li> <li>• Principle Psychologist, SEN/Inclusion Lead</li> <li>• Audit Project Manager</li> </ul>
4	County Council	DoH RGF for adults adapted into a Children's Services specific Research Governance Framework (RGF)	<p><b>Children's Services Directorate:</b></p> <ul style="list-style-type: none"> <li>• Research Analyst, Children's Services</li> <li>• Project Manager, Corporate Parenting</li> <li>• Parent and Carer Involvement Officer</li> <li>• Specialist advisor for parenting</li> </ul> <p><b>Researchers:</b></p> <ul style="list-style-type: none"> <li>• Academic: senior researcher</li> <li>• Academic: researcher</li> </ul>
5	London Borough	Arrangements depend on the project or service involved	<p><b>Children's Services Directorate:</b></p> <ul style="list-style-type: none"> <li>• Executive Director</li> </ul>
6	Unitary local authority	Research governance system developed for the Children & Young People Directorate	<p><b>Children's Services Directorate:</b></p> <ul style="list-style-type: none"> <li>• Research manager</li> </ul>
7	County Council	Whole LA research governance systems	<p><b>Local authority:</b></p> <ul style="list-style-type: none"> <li>• Research unit manager</li> </ul>
8	County Council	DoH RGF for adults extended to Children's Services	<p><b>Adult Services Directorate:</b></p> <ul style="list-style-type: none"> <li>• Research officer responsible for managing research governance process (extended to children's services)</li> </ul> <p><b>Children's Services Directorate:</b></p> <ul style="list-style-type: none"> <li>• Member of children, young people and parents/carers involvement team</li> <li>• Head of Partnerships and Business Support</li> </ul>

## 2.1 Project Advisory Group

A project advisory group was established, in consultation with the project commissioners, and met in January 2010. The purpose of the advisory group was to provide a forum for key stakeholders to discuss perspectives on emerging findings and recommendations from the project. It is anticipated that

the advisory group will meet again, to discuss this project report, and advise on next steps. The advisory group membership includes: representatives of independent research organisations that conduct research (including government-funded research) in children's services; senior university researchers; a representative of a major funding body other than the former DCSF; the Association of Directors of Children's Services; an organisation that represents children and young people; an organisation that represents voluntary sector provision; and representatives of professional associations.

## 3. Frameworks for research governance and ethics review

### 3.1 Local authority arrangements

#### 3.1.1 Research governance

Before we go on to discuss the findings emerging from this project, it is important to highlight a key caveat in relation to local authority survey and interview data. The survey response rate was 39% (59 responses), and the case study local authorities were selected from survey responders, purposively sampled according to sampling criteria that included research activity and presence of research governance systems. Accordingly, it is likely that both the survey and the interviews under-represent (a) local authorities with less well-developed or less formalised research governance systems, and (b) local authorities with lower levels of research activity. This caveat is important, since it means 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.

Two further considerations need to be taken into account at this stage. First, there is a need to take account of variation in who responded to the survey, and what they are likely to know. The survey was emailed to Directors of Children's Services, but respondents ranged from Directors and Assistant Directors to research analysts and managers responsible for research governance (in local authorities which had such systems) to other senior staff within the local authority. This variation in respondents is likely to depend, to some extent at least, on existing research governance arrangements, and this in turn is likely to influence their knowledge about research activity in their authority. Moreover, many survey respondents – including those in authorities with well-developed systems – noted that their knowledge of research activity was likely to be partial or incomplete. As one senior local authority manager observed, *'we don't know what we don't know [about local authority research activity].'*

The second consideration relates to the positioning of different stakeholder interviewees, and what that means in terms of the perspectives they bring to the research. For example, one might expect local authority staff who are involved in research governance to emphasise the importance of robust systems, whereas academic or independent researchers might be expected to be more concerned about access to research samples, and the need to facilitate the research process. To observe these differences in position is not to argue that these perspectives are biased, nor that any one position should be accorded more weight. However, it is important to bear these differences of perspective in mind, in interpreting the findings presented here, because they highlight one of the critical balances that must be achieved in developing guidance on research governance.

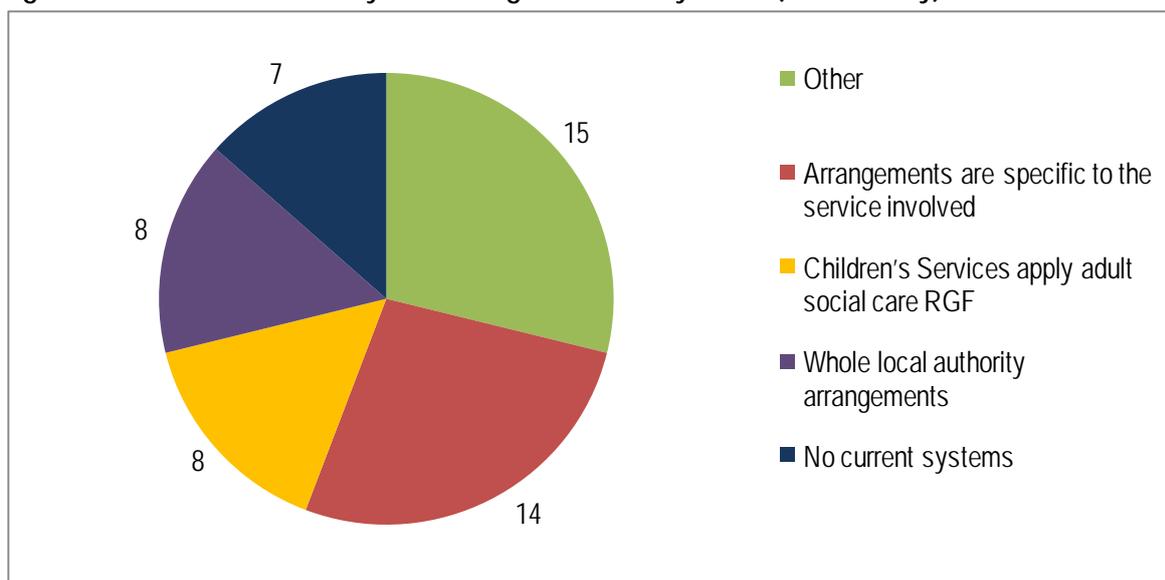
Given that context, it is perhaps not surprising that the great majority of local authorities responding to the survey had some systems in place for the governance of research in children's services (see Figure 3.1). Only seven out of 52 who answered this question said they did not have research governance systems. The most common responses were arrangements specific to the service involved in the research (N=14), or 'other' arrangements (N=15). The majority of those describing service specific or 'other' systems of research governance gave examples of arrangements which had some limitations – either in terms of the services covered, or in relation to the type of research activity encompassed. For example, among the 15 who reported 'other' arrangements:

- three authorities had extended their adult social care RGF arrangements to children's social care, but not to other areas of children's services;

- one authority had approval arrangements for consultations, but not for other forms of research;
- one authority had well-developed research governance systems for research involving children's services resources or services, but did not encompass 'small-scale school studies, over which the Head Teacher has ultimate authority';
- in two authorities, vetting and approval was carried out by senior service managers for research within their services, or by relevant partnership boards;
- in another, the Children's Services Directorate applied adult social care research governance systems to external projects, but internal research activity did not go through research governance systems.

This variation was even more pronounced for research involving private and voluntary sector services with local authority funding. Twenty of the 52 answering this question had no research governance systems in place for research in Private, Voluntary and Independent (PVI) settings, and another 12 described no routine systems, but service specific arrangements. The relative autonomy of PVI settings – as with research in schools, as noted above – poses a challenge to local authority research governance systems. This challenge was summed up by one respondent, who observed that *'this [research governance] relies upon knowledge of intended research and referral from independent children's services'*. This last respondent's comment about the dependence of research governance systems on knowledge of research activity reflects a challenge that is particularly acute given the autonomy and diversity of children's services. It raises a critical question for the development of guidance on research governance, about the extent to which governance systems can expect to 'capture' the range of research-like activity ongoing in children's services.

Figure 3.1 Local authority research governance systems (from survey)\*

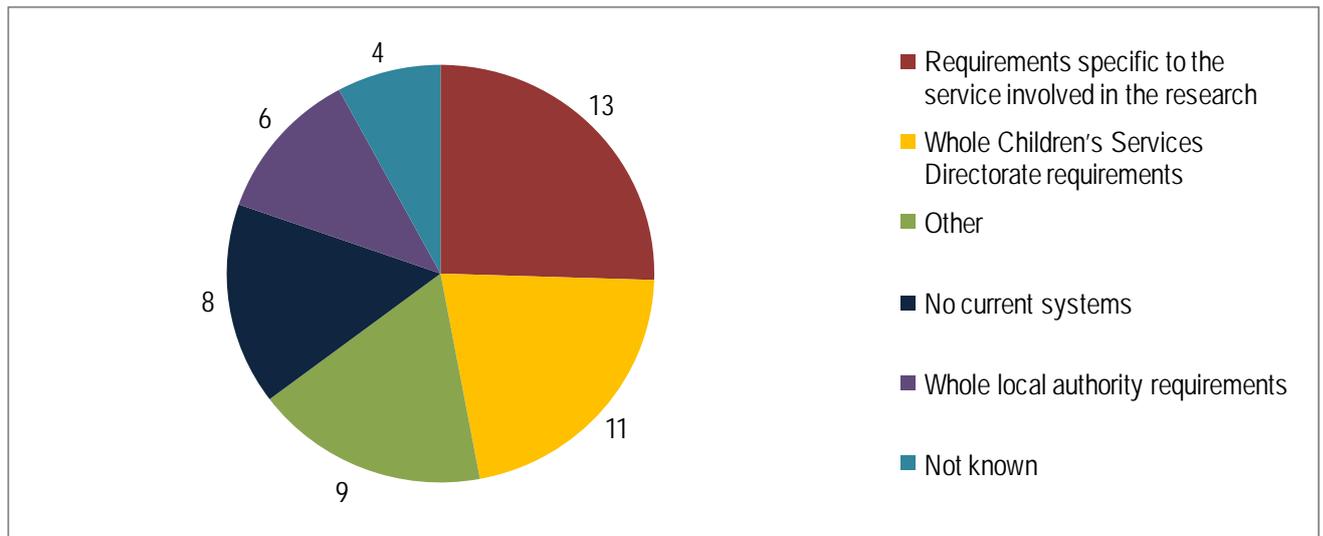


\* Responses show N in each category; categories are mutually exclusive.

### 3.1.2 Research ethics

Research ethics is a distinct, but critical, component of research governance. The survey asked about local authority requirements for ethics review, and about the systems that authorities themselves used for scrutiny of research ethics (see Figure 3.2).

Figure 3.2 Local authority requirements for ethics review (from survey)\*



\* Responses show N in each category; categories are mutually exclusive.

Seventeen respondents reported ethics approval requirements that spanned the Children's Services Directorate or the local authority. More commonly, requirements were specific to individual services, and thus varied. Thirteen described service-specific arrangements, and another nine described 'other' arrangements, which – as with research governance – were commonly limited to children's social care or to projects which raised safeguarding concerns. In some cases, an initial screening process was used to determine whether a project warranted further ethics scrutiny. For example:

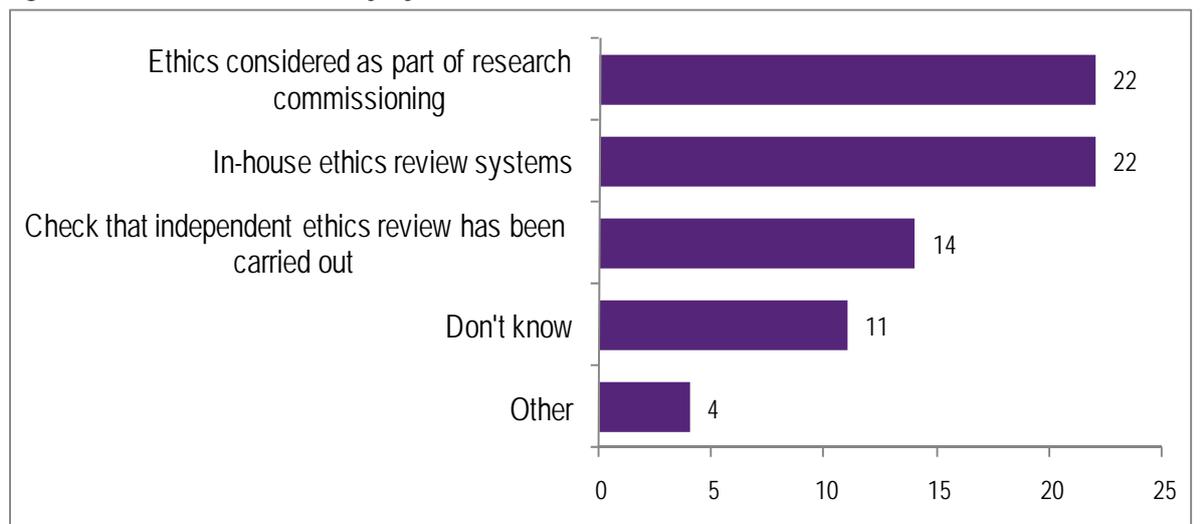
*'A judgement is made by the relevant Assistant Head of Service about whether issues of confidentiality and risk require further ethical consideration. They then involve the relevant expertise to make that judgement and put the necessary measures in place. Where Health service staff or service users are involved a joint approach engaging the PCT ethical framework is used.'*

*'There is an initial screening process for research proposals to decide if formal ethical approval is required. A risk assessment is carried out by the lead officers for research governance. If there is a level of risk involved in the research such as issues about confidentiality, information about sensitive personal issues, or the results of the research could put the organisation at risk, the research proposal will be reviewed by a panel (can be by email or by a formal meeting depending on the issues). The panel can also decide to escalate the review to more senior management or invite an independent view. If the research is straightforward with minimal risk the lead officer will provide approval.'*

*'For external researchers, proof of peer and ethical review by another body – e.g., university, health – ADCS [approval] is required. This approval may be sufficient, or further information and approval may be required if there are issues specific to the implementation of the research for [our] Council and its service users.'*

As shown in Figure 3.3, there was a mix of approaches to ethics review (respondents could choose more than one response option). Again, the variety of responses is perhaps the most striking observation from these data: no one system was reported by the majority of respondents.

Figure 3.3 Local authority systems for ethics review\*



Responses show N in each category; categories are not mutually exclusive, LAs could have more than one system in place.

### 3.1.3 Variation in arrangements

Whilst the survey suggested that most authorities responding to the survey had some systems in place for research governance, these systems were varied, both in terms of the nature of arrangements themselves, and in the range of research activity to which they applied. This is not to conclude that the governance of research was not taking place: in most authorities some research was subject to some scrutiny, but not necessarily all research activity, or through the same standardised procedures. This point was illustrated in interviews in local authority case studies. For example, in LA2, the Director of Children's Services considered *external* requests to conduct research in her directorate, with reference to key research governance standards such as quality and ethics:

*'Depending how esoteric [the request is], I may refuse. There is an issue, for example, of schools doing surveys – I don't want to overload them. So it depends how onerous it is, how intrusive, and if it is reasonable to be collecting such sensitive data.'*

In LA1, children's social care research was approved through a standard framework (an adaptation of the Department of Health Research Governance Framework), but this did not apply to other research activity in children's services. However, a senior strategic manager reported that other children's services research (including evaluation and consultation) was routinely subject to '*external check and challenge*', through a reciprocal arrangement with another senior manager, to ensure independent checks during the commissioning process.

In this local authority, ethics and quality considerations were also embedded within standards on the involvement of children, young people, parents and carers, as summed up by another senior interviewee:

*'It has a quality assurance aspect – it's not just about doing, it's about doing well. It does have guidance about having an ethical approach, for example, making sure the individual's voice is relevant and voluntary, treating them with respect, ensuring the right kind of environment. It's about imbalances in power and status, and taking that into account in how you work with children, young people, and parents and carers. It's promoted throughout the Trust, and so it applies to any research-like internal activity that we do.'*

However, this respondent also noted that, as a consequence of variable arrangements within her authority, there was no over-arching knowledge of what research was being carried out. This lack of knowledge about research activity was seen as potentially problematic, but it should be noted that such concern was not confined to local authorities with variable arrangements. As noted earlier, 12 survey respondents specifically highlighted concern that they did not know about all research activity in their local authority, and this was highlighted by those with established research governance procedures as well as by those with less well-developed arrangements. For example:

*'People not adhering to the requirements of the system [is a problem]. Often [they] say what they are doing is not research i.e. consultation, evaluation, etc. But we have a broad definition of what constitutes research and all these should be covered.'*

*'It's a fairly marginal arrangement. I suspect that research is carried out that doesn't go through RGF.'*

### **Consistency across local authorities**

Interviewees from a range of stakeholder perspectives were aware that local authorities varied considerably in their research governance arrangements, in line with the survey findings reported above. This variation was, to some extent, seen as problematic. For example, a local authority research manager (LA3) made the following point:

*'We know that people make applications [that we don't approve] and we know that at the same time, they have been conducting that research in other local authorities where there is no scrutiny and we have had grave reservations about their intentions. Surely local authorities want to know what is going on. So the point is not to stop research, but you do need to know.'*

She expressed these concerns in terms of a sense of responsibility to service users, specifically as a public employee:

*'If you work for the local council, you are paid by local people and are accountable to local people.'*

Researchers also expressed concerns about inconsistent practice within, and between, local authorities. For example, a senior academic, involved in research in LA2, but with many years of experience of research involving local authority children's services, commented that:

*'[it's striking] how research governance can go wrong and how it can be very different across local authorities. Each sector in a local authority approaches it in different ways.'*

Her comments about research governance 'going wrong' related to a variety of concerns: she gave examples of research governance acting as a barrier to research, or having a negative impact on research quality (an issue discussed later in this chapter), but also about the failure of research governance to capture some activity, because it was not framed as research.

Several survey and interview respondents advocated more standardisation of research governance across local authorities, including common forms or shared principles or minimum standards. One survey respondent summed this up, in advocating '*a national system, rather than allowing individual authorities to set up lots of different systems*'.

These findings suggest that government guidance could play a role in developing more consistent practice within, and across, local authority children's services. However, the research also indicates that guidance should not assume a common baseline across local authorities for any new developments.

A related consideration, raised by several survey respondents and interviewees, is the need to be sensitive to local authority resources and contexts, including their existing arrangements. One local authority interviewee (LA8) who had recently moved from a unitary authority to a large county council, highlighted the substantial differences between the two, in terms of population size and characteristics. He commented on the implications that these characteristics had for available resources, research needs and activity, noting that the scale and scope of activity was inevitably much smaller in a unitary authority than in a county council. He argued that research governance arrangements should take account of these differences. Similarly, a survey respondent advised that there was a need for the *'development of a range of good practice models to suit a variety of circumstances - one model will not fit all'*.

To follow this advice, and support the development of a range of good practice models, relies on consideration of the appropriate criteria for judging the suitability of any system of research governance. Within the scope of the present study, it was not possible to determine the relative effectiveness of different systems or local arrangements, although respondents discussed general issues of quality, including ethics, sampling, proportionality and timescales (see below). A judgement of relative effectiveness would require more detailed examination of local frameworks and processes, as well as some audit of projects that had been scrutinised within those processes.

To sum up, it appears that government guidance on research governance in children's services needs to strike a balance between the need to address variable practice across authorities, and to address many respondents' desire for greater consistency in arrangements, and the need to be sensitive to local contexts, and existing research governance arrangements.

### **3.1.4 Extended and adapted versions of the Department of Health's Research Governance Framework**

Several had developed systems based on the Department of Health's Research Governance Framework (RGF), which applies to adult social care. Six of our case study authorities had such systems; these authorities were purposely sampled so we could consider ways in which this model might be applied to children's services.

There were differences across the authorities in how the adult social care RGF had been extended to, or adapted for, children's services. In most cases, the RGF had been implemented prior to the separation of adults' and children's social care services, and this link was maintained following the shift to integrated children's services. In four authorities (LAs 3, 6, 7, and 8), arrangements based on the RGF spanned children's services. In LA7, for example, research governance systems were well-established within a research unit, and applied to social research across Council services, including children's services. In LA6, arrangements for children's services as a whole were established when children's social care split from adult social care; at that time, a new panel was established, to include staff from education and social care. In LA8, the respondent responsible for research governance in children's services explained that they had developed their systems, *'right back when DH did... When children's services split off, they didn't take research governance with them. In adult services we agreed to take that role... We're basically following the guidance of the adult RGF'*.

As this respondent's comments indicate, for several respondents (to the survey and in case studies) the Department of Health's Research Governance Framework had been very helpful, in providing guidance, and a framework on which to build, in the absence of any alternative models. For example, in LA4, research governance arrangements for children's services had been developed specifically in order to improve monitoring of research activity, and the Department of Health's RGF had been judged to be a useful model to build on. However, in this authority, as in LA1, these research governance arrangements were largely restricted to children's social care. As noted earlier, this arrangement was also described in other survey responses. In LA1, an arrangement for social care had been agreed with the research governance panel for adult services, following the integration of children's services. A simplified form of the RGF was developed for children's social care specifically, in what a senior manager described as a '*loose agreement*' with adult services.

In LA4, the focus on children's social care was said to reflect the autonomy of schools and early years providers and of the voluntary sector, as well as the statutory requirements for some forms of research activity, such as the TellUs survey. The research manager responsible for research governance observed simply that, there was no point in subjecting research to their scrutiny if '*we couldn't stop it*'. Similarly, in LA3, although research governance arrangements spanned children's services, the responsible research manager recognised that their systems did not necessarily capture research in schools:

*'This is a grey area, around what the situation is regarding the autonomy of head teachers. We don't want to step on toes, but ideally we would like to be aware of research happening in schools. Head teachers say 'I make decisions here, why does the local authority need to intervene?' But some are not versed in research or ethics. It's better that they come to us.'*

### ***The applicability of the RGF to children's services***

Views as to how well adult RGF systems applied to children's services were somewhat mixed. In some cases, this development was seen as very useful, not least in addressing a perceived need to stop research going ahead without any kind of scrutiny. Several respondents highlighted its potential as a foundation for any new developments, not least, in the absence of any alternatives. For example, the research manager in LA7, who argued that '*though not perfect, the DH system does have good elements*'.

However, several respondents – across local authorities and stakeholder groups – expressed concern that the RGF procedures could be unduly onerous, and could act as a barrier to research. Several interviewees, reported concerns about timescales for research governance, and several local authorities (e.g. LA3, LA6, LA7) had implemented electronic 'virtual' reviewing procedures in order to speed up research governance processes, and/or used a risk assessment framework to determine the level of scrutiny required.

To some extent, these concerns reflected differences in the positioning of stakeholders interviewed for the project. Unsurprisingly, research managers within local authorities had fewer concerns than, for example, researchers from academic or independent research institutions. However, respondents from a range of perspectives expressed reservations about the applicability of the Department of Health's RGF to the specific needs of children's services.

In two local authorities with extensive research governance procedures, respondents described their concerns in relation to specific cases where research had been delayed, or had not gone ahead, because of the governance processes involved. In one of these authorities, an academic researcher<sup>6</sup> commented that the research governance system had *'worked reasonably well but the form was not suited to our research'* and was *'fairly lengthy, given the previous processes we had been through'* – highlighting a concern about duplication of processes that was raised by a number of researcher interviewees. Similar concerns were raised by a number of interviewees, across stakeholder groups, and are discussed in more detail, below, in relation to proportionality in systems of research governance.

A related concern was the extent of 'fit' between a Research Governance Framework designed for health and social care, and the needs of research governance for children's services. For example, the lead manager for social care in LA1 remarked:

*'The problem with the DH model is that it derives from testing medicines – not just asking children in care for their views of foster care. It's care [it's a sensitive issue] but it's not going to kill anybody.'*

In LA8, another senior manager made the following observation:

*'The original RGF was based on legislation that preceded Children's Trusts and Every Child Matters. So we need to be in a position that is refreshed, we've got to catch up. Children's Trusts came in, in 2006, after the RGF, with a big emphasis on consultation with young people. The definition of research needs to be clarified in relation to that work.... It's taking into account that whole decade of development. We need a framework that correctly addresses Children's Trusts and Every Child Matters developments – the collaborative working. The context is very different from that original piece [the DH RGF].'*

As the above-quoted interviewee observed, the structure of children's services – in central and local government – has undergone substantial change since the implementation of the RGF in social care, and so it is not surprising that a framework designed for one context might not fit easily in a very different new context. However, it has evidently provided a useful foundation for work in some local authorities – not least, in the absence of any alternatives. The balance of concerns was summed up well by a representative of ADCS:

*Linking with existing arrangements is a good starting point. The DH RGF seemed like it would be a good basis on which to develop specific governance arrangements. It looked as if it would be adaptable. But from a local authority and children's services perspective, it is not necessarily fit for purpose with regard to integrated services.*

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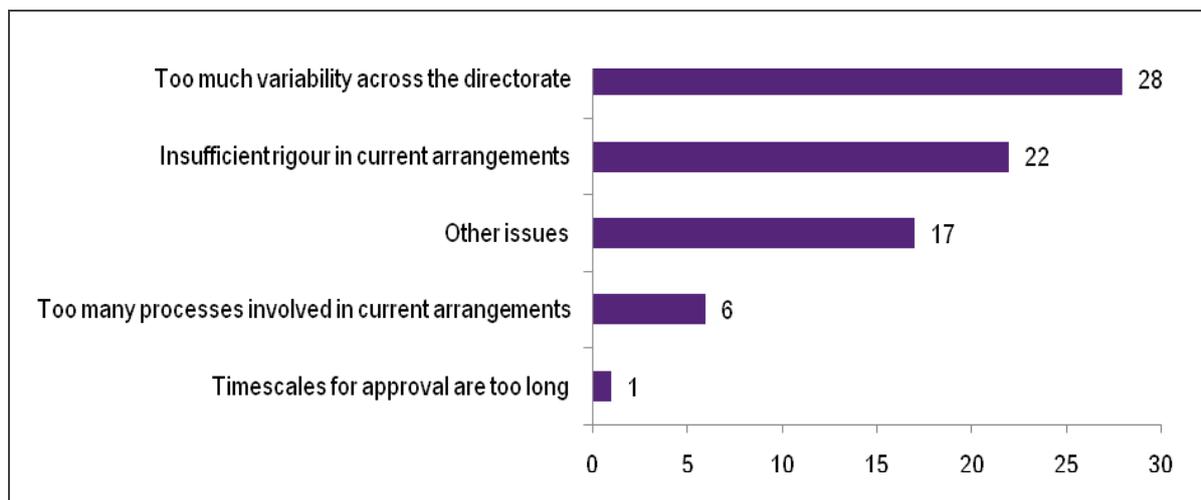
<sup>6</sup> Unattributed to protect anonymity.

### 3.2 The need for research governance in children's services

Despite concerns about the applicability of the Research Governance Framework to children's services, survey and interview respondents generally concurred that there was a need to develop research governance in children's services. For example, in LA8, reflecting the comments quoted above, there were plans to revise research governance systems for children's services to address the perceived lack of fit with the DH RGF, and all three participants in this authority expressed a wish for government guidance to inform that process.

There was wide recognition among respondents (in the survey and interviews) that some kind of research governance was necessary. As shown in Figure 3.4, the key concerns highlighted by survey respondents were the variability of arrangements, and a perceived lack of rigour in existing frameworks. These responses are perhaps not surprising, given the variety of arrangements noted above.

Figure 3.4 What would you change about research governance arrangements in your local authority?\*



Responses show N in each category; categories are not mutually exclusive.

A number of survey respondents specifically welcomed government's intent to develop guidance in this area. For example:

*'Very glad that this is taking place - has been a contentious issue for some time now.'*

*'Why has this area of work in Children's Services so lagged behind Adults' Services?'*

It is striking, however, that the need to develop research governance arrangements was recognised by stakeholders from a range of perspectives, including academic and independent researchers, who also expressed concerns that research governance could act as a barrier to research (as discussed later in this chapter). For example, in discussing ethics, a senior researcher from an independent research organisation commented that:

*'It would be sensible to have some ethical scrutiny; the issue is having nothing in place.'*

The perceived need for research governance in children's services related to a number of specific considerations. Scrutiny was seen as important in order to safeguard service users, and protect the local authority (or children's services directorate) against problems arising from poor research conduct (complaints or legal liability). Concerns about the ethics of research with service users in children's services, and particularly with children and young people, are a substantive – and critical – component of research governance, we will turn to these in detail in the next chapter.

However, concern with research governance was not restricted to ethics. Several respondents also highlighted a need to check whether proposed research met necessary quality standards, concerns about information sharing and use of data, and fundamental questions about whether the work was worth doing. Related to these considerations is an overarching question, about what 'counts' as research.

### 3.3 What 'counts' as research

#### 3.3.1 Messages from scoping reviews

A clear definition of research would seem to be a vital first step in the development of research governance arrangements. Establishing such a definition is not straightforward, however, and the definitions of research used in different documents vary in their scope. In terms of research governance arrangements, the breadth of the definition determines the scope of activity to which the arrangements apply. Consequently, definition is at the basis of critical debates about the proportionality of the system and should be at the forefront of the guidance that is developed.

The definitions contained in the documents included in our scoping review reflected their purpose. The broadest definition was adopted by HEFCE's new Research Excellence Framework (REF); the 2009 consultation on the new REF defined research as: *'a process of investigation leading to new insights effectively shared'* (p6). This definition is deliberately inclusive, because it determines the eligibility of academic activity for inclusion in the REF. It is broader than most definitions used for the purposes of research governance, which have tended to exclude some research-like activities from their parameters. For example, the Department of Health (2005, p3) definition of research within the Research Governance Framework for Health and Social Care (RGF) specifies that research seeks:

*'to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods'.*

This embeds an expectation of research quality, in stating that research is, by definition, both systematic and rigorous. Moreover, the research ethics review systems for the RGF distinguish between research and the research-like activities of audit and evaluation<sup>7</sup>. Only activities defined as research require ethics approval within the National Research Ethics Service (NRES) system. The key discriminating factors are defined by NRES as follows (2008):

- *Intent:* The primary aim of research is to derive new knowledge; audit and service evaluation measure level of care. Research is to find out 'what we should be

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<sup>7</sup> <http://www.nres.npsa.nhs.uk/applications/guidance/#researchoraudit>

doing'; audit is to find out 'if we are doing'. However, a project may have more than one intent; in such a case, a judgement is needed as to the primary aim of the work.

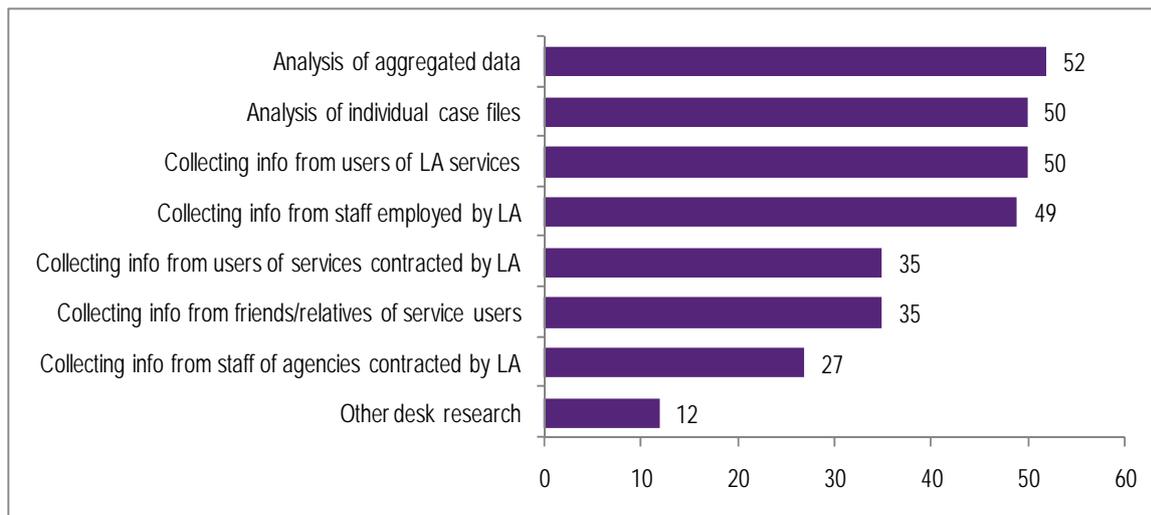
- *Treatment:* Neither audit nor service evaluation uses a treatment without a firm basis of support in the clinical community.
- *Allocation:* Neither audit nor service evaluation allocate treatment by protocol. It is by decision of clinician and patient.
- *Randomisation:* If randomisation is used, it is research.

Such exclusions meet a key pragmatic need, to ensure that the implementation of research governance arrangements is practical and achievable in its scope. Conceptually and ethically, however, this definition of research seems problematic. To limit the intent of research to finding out 'what we should be doing' restricts its function (to providing a resource for evidence-based policy or practice development) and contrasts with the Research Excellence Framework's definition of providing 'new insights'. The narrowness of the NRES definition of intent raises questions about how the framework would apply to more broadly defined research, that which may involve services but without a clear applied focus. In terms of ethics, there is a further tension. Exclusive definitions of research that are based on the *purpose* of the activity (as is the case in the NRES categorisation) are likely to exclude activities that are indistinguishable from research from a participant's perspective, and which could raise ethical concerns. Certainly, research methods for evaluation, audit or consultation may raise exactly the same ethics considerations (about valid consent, for example, or confidentiality) that are raised by more narrowly defined research activity.

### 3.3.2 Local authority perspectives

Research to inform the development of the implementation of the RGF in social care (see Pahl 2002; 2006; Boddy et al. 2006) identified a substantial volume of internal social services and other council research-type activity, including significant 'grey' areas where it was difficult to determine what does or does not count as research. Similar patterns were found in the smaller survey sample of the present study: the majority of research activity described in local authorities was internally commissioned and conducted, and when survey respondents were asked about research activity in their local authority over the preceding 12 months, the majority described 'research-like' activities, such as service user consultation and analysis of aggregated data (see Figures 3.5 to 3.7). These response categories were suggested in the survey, and so it may be that these activities were not subject to research governance scrutiny and/or that they were not classified as research for the purposes of governance.

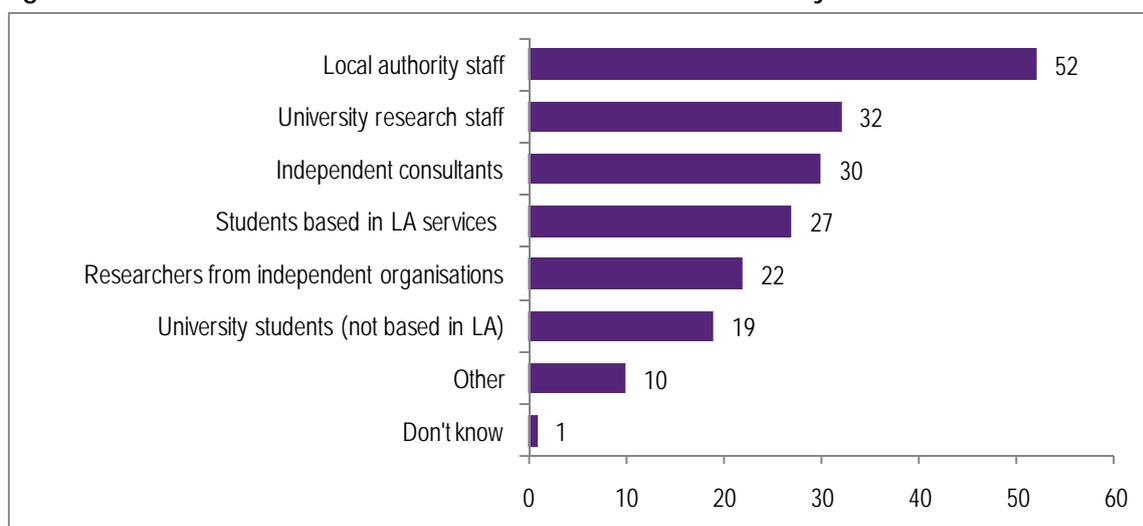
**Figure 3.5 Research activity in the local authority in the last 12 months?\***



\* Responses show N in each category; categories are not mutually exclusive.

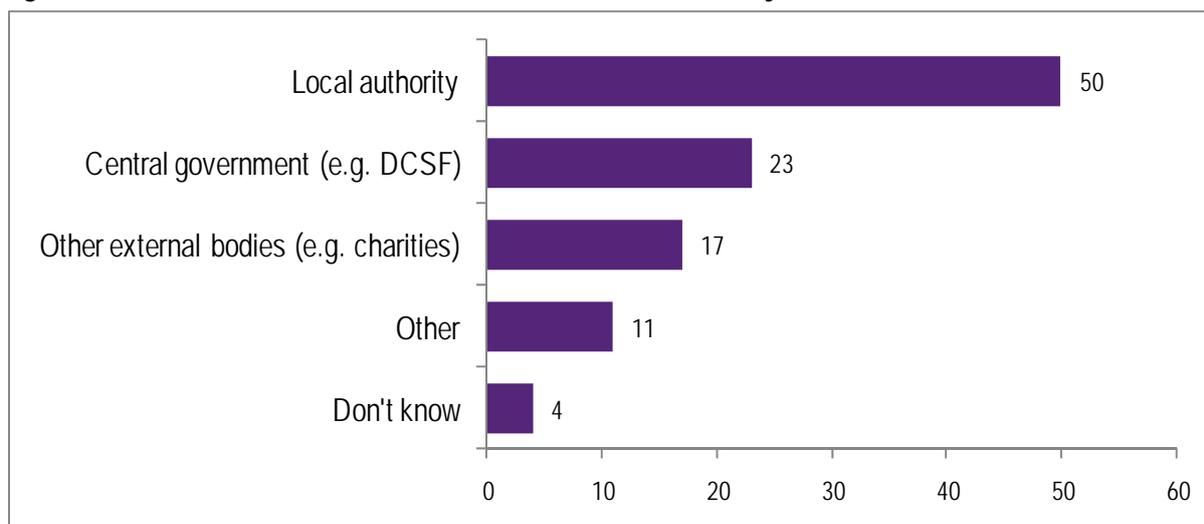
As noted earlier, the information that survey respondents provided was dependent on local authority systems of research governance, such that those with more comprehensive systems were likely have a fuller picture of research and research-like activity in their authority. However, respondents also noted that the categorisation of different forms of research and research-like activity was not always clear. Some noted concern that work would be categorised as audit, evaluation or consultation specifically to avoid the need for research governance review – described by one local authority manager (LA8) as ‘working the radar’ of research governance. Similarly – and in line with the patterns evident in survey findings – our ADCS interviewee remarked that the line between research and evaluation is *‘increasingly blurred’*, and noted that most research activity that ADCS is asked to review comprises evaluation. She commented on the current climate of *‘this whole evidence based culture of what works and what doesn’t, to the extent that DCSF and local authorities can’t implement something without evaluation.’* This context, she said, meant that research governance for children’s services must encompass evaluation, and she argued that the Department of Health also needed to shift its definition of research to include evaluation.

**Figure 3.6 Who has carried out research in the local authority in the last 12 months?\***



\* Responses show N in each category; categories are not mutually exclusive.

Figure 3.7 Who has funded research in the local authority in the last 12 months?\*



\* Responses show N in each category; categories are not mutually exclusive.

To observe this variety is not to conclude that all the activities described in Figure 3.5 should be incorporated within formal research governance arrangements. However, there was consensus among interviewees from a variety of stakeholder perspectives (local authority staff, independent and academic researchers, and service managers) that a broad definition of research should be applied to research governance, to ensure that activities which raised potential ethics or quality concerns should be subject to some kind of scrutiny. This was summed up by a senior manager in LA1:

*'There's a lot of 'stuff' that goes on that's like research. We should be as reasonable as we can be in encompassing the widest possible range of activity. Anything that elicits personal information on a reasonably wide scale – we need to think about what's going to happen and how it will be used. It's not impossible to do that without being overbearing. If guidance from DCSF includes a section called 'what could reasonably be called research', that would address it.'*

The manager of a research unit in LA7 also expressed concerns that the increased emphasis on consultation within the new children's services agenda meant that people were engaging in research-like activities without necessarily having appropriate expertise. He commented:

*'more emphasis on outcomes under the performance agenda means that more children and young people will be being approached for their views by people who do not have a research background. There needs to be clear guidance that professional researchers need to support the developing performance agenda, and ... quality assurance systems with minimum standards in place.'*

Similarly, a senior academic (LA2 case study) observed that narrower definitions of research can mean that some research-like activities are not subject to scrutiny. She described involvement in research projects in a local authority (not the case study authority) which had well-developed research governance systems that did not apply to her work, because *'we're seen as a service supplier [not as researchers], so we could be doing anything.'*

The manager responsible for research governance in LA6 observed that:

*'Research is quite a grand term to use in local authorities – more often it is evaluation or consultation that is involved, rather than formal academic research, and it's on a different scale. But the same principles apply.'*

She also noted that not all research-like activity was submitted for approval:

*'If they don't see it as research – for example, if it's consultation or monitoring activity – they don't submit an application.'*

This respondent tried to encourage staff to contact her if they were in any doubt about whether their planned activity was research or not. Her authority's systems excluded audit, because it does not involve talking to service users or staff. However, she also acknowledged that – despite her authority's efforts to have a proportionate system, with electronic reviewing and a 10 day turnaround on applications – some people sought to bypass the system. This issue of 'capture' for research governance arrangements was a strongly emergent concern from both interview and survey responses, and will be discussed further in relation to proportionality.

### **3.4 Information sharing and use of data**

#### **3.4.1 Messages from scoping reviews**

In terms of the reach of research governance arrangements, one common question relates to their application to secondary analysis or other uses of anonymised data (e.g. review of anonymised case files). In particular, there is a need to consider:

- the ethics principles of respecting the original terms of informed consent from those providing the data, including promises of confidentiality; and
- the legal principles of the 1998 Data Protection Act.

However, there is concern that these two considerations can limit potential research, by acting as a barrier to data sharing or secondary analysis of existing data. For example, web guidance published by the ESRC's UK Data Archive<sup>8</sup> highlights the number of research projects that maintain they are unable to share research data due to promises made to research participants and interviewees to keep all research data confidential. Addressing similar concerns, in 2008, the Ministry of Justice published a review of data sharing in relation to personal information in the public and private sectors, which concluded that greater use could be made of the ability to share personal data safely, particularly in the field of research and statistical analysis. The authors argued (Thomas and Walport 2008: 70) that:

*'the approach of creating and using coded data should be recognised as a legitimate way of safeguarding people's identities, and that data handled in this way should not constitute a breach of the Data Protection Act'.*

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<sup>8</sup> <http://www.data-archive.ac.uk/sharing/>

Tensions in the use and sharing of data necessitate a clear distinction between 'personal data' as defined in the Data Protection Act, and the potential use of anonymised data for research. Whilst the legal definition of 'personal data' contained in the Data Protection Act is complex, it can be understood simply as relating to information about a living, *identifiable* individual. Identifiability is key; UK Data Archive guidance states that the Data Protection Act no longer applies once data have been fully anonymised. This has implications for the ways in which local authorities may provide data for use in research, and it seems appropriate that guidance on research governance in children's services addresses this key issue. In this regard, the UK Data Archive's guidance on data sharing would seem to offer a useful basis for use of data involving children's services. They state that:

*'Archived data are typically anonymised, unless specific consent has been given for personal information to be included. Archived data are not in the public domain but their use is restricted for specific purposes after user registration. Users sign an End User Licence, in which they agree to certain conditions, i.e. not using data for commercial purposes, not identifying any potentially identifiable individuals and not sharing data with unregistered users. For confidential or other sensitive data stricter access regulations may be imposed, such as:*

- *requiring authorisation from the data owner prior to release of data to a user*
- *placing confidential data under embargo for a given period of time until confidentiality is no longer pertinent.'*

(Source: <http://www.data-archive.ac.uk/sharing/consentRECs.asp> )

Elsewhere, UK Data Archive guidelines note the need for care to ensure that, even in secondary analysis of anonymised data, individual cases are not identifiable after anonymisation, for example because of their social position or because they are distinctive in some way. This caveat seems particularly pertinent to data sharing involving children's services, because of the risk of revealing potentially sensitive identifiable data (e.g. about social care involvement).

### 3.4.2 Local authority perspectives

The development of integrated children's services was seen to pose key challenges in relation to information sharing, and a number of interviewees highlighted the potential for guidance on research governance to play a useful role in this regard.

For example, an Assistant Director (LA1) commented on the critical importance of information sharing protocols in an integrated service environment, remarking that:

*'Research governance protocols have to be agreed across professions and disciplines. We need common understandings in an integrated service environment – an integrated standard across children's services that all services sign up to and must abide by.'*

In another area (LA5), information sharing protocols had been agreed, and senior strategic agreement was seen as valuable in making sure these arrangements worked well, in the absence of any formal systems of research governance:

*'Information sharing protocols are important for us – this operates at a high level – senior staff are involved – and on specific issues such as teenage pregnancy. We have information sharing protocols across health and social care so that we can obtain information on individual*

*young people's health, background, schools attendance and this information can be shared across services.'*

In another local authority (LA1), an interviewee from health services commented on the differences between health and local authority understandings of information sharing, in relation to the question of what counts as research:

*'Coming from the NHS into the local authority... Information is shared on a whim, and at times seems unprotected. Not in research specifically – if the word research is used it acts as a trigger. But I've heard people say 'it's okay, it's only an audit' – as if that somehow makes information sharing okay.'*

Similar comments were made by a manager responsible for youth participation and inclusion. He observed that, whilst use of anonymised or aggregated data is usually outside the remit of research governance, this sort of work should not be assumed to be unproblematic, because analytic strategies could result in identifiability:

*'The further we drill down, the more sensitive it is. So for example, if you are doing analysis by postcode and age, you might have three young people in one street – and then they can be identified. We've got the expertise to do that kind of analysis, but we are not doing it because of the identifiability issue – we analyse on a locality basis instead. My perspective is that as we get more ways of coding and analysing questionnaires, it becomes very easy to identify young people.'*

In LA3, a research manager raised concerns about data security and identifiability. She noted that use of new technologies – such as MP3 files – posed new challenges:

*'Information can be retrieved even after deletion; hacking can take place; data can be lost. ... We are gatekeepers of data. There is a need to 'cleanse' the data to strip out names and make data anonymous.'*

### **3.5 Building awareness and research expertise**

One of the key arguments made for the introduction of government guidance on research governance in children's services, by both survey respondents and interviewees from a variety of stakeholder perspectives, was the need to increase awareness of research activity in local authorities. This awareness was seen as valuable for two key reasons:

- first, to avoid over-research of particular groups, by increasing awareness across the authority of research activity, and ensuring some kind of central point of information; and
- second, to develop a culture of 'research mindedness', of research expertise and a recognition of the value of research.

#### **3.5.1 Awareness of research activity**

Across different stakeholder perspectives, interviewees highlighted the need for local authorities to share research findings, within directorates and between authorities. This theme reflected concern about making the best use of research, related to a concern about making sure that the research really needs to be done. For example, a senior independent researcher (LA2) spoke of the need for local

authorities to work together, *'sharing findings, not reinventing the wheel'*. He advised that government should:

*'place more focus on working across LAs, and having less fragmentary work. DCSF are not great at capturing that – and therein lies the challenge. It's about looking beyond the immediate focus, or drawing the connections that haven't been made.'*

Within local authorities, academic and local authority interviewees highlighted the difficulties that could arise from a lack of centralised knowledge. For example, a senior academic researcher (LA2 case study) commented that a lack of oversight could be problematic across the life of the project – from research governance through the research process to the use that is made of research findings:

*'The biggest problem is not having some kind of committee overseeing the project. The infrastructure is not there to support that. It means you either do the work and the report lies on the shelf, or you have the issue in the local authorities I mentioned that no one is keeping an eye on the work. So you don't have governance across the life of projects.'*

In LA1, which did not have research governance across children's services, a senior manager expressed concerns about the lack of an overview of research activity:

*'Because we haven't got a panel, I couldn't say who is doing research across the directorate. It's not a good thing – not necessarily because of quality, but because of learning not being shared. For example, people might be planning research on linked topics and not realise.'*

In the same authority, another manager expressed concern about the risk of 'consultation fatigue' among particular groups, and highlighted a need for organisations to consider whether it is really necessary to do research. In another area, such concerns had been one of the key triggers for the research governance arrangements for children's services:

*'We got lots of applications to undertake research and these were dealt with on an ad hoc basis or research was taking place through managers that researchers had identified. So it was difficult to know what research was going on. I suggested that we needed a process to log and monitor research to prevent duplication.'*

(Research analyst LA4)

By contrast, in local authorities where research governance arrangements spanned children's services, the overview of research activity that this offered was seen to be valuable. For example, one survey respondent highlighted *'good management oversight of research'* as a key strength of their local authority's systems. Similarly, in another authority, a survey respondent observed that:

*'Current arrangements require that the relevant Service Director takes responsibility for the research project. This ensures additional checks before the project is approved. It recently became a norm that the Directors present research proposals to the DMT for discussion – this gives additional assurance and ensures 'buy-in' from the highest levels.'*

### 3.5.2 'Research-mindedness'

Several respondents talked of the need to build awareness of the potential value of good research for informing local authority services and practice<sup>9</sup>. The comments of a service lead in LA1 offered a useful summary of the views of a number of interviewees and survey respondents. She argued that:

*'There's a need for staff training – to bridge that gap between theory and practice, to build awareness of research, and to release time for people to do that training and to get involved in research. Staff need to trust research more.'*

Similarly, a strategic manager in LA2, who had previously managed a children's centre, commented on his experience of evaluation in his setting:

*'There's a need for some kind of education programme, which shows the value of independent research and evaluation for your setting. The research process also needs to be explained. We might jump for a consultant because we need to work very quickly, where you might get more robust evidence from an external academic. The message needs to be 'we really need to advocate this kind of work'. It can really energise teams, add power to your elbow. I don't feel threatened by that external perspective [that research brings]. It's about seeing wood for trees.'*

In part, the importance of research for local authorities reflects a climate that emphasises evidence-based practice, an issue highlighted by several interviewees. For example:

*'Local authorities are increasingly dependent on external research – it has huge value in terms of objectivity. ... [There is a] need for clarity that if an agency signs up to a research project, that everyone in that agency should agree to it. Potential partners need to know the purpose and value of research.'*

(Senior academic)

The value of building a research culture, and associated research expertise, was highlighted from a number of different perspectives. A manager in LA1 highlighted methodological standards as the cornerstone of a research culture:

*'You need to embed a culture that needs a strong research governance framework. Otherwise, for example, you think you've got strong evidence, but there are flaws in methodology. There's a certain discipline to evidence based practice – you must do it properly. To ensure those methodological standards, you need to approach research with a certain discipline.'*

Several respondents commented on the need for research expertise to inform the research commissioning process, from defining research questions through to scrutinising research proposals. A senior academic researcher spoke of the way in which lack of expertise in the commissioning process could affect the research that is done:

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<sup>9</sup> The increasing emphasis on practitioner led research in children's workforce reform is likely to be among the key drivers for this increase in research activity in local authorities. See for example the practitioner-led research projects funded since 2007 by the Children's Workforce Development Council: <http://www.cwdcouncil.org.uk/plr>

*'Commissioning Officers tend not to have the skills needed to evaluate research protocols and ethics. There is a need for skilling those people at entry point – their role is almost administrative and they don't have the research know how. If there is not someone at the point of entry who is critically appraising that [the key issues with regard to research protocols and ethics], then a lot comes down to budget and deadlines – or commissioners asking for something inappropriate. How much of that kind of work just gets funded?'*

In a similar vein, a senior local authority manager spoke of his concern that lack of independent scrutiny in the commissioning process could lead to bias in the way that research questions are framed:

*'The major issue I have is the idea that people have that you should be looking for the good, rather than looking for the truth. For example, when the UNICEF Child Wellbeing Index was published, we immediately leapt to replicate it in [our LA]. The issue was not what we could learn from it, but rather trying to show that our children were happier than elsewhere in the UK.'*

## 3.6 Quality

### 3.6.1 Messages from scoping reviews

The overarching aim of research governance is to improve research, and consequently it is concerned in part with standards and research quality. As noted above, research quality (or excellence) is a key guiding principle of many governance documents (e.g., Department of Health 2005; Research Councils UK 2009). If governance arrangements are to ensure that research meets the highest standards of good practice, this requires a check on research quality. There are two distinct issues here: first, the need to take account of disciplinary perspectives on quality; and, second, the need to distinguish between (a) assessment of quality and (b) responsibility for checking that quality has been assessed.

Judgements of research quality can stray into contentious territory. As was noted during the development of the Department of Health Research Governance Framework, there is a need to take account of the many differences between research domains and disciplinary perspectives. In particular, quality criteria based on generalisability are not readily applicable to in-depth qualitative methodological approaches, and could create difficulties in the governance of certain forms of research. This concern is particularly relevant to research involving children's services, because this is an area of rapid methodological development, with innovative participatory techniques designed to ensure children's rights and that their voices are heard.

The resultant practical tension, in terms of regulation, is summed up in the BERA Ethical Guidelines (2004, p5). In discussing how to accommodate the variety of methodological and disciplinary perspectives encompassed by educational research, BERA set out the need to ensure that their guidelines:

*'do not selectively judge or constrain, directly or indirectly, the methodological distinctions or the research processes that emanate from them'.*

This intent seems highly relevant to the similar challenges of governing research in children's services. But the importance of sensitivity to different disciplinary or methodological perspectives on research quality also raises a practical question for the development of research governance arrangements – who is best placed to determine whether planned research meets a criterion of quality?

Langfeldt (2006, p34) speaks of the '*inherent uncertainty in judging research quality*', commenting particularly on the challenges of interdisciplinary review. Similar concerns were noted in the Research Councils UK (2006) report on a study of the peer review process in Research Council funding, which noted '*particular concerns ... regarding the treatment of both adventurous and interdisciplinary research*' (p45). These papers are concerned with expert peer review, yet still note the ways in which discipline-specific conceptions of research quality can lead to conservative decision making, and thus limit opportunities for innovative or cross-disciplinary research. This observation is very relevant to arrangements for research governance, because it indicates that overly conservative decision making is a risk when assessments of research quality are made by those who are not academic experts in the field.

That concern raises a question about whether those responsible for the *implementation* of research governance arrangements in children's services have the necessary methodological expertise to make sensitive cross-disciplinary judgements of research quality. There is a need to distinguish between responsibility for ensuring that assessment of research quality has been carried out (to agreed standards), and responsibility for making that judgement of research quality. This distinction implies a need for government to specify which assessments of quality should be acceptable to local authorities, and which require further scrutiny.

### *Independent checks on quality?*

Cleasby's (2008) review of the Science Review Programme for the Government Office for Science argued that '*the principle of independent scrutiny as a means of raising or maintaining standards is strongly supported*' (p 3). Similarly, the Department of Health's Research Governance Framework requires that the sponsor ensures 'that an appropriate process of independent expert review has demonstrated the research proposal is worthwhile, of high scientific quality and represents good value for money' (RGF paragraph 3.8.7). The UK Research Integrity Office and Research Councils UK both emphasise independent academic peer review as a mechanism for ensuring research quality standards. The consistency of these expectations suggests that governance of research in children's services should also require that there has been independent scrutiny to assess the quality of proposed research. But how can that be achieved?

Expectations for academic peer review may not be appropriate for research conducted by non-academic sector organisations (e.g. independent research organisations and consultancies or voluntary sector providers), although these organisations may have other forms of internal peer review. Similarly, depending on the commissioning process, projects may have policy or commissioner review, but not academic peer review. In the context of research in children's services, then, it would not be appropriate to require *academic* peer review as a mechanism for ensuring research standards.

Moreover, it seems likely that a substantial proportion of research involving children's services might be commissioned without wholly *independent* review. Would internal peer review within the researchers' organisation be judged sufficiently independent to ensure quality? Whilst the research organisation has an interest in the project going ahead, it also has a vested interest in ensuring quality in order to protect and maintain its institutional reputation. This latter safeguard provides the basis on which University Ethics Committees function – the institutional concern with liability and reputation is generally seen to over-ride any vested interest in the research going ahead.

Alternatively, independent expert review might be addressed through the commissioning process. Would review through competitive tendering be sufficient to provide evidence of research quality? Competitive tender is, after all, intended to ensure research quality, as the process of commissioning

and review aims to ensure that the best researchers are appointed to the project. But what about projects that are commissioned without competitive tendering *or* review that is independent of the funders or research organisation? Would review by the project commissioners be sufficient to ensure quality? Arguably, project commissioners might not have the training or expertise in research design to assess quality, or they could have a vested interest in a particular research design (e.g. because of budget or timescale) that could over-ride their assessment of quality or integrity. It seems very likely that research commissioners will be concerned with assessing quality, whatever the commissioning process, to ensure that the work they are funding will deliver their desired objectives. But there remains a need to consider how research governance arrangements for children's services could operate to ensure that quality standards are met for research that is commissioned without any formal process of independent review, particularly if those who have reviewed the proposed project have a vested interest that could compromise research quality or integrity.

### 3.6.2 Checks on quality

Interviews with stakeholders from a range of perspectives recognised the need for checks on quality as part of research governance, but their views were closely tied to their professional positioning, and the demands on their role. For local authority interviewees, the need for quality checks partly reflected the challenge of determining which external requests for research were worthwhile. One respondent (a research analyst involved with research governance in LA4) commented that RGF systems also helped address the risks of over-researching particular groups, because they enabled an overview of local authority research activity. She described a recent student application which addressed a topic that *'has been done to death locally'*. The issue of quality was also addressed by a senior manager in LA1, who stated that:

*'The advantage of some kind of scrutiny is that it gives you a sense of worthwhileness, it puts a bit of a quality veneer on things. Some people do ask silly questions [under the guise of research], or frame their research in such a way as to come out with particular answers. I'd much rather see the truth. I think this review model helps with that – it's not the full answer but it gives an independent perspective.'*

In the same authority, a senior manager highlighted the value of ADCS Research Committee scrutiny in making a judgement about which external requests for research should be accepted. She commented that:

*'I get hassled by all kinds of people, I have to choose which is worthwhile.'*

This manager also observed that she took advice from a colleague involved with Research in Practice, as a way of checking on the reputation of researchers approaching her authority. However, a research manager in LA3 commented that there were limits to the assurances brought by external scrutiny:

*'If a study has ADCS and University ethics approval, then that's some level of assurance, but a further level of scrutiny is needed to protect the local authorities' interests.'*

Similar sentiments were expressed by a research analyst in LA4:

*'But researchers need to understand that ADCS approval is not a ticket for local authority acquiescence. We can still say no. It might not be right for us at this particularly time, or it might not be a priority, or we have done a lot of research in that area already.'*

So, ADCS Research Committee approval was seen as helpful, but not sufficient, of itself, to address local authority research governance needs. In this context, it is worth remembering that ADCS scrutiny differs in its scope and focus from research governance systems. ADCS approval only applies to external requests (not internal local authority activity), and to research involving four or more authorities. One respondent also commented ADCS *'don't check CRB status'*. However, this simply reflects the committee's remit. ADCS approval is not concerned with research governance per se; its guidance states that its function is to:

*'ensure that the projects carried out are worthwhile and that the topics best reflect the main concerns of departments', and their guidance states clearly that 'an approval does not guarantee that any individual department will agree to take part in the project'*

(ADCS, undated, p1).

Concerns about quality were also expressed in relation to disciplinary perspectives, and respondents' beliefs about which models of research were most worthwhile. In line with messages from the scoping review (see above), several respondents commented on the need to accommodate qualitative and quantitative methodologies, and different research paradigms. For example:

*'Research is very important, especially in a time when we are outcome focused. Small qualitative studies 'tell a story', and can be more persuasive than quantitative statistics.'*

(Service lead, LA2)

Another respondent cautioned against the temptation to privilege empiricist paradigms, which, when applied to the complexities of applied research, risk giving *'trite results'*:

*'Also, a lot of what gets commissioned in local authorities tends to be quite low level [in terms of funding]. ... But then you have to think about what kind of research is affordable and acceptable – and useful to teachers. Good teaching is often informed by theory, but it is essentially a pragmatic business. Research as a science is something different. The average teacher needs good ideas about 'what works'. Even if something is 'right' – it's not necessarily going to be the best thing to do. Phonics is a good example of that – it's seen as real science, but it is reductive. So the limits of the whole paradigm are quite tricky – and can mean that you miss constructivist activities.'*

(Independent research consultant, LA2)

Quality concerns were also raised in relation to internal research activity, and this was seen as particularly important given the growth of service user consultation and evaluation. For example, a senior manager in LA1 observed:

*'If we are interviewing young people, we have to make sure the data are reliable. So do we do it well? How confident can we be about what the data show – in terms of sample size, for example. We've got lots of well-meaning people finding out things – some are doing it well, others are not so well-trained.'*

### 3.6.3 Negative impacts of research governance on research quality?

The discussion above is centred on the role of research governance systems in assuring the quality of research; this is a key function of research governance. However, several interviewees, particularly (but not only) researchers, expressed concern that research governance frameworks could adversely

affect research quality, especially with regard to the representativeness of research samples. A senior academic researcher (national interviewee) observed that:

*'this [issue] is critical because the more problematic access is, the more skewed your sample, and the less valuable the research.'*

She commented that local authority partners *'need to understand the potential to damage a research sample, particularly in longitudinal studies. If you have a distorted sample to start off with, the picture becomes even more biased along the way.'* In effect, she argued, research governance arrangements have the potential to waste significant amounts of public money, by delaying research and by biasing – and thus limiting the value of – research findings. She noted, in particular, the need for clear guidance on the distinction between permission to approach and consent, in terms of opt-in and opt-out sampling. Her concerns were echoed by another senior researcher (LA2), who observed that:

*'When we've had active [opt-in] consent from parents, we get 3-4% participation [by young people]. With passive [opt-out] consent from parents, that rises to 70-80%.'*

In the research she described, requirements for opt-in consent from parents had meant that some schools had to be excluded from the study, because the measure being used (the Strengths and Difficulties Questionnaire) requires a 70% minimum response rate for validity.

The same concern about sample bias was highlighted by a local authority manager responsible for consultation with children and young people. He described a key piece of consultation with young people, which had not gone ahead, once again because the research governance panel required opt-in parental consent. Issues of consent are discussed in the next chapter, and will not be addressed here. However, these experiences are relevant to discussions of quality because they illustrate a methodological effect of research governance requirements on the likely representativeness of a sample. The local authority manager spoke of the need for research governance to:

*'provide an ethical framework that is practical and deliverable, and gives us the sample we need to ensure that young people's voices are heard in the design of services.'*

Other interviewees discussed the potential negative impacts of research governance systems with reference to questions about relevant research expertise among those scrutinising the research; these concerns were not confined to local authority systems. The academic researcher quoted above discussed her experience of a university ethics committee, noting that *'the disciplinary focus of ethics committee members [meant that] they have no clue about vulnerable children'*. Another senior academic researcher (LA2), himself the chair of a research ethics committee, expressed specific concerns about research expertise within local authority systems:

*'There is an issue about whether the people who are deciding on research ethics are researchers. Our committee is, so the points they raise are relevant. But if people are career committee members, it becomes counter-productive. There is no over-arching theory, no evidence base. The concept of preventability is woolly – people confuse bad luck with bad practice. If you are going to have ethics committees, you need the right people, with the right language. You can see a parallel in discussion of serious case reviews – where everyone is protecting their empire. The bureaucracy displaces research.'*

Respondents also raised questions about appropriate levels of scrutiny within research governance arrangements. For example, in LA4, the officer responsible for research governance described several

examples of checking what questions would be asked of participants, as part of the research governance process. Another respondent in this authority, with experience of this process, commented that *'at the moment, it's over to you and then they pick holes in it until it's in the language they want it to be in'*. This respondent was not a researcher herself, and overall, she said found the research governance committee feedback beneficial. However, an academic researcher, interviewed as part of another local authority case study, expressed serious concerns about this level of scrutiny:

*'There are issues in particular about ethical clearance for sensitive questions, and about instrument fidelity. For example, LAs and schools are keen to get insights about family relationships and so on, but they get edgy. They might say they only want part of a scale – and exclude questions for so-called ethical reasons, but then there are ethical issues about invalidating a scale. We would say you use the whole scale or not at all – you can't do anything with it or you invalidate it. There's no compromise on scale fidelity.'*

Another academic researcher, who was positive about research governance arrangements in our case study local authority (LA4), expressed concerns about inappropriate – and, she believed, excessive – scrutiny in another authority:

*'A second local authority had a similar form, asking for a similar level of detail. The problem was that the form was sent back and we heard nothing for a few weeks. They wanted some additional information, which we provided, and then again we heard nothing for a few weeks. Then they asked for more information such as copies of CRB checks. They dug their heels in, and we provided that information against our better judgement and the CRB Code of Practice. Another few weeks passed, and more information was requested.'*

In LA1, a service lead described problems with local authority implementation of a national evaluation, related to managers' understandings of – and ethical concerns about – randomised controlled trial methodology:

*'Some of the service managers didn't understand what an RCT was, what they were signing up for. The most obvious and immediate [issue] is that we have to double our number of referrals, for half to be randomised out. This was seen as an ethics issue around the table of service managers – that families come in needing a service, but we are not giving it to them. It is predominantly a management concern, rather than a reaction from the families themselves. ... The problem is that there is no ethos in the local authority about engagement in research or evidence based practice – there's not a culture in the local authority.'*

## **3.7 Proportionality**

### **3.7.1 Messages from scoping reviews**

In considering how research governance is implemented in practice, proportionality is a critical consideration. Much has been written in the academic literature about the perceived adverse effects of NHS research governance arrangements on research in health and the social sciences. Particular concern has been expressed about the tendency for research governance requirements – such as honorary contracts with participating PCTs – to delay or act as a barrier to the effective conduct of research (e.g., Elwyn et al. 2005; Hewison and Haines 2006; Munro 2008; McCrystal 2008; McDonach et al., 2009).

The growth in regulatory requirements can act as a barrier to quality research, and, arguably, can mean that some topics or groups of participants may become unresearchable (see Allen 2005; Crow et al. 2006). This is a concern that has been raised in the academic literature. For example, Crow et al. (2006, p88) quoted one researcher who observed that *'there's a danger that we're going to exclude so-called vulnerable groups because we make doing research with them so difficult'*. In Crow and colleagues' study, such 'pessimistic' views were balanced by those of other researchers who saw benefits in the development of ethical awareness as a consequence of increased regulatory requirements. However, Allen (2005, p 18) warned that:

*'There is a very real danger that, in the rush to establish rigorous research ethics arrangements that manage an institution's risk exposure, an institution will actually impede research without actually doing anything to promote ethical conduct.'*

In addition, it has been argued that – despite the efforts of the Implementation Plan for the RGF in Social Care – governance and ethics approval requirements continue to value quantitative and experimental methodological paradigms at the expense of qualitative social science research. Whilst some problems have been addressed, others remain, and NRES systems continue to be described as causing problems (e.g. Allbutt and Masters 2009; Mallick and O'Callaghan 2009). As McDonach and colleagues observed, *'despite good intentions, lessons from the past may not always be learned'* (2009: 227).

Nonetheless, our review of research governance systems indicated a shift, over recent years, towards the development of proportionate systems of governance. For example, the recently published ESRC Framework for Research Ethics (2010) includes new guidance on expedited and light touch reviews, and, at the time of writing, the NHS NRES system is trialling a system of proportionate ethics review in six MREC committees. Perhaps of particular relevance here, systems of proportionate or light touch review<sup>10</sup> do not automatically consider research involving children to be high risk, although they recognise that research involving children and young people incurs particular considerations, for example in relation to valid informed consent. The approach of these frameworks is consistent with the academic literature on ethics in research with children, in indicating that children should not be seen as inherently vulnerable, and that research with children is not inevitably high risk.

### 3.7.2 Stakeholder perspectives

Both survey respondents and interviewees from a range of stakeholder perspectives expressed significant concerns about the need for proportionate systems, and the potential for research governance arrangements to act as a barrier to research. Echoing the academic literature cited above, two interviewees with experience of health research governance systems (one a researcher, one a service lead in a PCT) commented on the challenges posed by these systems:

*'The ethics committee is a barrier to doing research, in terms of the pressures on our time – It's just made it impossible really.'*

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<sup>10</sup> Including the NRES pilot, the ESRC Framework for Research Ethics, and the Government Social Research Unit Ethical Sensitivity Checklist.

*'In the health sector, the hoops and the paperwork almost stop you doing research. ... Without exception, getting health involved has been a barrier – and it means you end up doing work without them, the timescales mean that the project is over by the time you get permission.'*

Several respondents expressed similar concerns about the impact of local authority research governance systems. As noted above, in some cases, respondents noted that research governance requirements had prevented research from going ahead. A senior local authority manager (LA8) remarked that *'the bar is set so high that we can't actually get over it.'* One senior academic described work on a study where, she said, it took two years to secure access to some case files. She noted that:

*'by the time we got permission, the files had been archived – and the staff responsible for the archive required a new round of negotiation before they would give permission for access.'*

Another researcher commented that the pressure on timescales for research meant that in some local authorities, by the time permissions were secured:

*'the window of opportunity for the research had passed. ... If you are working to tight deadlines, as in our case – as the Department needs information when it needs it. So families in that area will have been denied the opportunity to take part.'*

This last comment highlights a conceptual distinction that was apparent among participants, in relation to perceptions of research. On the one hand is the notion that research is inherently a worthwhile activity, and so people should have the right to be given the opportunity to take part. On the other, a conception of research as potentially harmful, so local authority staff have a duty of care to protect their service users. This perspective was summed up by a local authority research manager, in expressing concerns about local authority liability for poor research practice:

*'If someone did something that was harmful, the community and the media would blame the local authority. And I don't believe in crisis management.'*

In practice, of course, research is both potentially beneficial and potentially harmful. Proportionality depends on finding an appropriate balance between the two. However, as several interviewees observed, the potential risks in children's services research are not of the same order as the risks of clinical health research. For example, one senior local authority manager (LA1) argued that:

*'we need to distinguish between research that can have a risky impact versus research that does not, and which is likely to benefit services. If you are focused on views of the service that is not necessarily high risk.'*

This tension, between perceived benefits and risks, is perhaps particularly acute in research involving children and young people, tied to debates about their immaturity or vulnerability, versus their rights to have their voices heard, and their views included in the development of services. These ethics debates will be explored in more detail in the next chapter.

The need for proportionality was also discussed in terms of cost implications, because long timescales are expensive in terms of researcher time. A senior academic researcher (national interviews) questioned whether this is a good use of public money, talking in relation to large-scale nationally funded studies. Her concerns were echoed by a number of local authority respondents, in both survey and interviews. For example, one survey respondent, answering a question about potential barriers to the development of research governance in their authority, spoke of:

*'The fear that we would introduce another bureaucratic barrier to learning, evaluation and development. Fear of a time delay in our ability to be responsive to research opportunities. Fear of additional costs involved in meeting the requirements of a more stringent system. Loss of flexibility and proportionality.'*

Eight of the 59 survey respondents highlighted quick decision-making as a key strength of their research governance systems; one specifically highlighted the importance of proportionality:

*'I think our approach provides an appropriate level of scrutiny. We were keen to avoid over bureaucracy, and therefore dissuade people from undertaking research at all.'*

Relatedly, capacity issues were the most commonly cited barrier to developing research governance among survey respondents. For example:

*'Capacity to assess proposals - one part time research officer for all children's services responsible for all research governance leads to a slow process. This also means that there is an unwillingness to push research governance too far as the capacity may not be there to deliver on the requirements.'*

*'Our child population is growing much faster than the resource so these issues are not always high priority and therefore sometimes we decline to take part in research rather than investing the time in developing governance arrangements.'*

In keeping with these comments, interview and survey respondents in local authorities also expressed concerns that overly demanding research governance arrangements might put people off doing research, and that this could undermine attempts to develop a culture in local authorities of research-based and evidence-based practice. For example, the Director of Children's Services in LA2 commented:

*'That's part of my anxiety – that you'll end up with no evaluation being done. If you make it difficult, people won't bother.'*

Similarly, a strategic manager in LA1 observed that:

*'There is also an issue of raising awareness of research, within and beyond the local authority. How do we organise ourselves to know what's going on? I wouldn't like to have such bureaucratic processes that we never learned anything because you are always going to this that or the other committee.... There's a lot of good work going on that you could stop – you don't want this to have a negative impact.'*

Other respondents expressed concerns that the consequence of onerous systems is that people find ways of avoiding research governance. The issue of how much, and what kinds of, research-like activity was captured by research governance systems was a recurrent theme. Even in local authorities with well-developed research governance arrangements, there was recognition that *'some services may avoid using the system completely'* (survey respondent). As noted earlier, this partly reflects the

challenges inherent in encompassing research involving relatively autonomous services such as schools and voluntary sector provision. However, several respondents, across local authorities, also suggested that concerns about the timescales and demands of research governance approval meant that – as one senior manager<sup>11</sup> observed:

*'People work the radar of research governance. They think 'what we're doing isn't worth that process'.'*

This respondent said he guessed that there was *'three times as much'* research going on as was scrutinised by the research governance systems in his authority, because *'people either don't think it is research, or they think the research governance process is too unwieldy'*.

In a similar vein, a senior academic researcher (national interviews) advised that:

*'There is no point in having excessively restrictive guidance – it's counterproductive because people find ways to get round it. E.g. in the NHS, people classify their work as audit to avoid the NRES system. There's a lot of anecdotal evidence that this happens. The concern should be about the principles, not the bureaucratic process.'*

### 3.7.3 Flexible systems

In considering how to develop guidance for the governance of research in children's services, there is a need to ensure that any new frameworks for governance do not adversely affect research conduct or quality, or the ability of government to develop evidence-based policy. However, concerns about proportionality, such as those outlined above, need to be balanced against evidence of a clear recognition among respondents that there is a need to develop better scrutiny of research, and more consistent practice within and between local authorities.

In several local authorities, the flexibility of research governance systems was seen as advantageous in this respect. For example, in LA7, a research manager described the development of frameworks for expedited review, and the use of the Social Services Research Group's *Research Governance Risk Assessment Tool* (2005), as a means of ensuring that levels of scrutiny are proportionate to the likely risks of the work. Similarly, in LA3, a research manager observed:

*'A lot of people do not have a lot of time, and the system allows the level of scrutiny to escalate if needs be.'*

Flexibility was the most commonly cited strength of existing research governance arrangements among survey respondents, highlighted by 11 of the 50 respondents who answered a question about the key strengths of their systems. For example:

*'Governance is specific to the piece of work being undertaken, and therefore arrangements can be adapted to suit specific pieces of work and arrangements.'*

*'Flexibility to tailor arrangements to requirements of specific projects.'*

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<sup>11</sup> Unattributed to protect confidentiality.

*'There is a process in place which covers both ethics and methodology issues. It provides a clear but flexible framework for a range of research activities.'*

Reflecting such considerations, one survey respondent offered the following advice:

*'I don't think you can be too prescriptive and different arrangements will work for different people. I would favour a simple one side of A4 guidance sheet that maybe sets out the minimum criteria that a research governance process must have.'*

Flexible systems were also seen as important because, in the words of one senior service manager (LA4) *'you can't cover every eventuality'*. Our review of research governance and ethics review systems indicated a growth in principles-based approaches. This reflects recognition of the dialogic process of good research practice, and of the impossibility of anticipating everything that could happen in a rapidly developing field. As the new ESRC Framework for Research Ethics (2010) observed:

*'In a fast moving research environment, new situations arise and new forms of research emerge which cannot all be covered.'*

The need for guidance to be flexible to different contexts was highlighted by a number of respondents, from different stakeholder perspectives. A senior manager (LA1) talked about the need for guidance to accommodate local authorities' differing contexts, *'rather than putting us in a straitjacket'*. A senior academic researcher who had worked in LA4 praised the flexibility of their systems; this was important, she said, because the forms had not fit well with the needs of her research. In LA1, another senior academic researcher discussed the need for flexibility in terms of the contrast between abstract principles and real life practice:

*'We can stand in lectures and discuss [ethics], but it is a bit muddy – you can't have absolutes. You couldn't policy legislate for every scenario.'*

## 4. Ethics considerations

Ethics comprise a critical but distinct component of research governance, and will be discussed separately in this chapter. The chapter is not confined to ethics in research with children, but this is an area which necessitates particular attention with regard to the project's focus on research in children's services. There is a critical question for the guidance, 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, and relatedly, the extent to which any research involving children or young people should be seen as potentially high risk.

There has been a burgeoning interest in children's views and experiences on a wide range of social issues (e.g., Children and Young People's Unit 2001; DCSF 2008). For local authority children's services, this increased focus partly reflects requirements to take account of the views of children, young people, parents and carers in the development of services. At the same time, the academic literature increasingly pays attention to the views and experiences of children and young people, concerning a wide range of topics (Morrow, 2009). The conceptualisation of children as social actors (Christensen and Prout, 2002) has contributed to a growing emphasis on research that explores children's views and perspectives on their everyday lives (Mayall, 2002).

Debates in the academic literature highlight the question of whether research ethics guidelines can function as a paternalistic regulatory device that constrains, rather than supports participatory approaches to research with children and young people. At the heart of this question is a tension between conceptions of the child as vulnerable and immature, in need of protection, and the argument that engaging children and young people in research is an important dimension of ethical practice. Research may provide a space for children's views to be heard and taken into account by adults.

Such issues provide a critical context for the development of research governance arrangements for children's services, because they inform judgements about the degree of scrutiny that research governance arrangements should require, and the necessary independence of that scrutiny. For example, one driver for the newly established Social Care Research Ethics Committee was the definition of an 'appropriate body' for ethics review, within the terms of the 2005 Mental Capacity Act. Specifically, research organisations' ethics committees (such as University committees) do not meet the Act's requirements for independence (from the researcher) - an emphasis on independence that has its origin in concerns about the vulnerability of research participants. These tensions are also relevant to questions about the potential applicability of the Department of Health's Research Governance Framework to children's services, since this is a framework developed, in part, as a response to concerns about safeguarding individuals who may be vulnerable (social care service users).

In this chapter, we turn to respondents' views of key ethics considerations in research in children's services, and consider the consequences of those perspectives for the involvement of service users – and children and young people in particular – in research and research-like activities such as consultation or evaluation. However, the caveats about the representativeness of the survey and interview sample that we noted in Chapter Three apply equally to a discussion of research ethics. In particular, respondents' perspectives reflect their professional positioning – for example, as researchers, or as local authority managers – and their associated responsibilities are likely to colour their views. Consequently, there is also a need to look more broadly, to take account of debates in the academic literature, and the approaches of other relevant research governance frameworks.

## 4.1 Competence or vulnerability?

### 4.1.1 Messages from scoping reviews

The ethics principles that have been derived for research with adults – such as that of ensuring freely given fully informed consent, and the right to withdraw from research participation – apply equally to children, but according to Morrow (2008), there are four additional provisos specific to research involving children:

- children's competencies, perceptions and frameworks of reference, which may differ according to factors including – but not only – their age, are different to those of adults;
- children's potential vulnerability to exploitation in interaction with adults, and adults' specific responsibilities towards children;
- the differential power relationships between adult researcher and child participant; and
- the role of adult gatekeepers in mediating access to children, with concomitant ethical implications in relation to informed consent.

This last point – about the role of adult gatekeepers – is pivotal in debates about children's competence and vulnerability, because it rests on judgements about whether children are competent to decide for themselves. Legally, this is something of a grey area. Whilst children under the age of 18 years are considered minors, there is no explicit requirement in law for adult consent to children's participation in research. Conceptual debates in the academic literature about children's competency and autonomy to make decisions about whether to participate in research sit alongside legal requirements, including frameworks such as the Fraser Guidelines, based on the Gillick Ruling (Gillick [1985] 3 All ER 423), which are not intended for – but which may be applied to – research.

Given this lack of legal clarity, it is perhaps not surprising that the review of research governance frameworks revealed little consistency in guidance on research involving children and young people, which differed in their relative emphasis on adult and child consent in different frameworks. For example, the Government Social Research Unit guidance states that parents or legal guardians *must* be approached for consent for children aged under 16 to participate in research, but only requires that 'reasonable efforts' be made to inform children under 16 about the purpose of the research and to seek their consent to participate. Similarly, the Market Research Society guidelines require parental consent for research with children under 16 years of age<sup>12</sup>, but states only that 'the child should have the opportunity to decline to take part'. Other frameworks – such as the British Sociological Association guidelines – place priority on consent from the child him or herself. This approach prioritises the child within the decision-making hierarchy, and is consistent with an emphasis on children's human rights and agency, rather than their vulnerability. It is summed up well in the National Children's Bureau's (2004) guidelines on consent, which state that:

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<sup>12</sup> With the exception of young people in public places, in which case parental consent is not required for those aged 14 years or more.

*'While we believe that children themselves must give their consent to participate, we recognise that it may be necessary to ask permission from parents or other gatekeepers to approach the child.'*

As Alderson (2007, p2273) observed, debates about minors' consent can appear to be *'less concerned with children's rights than with adults' freedoms'*. Regulatory requirements which emphasise safeguarding concerns risk focusing on securing consent from adult gatekeepers, at the expense of children's voices. Consequently, agreement to participate from children may be elided, or based on passive assent rather than freely given and fully informed consent.

There is potential conflict between adults' role as gatekeepers to children's participation in research, and their duty of care to potential child participants. Gatekeepers to research with children and young people commonly include parents and professionals in mainstream services such as schools. Additional layers of gatekeeping govern access to children and young people classed as 'vulnerable' – such as children excluded from school, young offenders, young people with additional or complex needs, and looked after children (e.g. McCrystal 2008; Munro 2008). Issues such as vulnerability and potential imbalances in power relationships may be particularly acute in research with these groups of young people. Arguably, however, there is also a need to recognise children's competency and autonomy to make decisions about whether to participate in research, even when the research is concerned with sensitive issues, or when the young person is involved with services within which they are classed as 'vulnerable'.

Jenks (1996: 14) argued that adults make decisions about whether their child should participate in research according to a *'principle of care'*, but there is evidence that obtaining adult consent for research with children on 'sensitive' issues can be particularly challenging, especially if adults are concerned that the child's perspectives might leave them open to criticism (e.g., Hood et al. 1996; Valentine et al. 2001). Moreover, Maguire (2005<sup>13</sup>) countered that an *'ethical rhetoric of protection'* can position children as *'voiceless, vulnerable victims of research'* and noted that:

*'at the ethical core of researching with children then are issues of equity, inclusion and exclusion and who gets to speak after all and whose voices are heard, recognised, or silenced'*

#### 4.1.2 Stakeholder perspectives

The question of 'who gets to speak' depends in part on the power dynamics of settings in which research takes place, and on the relative authority of adult figures in those settings, such as parents, teachers, and social workers. Stakeholder interviews in the present study indicated some variation in conceptions of children's competence and vulnerability, tied to respondents' professional roles and responsibilities. In particular, there was a distinction between those who emphasised the safeguarding and protective function of research governance, and those who emphasised the need to ensure that the voices of children and young people are adequately represented in research and activities such as consultation. This difference relates to professional responsibilities; for example, one senior manager (LA4) observed that:

*'We are the corporate parent or in loco parentis – so I'm looking at this as a corporate parent. What are the potential benefits? What are the safety issues?'*

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<sup>13</sup> Online publication; no page numbers.

Equally, the following quotes highlight protective concerns:

*'People who are not in the 'child protection' field don't always consider this, but we know the world is a horrible place for some people. Some (researchers) are very naive about eliciting child protection issues. The warmth of an interviewer could lead to a disclosure – our RGF covers this.'*

(Research manager LA4)

*'[We have a responsibility for] vulnerability of children and families to be protected.... [There is a] need to consider impact on young people of re-living experiences.'*

(Research manager LA3)

*'Young people are so vulnerable – and collectively as a group – by the nature of the adversity they have faced. Then there's the sophistication of those who prey on vulnerability of young people in care – we haven't even ruled that out among those working in social care.'*

(Senior manager, looked after children, LA3)

A related concern was about the risk of parental complaints, if their consent is not sought for research with children. For example, the above-quoted research manager in LA4 described the situation as 'a minefield'. She noted that:

*'For safety and for statutory reasons, schools have said they will seek parental consent for children under 16. We need DCSF guidance on this. There is no law. ... Our argument is that they [researchers] will be in and out, but we [local authority staff] are in for the long term so we have a different approach to informed consent [compared with researchers].'*

The head of a primary school in LA2 had also prioritised parental consent for children's participation in research, partly out of concern for those ongoing relationships:

*'I always would [use opt-in parental consent] because I don't want any misunderstandings. If a child comes home and says 'I met Mr. Bloggs today' – I don't want to lose the parents' trust.'*

Other respondents argued more specifically that the risks of research participation depend on the focus of research, suggesting that parental consent, or opt-in parental consent, might be required for some research activities but not for others. For example:

*'On a street corner it is easy to say 'no one's got to do it'. But if you are in school, a member of staff may say 'you've got to'. You need to make sure the member of staff makes clear that it is voluntary. But we still say to young people that this is one way of getting your voice heard. .... [But] there need to be certain areas where parental consent is necessary, for certain behaviours or topics of research. For example, if I'm doing research in a primary school on alcohol use, there is a potential child protection issue. You can't just say, I'm not taking children's names, if you are asking for information where the response might be a child protection issue.'*

(Service manager with responsibility for consultation, LA1)

*'We gave schools template letters to send to parents, and prepared information sheets explaining why it was an important project, how we protected information and so on. Then we did a [parental] opt-out. It is less robust, but we judged we were not doing children any dis-service – there was no risk for them. The worst thing would be that we would be alerted to*

*possible mental health difficulties. If that happened, and there was any follow up, we would discuss it with parents. So ethically, I couldn't see any damage being done to the child. The data were not going anywhere. It depends on the nature of the work. [In this case] it's not much different to doing a spelling test.'*

(Senior strategic manager for schools, LA2)

*'If you are not asking them for their experiences, but their views as a young person – I'm sure most young girls in secondary school aged 13, 14, 15 upwards are more than capable of having views and should be entitled to. We are not asking them to participate in any intervention therefore there should be no need for parental consent at that level.'*

(Senior educational psychologist, LA3)

The tension between different professional perspectives was highlighted by two interviewees. One, a manager in LA4, had experience in work with parents and in youth work. She noted:

*'There's a tension between parents' rights and children's rights. We have different fields of work. For example, in the education field, it is expected that parents will be informed if children take part in research. It's a clearly defined area of good practice and common sense, and parents can withdraw a child. Compare that with youth work – they wouldn't dream of thinking that parents need to consent and would resist it. ... It would be useful to look at this more robustly – it is a sea of contradictions. When do we have to tell a parent? It's not clear in legislation.'*

The same tension was discussed by a local authority respondent in LA8, who was responsible for consultation with children and young people. She said:

*'The biggest issue is the conflict between children's rights, and protecting the vulnerability of those individuals. The concerns in ethics are about our reluctance to push forward because of the risk of complaints from parents. ...[Our approach] covers our ethics – making sure [young people's participation] is voluntary, what if someone says something upsetting. Our greater concern is about parents and children's consent. From my experience, children and young people are very happy to give their views.'*

Elsewhere, two experienced researchers highlighted the importance of allowing young people to express views that might differ from parental perspectives:

*'we asked young people aged 11 or older about things like aggression in the home – without asking for any detail. There was a sense that they provided a very different perspective from adults. It questions the validity of data you get from parents.'*

(Senior academic researcher, LA2)

*'There is a question about having parents present in interviews. We don't have a requirement for parents to be present (and young people can have someone present if they want to) but our interviewer guidance is that, where possible, it is better for the parent not to be there – because of the impact it has on the interview. We also have self-completion elements for more sensitive issues in the interview, and we record if anyone else is present.'*

(Senior researcher, independent research organisation, national interviews)

## 4.2 Consent

Interviews with key stakeholders generated much discussion about consent in research with children and young people, and indicated a need for government guidance to clarify three key areas of consent:

- (a) when parental consent is required, and when the child's consent alone is sufficient;
- (b) whether parental consent should be opt-in, or opt-out;
- (c) hierarchies of consent, in terms of the relative priority attached to parents' or children and young people's consent.

### 4.2.1 Requirements for parental consent

As indicated by the scoping reviews, questions of consent and competence in research with children are a legal grey area, and this was reflected in differences of perspective, and differences in approach, across the case study authorities. Several interviewees referred to use of Fraser Guidelines, but there were differences in interpretation and application, as the following quotes<sup>14</sup> illustrate:

*'We have practitioners adhering to Gillick. For safety and for statutory reasons, schools have said they will seek parental consent for children under 16.'*

*'In terms of age and capacity to consent, I would say that if you can get consent from the young person there should be no limit. Legally, Gillick competency is 14 years. In terms of treatment, we try to work from the principle that as long as one person has opted in, and they are capable, that's all you need. So if a young person opts in, and they are 14 or over, that's all you need. In the same way, if one parent opts in and the other doesn't, that doesn't matter – so long as you have one, that's all you need. That's helpful when you have divorced parents and they don't agree. We've got more confident about doing that.'*

*'We've come to an agreement with our user group about applying Fraser competence. If someone is consulting with children aged 14 or more, you don't need parental consent unless it's very sensitive.'*

*'The way laws are structured – it assumes ability and experience at different ages, but frankly it is not that simple. Is this person at this moment in time mature enough to appreciate and understand what they are consenting to? For example, with learning difficulties, this is very difficult. For their protection, adults should support them.'*

*'A grey area would be 16-17 year olds and the Gillick ruling etc. I suppose you could argue that if you can get married, have sex and (access to) contraception – so why not take part in research? But you can't get a passport without consent of the parents. Certainly with young children it's more straightforward – with teenagers, it's less clear.'*

*'I don't think there's a hard and fast age [for children's consent]. The Gillick model is that you assess capacity to understand. Even at a very young age, the child needs to understand that if*

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<sup>14</sup> Unattributed to ensure anonymity.

*they don't want to, that's fine. They may not fully understand the implications of taking part in research.'*

As indicated above, some respondents' comments suggested that the Fraser Guidelines are age-related, although they are not. They also indicated a cautious approach to interpreting the Guidelines, which echoes Piercy and Hargate's (2004, p 260) observations:

*'it appears that there is an increasing separation between the ability of a young person to consent to treatment and to consent to research. In consequence, the age at which a young person is deemed capable to consent to participate in research is rising, not falling'.*

The risk is that this caution can lead to parental consent being privileged over the rights of young people to decide whether or not to take part in research. This is illustrated in the comments of two local authority managers (both from LA3) who expressed concerns about prioritising young people's consent, over that of parents:

*'I believe in children's rights but they are not independent individuals because they are children.'*

*'My first reaction would be that [child-led consent] would not be appropriate. Always taking into account wishes and views, according to children's age and level of understanding, I would still think in terms of parental responsibility. I think there needs to be involvement from the parent.'*

These comments sit in contrast to discourses in the academic literature that emphasise children's rights and voices as individuals, and those which argue for the need to ensure that children's voices are heard in the design and delivery of services. However, not all respondents agreed. A contrasting perspective was expressed by the children's social care manager interviewed in LA1, who highlighted the problem of assumed consent in research with children:

*'Children are assumed to be the property of either their parents or their school. They don't always realise that they are giving personal information and that they don't have to do it. The TellUs survey was one example. Another [example in our authority was] a financial project, aimed at improving performance in schools with socio-emotional interventions. Children had an intervention done, and there was a desire for before and after measures. But they were asked to be quite personal about their performance in school and about what was going on in their lives. It was given to Years 7, 8, and 9. I queried the process. Schools wrote to the parent, the parent could withdraw – and once you had done that, the child's consent was assumed. No one was saying 'it's up to you' or 'take your time to decide'. There's a blurring of boundaries about what is research, but also in terms of how personal – and how anonymous – the work is. If you know the schools, there could be identifiability – and the children are a captive audience.'*

#### 4.2.2 Hierarchies of consent

One of the challenges of privileging consent from adult gatekeepers is that it may undermine the child's freedom to decide for herself whether or not to take part in research. This is a particular concern because of the power differential between adults and children, as was highlighted by a number of interviewees. David et al. (2001) noted particular concerns about providing information in school settings, where researchers may unwittingly appear to be 'quasi-teachers'. In line with this observation,

several respondents commented that young people's freely given consent may be curtailed or undermined in schools research. For example:

*'We have discussions on the ethics committee about age-related consent. For example, what does 'opt-out' mean if you are a seven year old in a class and your teacher is telling you the project is a good thing? But we also have opt-out models for parents for other things – like sex education in schools – so that should be okay too.'*

(Senior manager, LA2)

This point seems particularly apposite given the growth of practitioner-led research<sup>15</sup>, which means that research-like activity may be increasingly conducted as part of the professional role of workers such as teachers in schools.

Similar concerns about assumed consent were noted by several interviewees, and three raised particular questions about the TellUs survey. One research governance manager cited it as example of research within schools that did not fall within her panel's remit, because it was statutory. Elsewhere a local authority manager commented that *'we have had complaints from some parents about the questions on drugs and sex – usually from religious families.'*

As this last example implies, reliance on adult consent may also mean that children are excluded from the opportunity to take part in research when they may want to – so the adult gatekeeper's choice overrides the child's freedom to decide. One senior academic researcher (LA4) observed:

*'Most parents are willing [for their children to take part]. But it's the dog that doesn't bark – we don't know if children are being excluded. Parents have different views of what is right for children.'*

Similarly, a local authority research lead (LA8) highlighted the tensions involved in seeking consent from parents of looked after children:

*'[Even] if children are looked after, parents shouldn't be undermined. But the worry is that they'll all say no because they're worried about what children will say.'*

This last concern has been noted in the academic literature, where, for example, Hood and colleagues (1996) commented that parents may be reluctant to consent to their child's participation in research that may expose their parenting or leave them open to criticism. At the same time, Reeves and colleagues' (2007) study of children's views of their involvement in survey research noted that children and adults may not agree on which issues are 'sensitive' for the purposes of research; in their study, young people described school and friendships as potentially sensitive topics, whereas adults may not share this view.

As discussed earlier, the relative position of children's perspectives within hierarchies of consent depends on the extent to which they are considered vulnerable and immature, or as competent agents. In this regard, the academic researcher (LA4) quoted above drew a parallel with the terms of the Mental Capacity Act. Guidance on the Mental Capacity Act states that researchers should assume that a person has capacity, unless there is proof that they do not have capacity to make a specific decision,

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<sup>15</sup> See for example: <http://www.cwdcouncil.org.uk/plr>

and that potential participants must receive support to help them to try to help them make their own decision. Could the same principles be applied to research involving children and young people? She argued that:

*'We need to work from the presumption that children are willing and able to take part, and may enjoy taking part. Assume from the start that they have the capacity to make an informed choice. We use the basic principles of the Mental Capacity Act – capacity is assumed unless proved otherwise.'*

#### 4.2.3 Parental consent: opt-in or opt-out?

There was general consensus among interviewees that parents should at least be informed about children and young people's participation in research, and that it was good practice to seek parental consent unless there were compelling reasons not to do so. However, the extent to which parents should *actively* consent to their child's participation was more controversial.

Not surprisingly, particularly in light of the discussion in the previous chapter about research quality, and the representativeness of samples, several interviewees advocated 'opt-out' or 'passive' consent from parents – with the proviso that freely given and fully informed consent should be secured from children and young people themselves. A senior researcher in an independent research organisation summed up the complex issues involved:

*'It's critical to make sure you get informed consent from the young people themselves. For example, we might sample through the [a national database], and write to the parent to forewarn them that a researcher will be calling. We then get consent from the parent when the interviewer calls at the house – and also informed consent from the young person him or herself. So parents can opt-out of us calling at the house when they get the letter, otherwise we seek consent [from both parent and child] when we visit. We never do a complete opt-in – that would be disastrous in terms of the quality of the survey sample. That's a key issue for us in terms of the kind of research we do, because of the impact of opt-in on the representativeness of survey samples. The quality of samples would be a big concern for us.'*

Similar concerns were raised by four other respondents – two other researchers, and two local authority stakeholders who were responsible for consultation with service users. All noted the difference in response rates depending on whether parents were required to give active (opt-in) or passive (opt-out) consent. The local authority manager gave an example of a consultation exercise that had not gone ahead because of research governance requirements for opt-in parental consent. He warned that such requirements '*will stop consultation*' with young people, because it would become too difficult and costly, and too demanding for schools in terms of administrative time, whilst failing to achieve representative results.

Discussions about consent in research with children and young people are complex and, undeniably, emotive. Local authority stakeholders are concerned to protect their service users, but are also wary of parental complaints if not given adequate opportunities to opt children out of research. For example, two interviewees commented that the key practical problem with opt-out consent from parents is that there is no way of knowing whether information has reached parents, or whether '*a general note goes out and it can go straight in the bin*'.

### 4.3 Gatekeeping and access

Related to the above discussion about hierarchies of consent is a question about gatekeeping. Gatekeepers to research with children and young people commonly include parents and professionals in mainstream services such as schools. Additional layers of gatekeeping govern access to children and young people classed as 'vulnerable' – such as children excluded from school, young offenders, young people with additional or complex needs, and looked after children. Several interviewees commented on problems that could arise when a variety of adult gatekeepers govern access. For example, a senior academic researcher described her experience:

*'Who has authority in the local authority to give permission for research to go ahead – or not? People can block your research even if you have approval at Director level. We've had cases where even when we've had parental consent, we haven't been given access to case files. And an issue that consent has not been passed on – for example, when a child has been placed in care, or has changed placement, or moved to adoption.'*

Similar difficulties were described by another senior academic:

*'The key issue was gaining access to teams in children's services ... We needed their permission to carry out the research. The next day [after research governance approval was obtained] we got a message from another department saying we could not contact the children with disabilities team to help identify parents and children. I'm not sure about their status. It was very ambiguous. In the end, we had to ask the PCT to get involved and we had to develop an alternative strategy to identify parents. We could speak to the children with disabilities team, but not to identify parents. ... Some key people in children's services were very helpful but there was internal politics – I didn't understand.'*

In another local authority, a service lead who was involved in a randomised controlled trial described ethics concerns among managers – but not families – about the control arm of the trial (which was 'management as usual'). He explained that managers' concerns related to the idea that *'families come in needing a service, but we are not giving it to them'*; and this perception had caused difficulty in accessing potential participants. He cited the example of one local project that had refused to participate in the RCT, so families themselves did not get the opportunity to decide whether or not to take part.

There are two critical points to consider here, for the purposes of research governance. First, given the small size of the present study, it seems striking that such examples were relatively common place, and that they were highlighted as problematic by local authority stakeholders as well as by (academic and independent) researchers. Second, they raise a question about how much service providers – as gatekeepers – 'buy in' to the objectives of research, and how much they understand, and agree with, the proposed methodology. This is not strictly a question of research governance – because it applies even if a study has research governance approvals – but it has implications for research governance, in terms of the impact on the quality of research if access to samples is skewed or obstructed.

These difficulties reflect the challenge, for those in the gatekeeping role, of deciding which requests for research access are worthwhile, and/or reputable. ADCS has a role to play in that assurance for larger studies (involving four or more authorities), but – as one senior manager (LA2) noted – even (or perhaps especially) national evaluations with high level approval were not readily accepted by gatekeepers on the ground. This manager contrasted the experience of schools involved in a national

evaluation with another study, which had taken a collaborative approach with schools. He commented that, in the national evaluation:

*'Our schools have no ownership of the evaluation tools. For example, they don't like the questions in the online parent questionnaires – so they are very sceptical. Our approach [in the other study] was much less robust [methodologically], but we had total buy-in.... People were very receptive.'*

There is tension inherent in the local authority's role in research governance, and for service providers, in allowing researchers access to service users. This relates to another, more fundamental tension, about the perceived risks and benefits of participation in research, in a climate where local authority staff are concerned about their accountability to service users, and in light of the above noted protective discourse about the potential vulnerability of children and young people. As one senior researcher remarked:

*'Generally, local authorities are protective of families and there are some concerns about not making families feel pressured to take part.'*

## 4.4 Providing information

### 4.4.1 Messages from scoping reviews

Debates about the competency of children to judge whether or not to participate in research cannot be addressed without considering information provision, because such judgements depend on the clarity and accessibility of the information provided. Several ethics frameworks and codes of conduct highlight the need to ensure that participants understand the information provided – this requirement is at the basis of the notion of *fully informed* consent. However, the critical ethical point – particularly true for children, but equally applicable to research with adults – is that the researcher is responsible for that accessibility.

There is wide agreement in the academic literature that information should be specifically designed for children in age-appropriate ways, to ensure they fully understand the information provided and feel genuinely engaged in a decision-making process (e.g., Thomas and O'Kane, 1998; Alderson, 2004). There is also some debate about whether it is always appropriate to provide written information, and it has been argued that some settings or topics may require a more informal approach (Wiles et al, 2005). Similarly, most codes of conduct and research governance or ethics review frameworks do not require written models of information provision, although the expectation that such materials will be used is implicit within some frameworks<sup>16</sup>.

### 4.4.2 Stakeholder perspectives

The interview topic guide for stakeholders asked broadly about what they saw as being the key ethics issues in research with children and young people, and with that in mind, it is perhaps not surprising

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<sup>16</sup> For example, the Ministry of Defence Research Ethics Committee (MODREC) provides specific guidance on what to include in information sheets and consent forms. See: [http://www.science.mod.uk/Engagement/documents/ethics\\_researcher\\_guide.pdf](http://www.science.mod.uk/Engagement/documents/ethics_researcher_guide.pdf)

that most responses focused on consent – as outlined above – and less on information provision specifically. That said, stakeholders from a range of perspectives highlighted the importance of providing accessible information – for parents and carers as well as for children and young people, and several gave striking examples of good and innovative practice in ensuring such accessibility. For example, one local authority research manager in a local authority with a large non-English speaking population (LA3) gave an example of an external project where the local authority had provided interpreters, at their own expense, to ensure that the research was accessible across their local community. In another authority (LA1), a service lead was involved in a randomised controlled trial which used DVDs, instead of written information sheets, to tell families about the research – reflecting concern about the likelihood of low levels of literacy in their prospective sample.

Other respondents – particularly those involved in research governance or research ethics review – highlighted concerns about the quality and clarity of information provision in some cases. For example, one local authority manager (LA4) cautioned that *'information needs to be in plain English, not research-speak'*. In LA8, another research manager described variable experiences, in terms of the extent to which research methods and information provision took account of young people's likely levels of understanding. She described a recent survey as looking *'exam-ish'* and *'not very user friendly'*, and noted that:

*'I was still concerned for less academic children. I've worked in a secondary school [so I have relevant experience] and I thought that even if it was sensitively explained it could still be upsetting [because of the level of complexity].'*

She went on to argue:

*'It's about methodological quality – and if it's methodologically inappropriate, it is not ethically appropriate.'*

## 4.5 Confidentiality and disclosures

Reflecting the tensions noted earlier about children and young people's potential vulnerability when taking part in research, one of the key ethics concerns highlighted by respondents was about disclosures, and limits to confidentiality, in research with children and families.

The importance of these considerations was summed up by a senior researcher from an independent research organisation, who observed:

*'We are not above the law. If an interviewer has concerns that someone may be at risk, they refer back to our offices to determine what happens next.'*

This organisation's interviewers underwent specific training on dealing with disclosures, as part of their standard training and induction procedures, and as part of project-specific training.

Elsewhere, protocols for disclosures were often a matter of negotiation between researchers and the organisations that hosted or gave access to the research. These protocols and assurances were seen as critically important by local authority stakeholders, because of their accountability and duty of care to their service users. Three respondents gave examples that illustrate the need to establish agreements that are acceptable to both parties.

A research manager (LA3) gave an example of a proposed study which planned to ask young people: 'Have you self-harmed?' and 'Do you intend to do it again?'. She commented:

*'We would be liable if we did not institute child protection procedures. The study didn't go ahead because the researcher didn't want to [do what we required]. We had sorted out a school counsellor to be on site and this was a condition for the research before it could go ahead.'*

In LA2, a study involved completion of the Strengths and Difficulties Questionnaire to primary school-aged children, within schools. A senior local authority manager who was involved in the work noted that schools had concerns about what would happen for children who scored high on the scale:

*'The SDQ gives a prediction, it's not diagnostic individually – it's a cohort measure. But schools said what happens if an individual child does score high? [It was agreed that] each school got a report and the school's educational psychologist would have access to the same report – the overall results and results for individual children. They might already know about the child, or not, but it meant they could follow up [any that scored high].'*

This compromise was seen as necessary to satisfy this ethical concern, and ensure schools' agreement to take part in the project.

Finally, a senior researcher, also interviewed as part of the LA2 case study, described her experience in another project, of negotiating disclosures protocols with children's social services departments:

*'We had some success in getting those kinds of agreements, because we worked with social services to agree trigger thresholds for disclosure protocols. Interviewing was being done by a survey company – sensitive questions were completed by self-report and put into a sealed envelope. We checked if families had met the trigger threshold, and if they had we sent a letter with their contact details to social services. In the informed consent process we explained this could happen and said 'we are here as researchers, not as social care professionals'. But we were simply passing on their contact details – not any other information.'*

Together, these experiences suggest the need for the guidance to address the balance between researchers' concerns for confidentiality and service providers' duty of care to their service users, in recognising the need for disclosures protocols to be agreed by the parties' concerned<sup>17</sup>. Perhaps inevitably, the service provider's role as a gatekeeper of access to potential participants means that their organisation's requirements set minimum standards. But the researcher also has a duty of care. As one respondent observed, they have a responsibility to go beyond minimum standards if they feel those standards are inadequate in any given situation:

*'Often schools have their own policies on disclosure by a young person. [But for example] an issue emerged earlier this year. What is our responsibility if a child discloses about a teacher who is themselves the lead adult on safeguarding in the school?'*

(National interviewee, organisation that represents young people)

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<sup>17</sup> Within the framework of *fully informed* consent, researchers also have a duty to tell respondents about the limits of confidentiality in relation to information they provide.

## 4.6 Dissemination and feedback

### 4.6.1 Messages from scoping reviews

Ethics considerations span the research process, and are not confined to research design or data collection. Alderson (e.g. 1995) commented on the lack of attention given to reporting back to children and young people who take part in research, as compared to adult stakeholders. Because dissemination activities relate to how research is used – to its wider impact once it is launched into the public domain – they can also highlight participants' lack of control of the research process. However, these concerns about dissemination are not simply a matter for academic debate. They are particularly relevant to the present discussion of research involving children's services, because of the intent that activities such as user consultation should inform local authority strategy and services (including, for example, Children's and Young People's Plans). Those intentions require that governance addresses the ethics of how research is used, and in particular, the position of children and young people's voices within that.

Manzo and Brightbill (2007) discussed ethics considerations involved in participatory approaches to dissemination, and argued that *'ethics as conventionally interpreted tends to buttress existing power relationships in research and in society'* (p39). Involvement of participants in dissemination offers one way of forefronting their voices, rather than the authority of the 'expert' researcher, and it has been argued that children and young people themselves may want to disclose their identity (Valentine 1999). However, concern has been also been expressed that children and young people may feel pressurised into disclosing information in a public forum that adults would not be willing to share themselves (Allard, 1996). Alderson (op.cit.:151) argued that children should be given sufficient space to decide if they would like to take part in dissemination activities and in what ways, rather than *'being wheeled out as walking/talking case studies to illustrate an academic point of view'*. This advice seems very apposite given the purposes of much service user consultation in local authorities.

### 4.6.2 Stakeholder perspectives

In contrast to the academic literature considered in our scoping review, which indicated that dissemination is a key element of ethical research practice, most interviewees did not highlight this issue. Those who did, however, were consistent in highlighting the importance of feedback to service users, and of making sure that lessons are learned from research. However, interviewees' comments also indicated that dissemination, and feedback to service users in particular, could be a neglected area. For example:

*'Lots of young people want to know what difference the research will make. This enables young people involved to grapple with issues of impact.'*

(National interviewee, organisation that represents young people)

*'Young people say 'we're always being asked our views, but we never hear anything back''*

(Representative of involvement team, LA8)

*'People seem to be better at starting something, and don't always complete the cycle. It's the finishing and the learning that doesn't always get done. I would like to see a requirement to report back, and action planning.'*

(Service lead, LA1)

*'It's partly good manners but also part of an on-going relationship – children wanting to know – what was the point? What difference did it make?'*

(Research manager LA4)

*'Young people need to know what's going to happen, and whether they are going to get feedback from the research.'*

(Inclusion manager, LA1)

Some respondents noted concerns about the ethics of dissemination, particularly in terms of considerations about the potential identifiability of young people, and the ways in which they could be portrayed in reports of research findings. For example:

*'We also try to make sure that young people are not being used, for example, in sensationalised accounts. And [we] make sure findings are completely anonymous. Sometimes samples are too small and there is a risk that confidentiality will be breached.'*

(Senior manager, LA5)

*'[Dissemination] issues usually focus on the PR side of research. It's important to be clear from the outset. No more than age and first name may be quoted. Newspapers are not permitted to follow up on stories by going back to young people and doing in-depth case studies. The researcher is the guardian of the young person's reputation as far as dissemination of research is concerned.'*

(National interviewee, organisation that represents young people)

#### **4.6.3 Dissemination and feedback: summing up**

The contrast between the emphasis on dissemination and feedback in the academic literature, and the relative lack of concern about this area of research practice among interviewee and survey respondents (in comparison to consent, for example), is striking. The findings indicate a need for government guidance on research governance in children's services to attend specifically to this potentially neglected area of ethical practice, in order to address the whole of the research process, from commissioning to dissemination and reporting. The debates about dissemination, outlined above, also highlight a more general theme which has consistently been raised in this chapter, about the responsibilities – of researchers and those responsible for research governance – to the individuals who take part in research, and the need to take account of their views and preferences, regardless of their age.

## 5. Conclusions and recommendations

The over-arching goal of the work reported here was to inform the development of guidance for the future development of research governance arrangements, in order to ensure a more coherent and transparent system that is proportionate to the governance needs and ethical risks in research involving children's services. But what does that mean, in practice – and in light of the findings presented in Chapters Three and Four?

To ensure *coherence* and *transparency* there is a need to develop greater consistency, to establish some clear common ground between local authorities in their approach to research governance in children's services. To what extent is that achievable, or appropriate, given the variety of existing arrangements across local authorities, the diversity of children's services, and the integration of children's services?

The desire to develop a system that is *proportionate* to the governance needs and ethical risks of research in children's services raises two further questions. First, can (or should) guidance accommodate the existing landscape of research governance in children's services – and to what extent? Second, what are the specific needs for children's services, related to the involvement of children and young people in research, and to the diversity and integrated context of the work?

This final chapter will address these critical questions in relation to themes emerging from the research, and will use them to draw out key messages and potential ways forward.

### 5.1 Existing arrangements

We began our discussion of results in Chapter Three by warning that the sample was likely to over-represent local authorities that were research active, and which had established research governance arrangements in place. Despite that caution, it was evident from the survey and local authority interviews that research governance arrangements for children's services were variable. All the local authority respondents, in the survey and in interviews, were concerned about research governance, and respondents generally welcomed the development by government of guidance for children's services. Most local authorities in the survey had some systems in place for research governance, including checks on research ethics. However, for the most part, these arrangements were not comprehensive – either they did not apply to all research in children's services, or different arrangements applied to different divisions within children's services. Within this context, it has not been possible to assess the nature and extent of research in children's services that is not covered by existing research governance and ethics review systems.

In as much as there were commonalities across local authorities, the Department of Health's Research Governance Framework (RGF) had been extended by a significant minority of local authorities, to apply either to children's social care research or (less commonly) to children's services as a whole. This was seen as valuable by many respondents, in addressing a need and in allowing them to build on existing systems. However, there was also concern about the applicability of research governance systems designed for adult social care to the diversity and particular needs of children's services. These concerns were focused on proportionality and timescales, within the context of (a) integrated children's services and (b) an emphasis on consultation with service users and on service evaluation.

## Message 1. Variation across local authorities

The guidance 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?

Whilst the Department of Health's Research Governance Framework has a potential role to play, in providing a basis for research governance in children's services, the research suggests some lack of fit with the context of children's services, particularly with regard to:

- (a) integrated services;
- (b) statutory requirements for consultation with service users; and
- (c) the development of evidence based services, and the role of research and of service evaluation within that agenda in children's services.

## 5.2 Defining 'research'

There was a clear consensus among respondents that guidance on research governance in children's services should adopt a broad definition of research. This argument was focused on two key concerns:

- first, the need to encourage the development of a research culture within local authorities, by raising awareness of research, and of its value; and
- second, the need to accommodate different methodological approaches, and relatedly, to encompass the range of research-like activities ongoing within local authority children's services.

Many respondents highlighted the need for some kind of oversight, or collective knowledge, of research activity within children's services. Some argued for national information that brings together findings from smaller local studies; others were primarily concerned about developing local knowledge, within authorities. These concerns were partly motivated by a desire to avoid the problems caused by duplication of research, in wasting money and participants' time, and potentially over-researching certain groups in the population. But respondents also expressed a broader wish to raise awareness of research and research methods, and, in particular, of the potential value of research as a resource for policy and services.

In a climate in which research-like activity is increasingly used to inform policy and service development at a national and local level, the boundaries that define research in relation to other activities that use 'research methods' have become increasingly blurred. Respondents consistently argued that governance arrangements should encompass not only 'pure' research (in line with the narrower definitions that are found in other research governance documents), but also 'research-like' activities, such as consultation and evaluation, and even audit or data review, where identifiability is a risk. Whilst

concern about research ethics is often focused on methods that involve direct data collection from participants, both scoping reviews and interviews highlighted concerns about data protection and information sharing in relation to the use of existing data. In light of such considerations, it was seen as critical that guidance should address a broad range of 'research-like' activities. Governance concerns – for example, about quality, ethics, or avoidance of conflicts of interest – were seen as equally pertinent for work that does not meet conventional definitional criteria for research.

Narrow definitions of research may also be problematic, for the purposes of governance, because criteria such as generalisability may be criticised for favouring a particular empiricist methodological paradigm, and for failing to reflect adequately methodological developments in research with children and young people. Concerns about the problems of privileging some methodologies over others were highlighted by respondents from a range of perspectives, although the concerns raised inevitably reflected their professional roles. Some expressed concerns about the tendency to prioritise measurability and outcome evaluation over process-oriented work. Others, involved in large-scale studies, highlighted problems with the representativeness of samples, as a consequence of research governance requirements. To take account of such concerns, whilst accommodating the current landscape of research activity in children's services, a broad definition of research is needed – a definition that does not privilege or disadvantage specific methodological approaches. However, the study also highlighted concerns about the potential negative impact of research governance systems on research and research activity, and about local authority capacity to address research governance. In this context, it is important not to 'overload' existing systems, but rather to propose an incremental and flexible approach, which promotes good practice without being inappropriately burdensome, or acting as a barrier to research.

### Message 3. A broad definition of research

Guidance on research governance for children's services should adopt a broad definition of research which:

- (a) explicitly highlights the value of good quality research as a resource for policy and service development;
- (b) encompasses 'research-like' activities that use research methods, including consultation and evaluation, and data review or audit where individuals may be identifiable; and
- (c) does not privilege any specific research methods or methodological approaches.

## 5.3 Quality

Quality assurance is a key function of research governance, and was seen as necessary for research in children's services. Within a culture of service evaluation and consultation, respondents highlighted the need to have some kind of 'external check and challenge' on the ways in which research questions are framed, as well as in relation to ethics or methodology. Research governance needs to incorporate some kind of independent scrutiny *across* the research process, beginning at the stage of commissioning, when research questions are defined.

The need for an approach that addresses the *whole* research process was highlighted from a range of perspectives. Thus, for example, one theme to emerge from the scoping reviews of ethics and of governance frameworks – and which was also highlighted by several interviewees – was the need to conceive of research ethics and governance as a dialogue that spans the research process from commissioning to dissemination.

Concerns about quality also related to the ways in which research governance scrutiny could act as a barrier to quality research, if disproportionate, or lacking in appropriate expertise. Respondents gave examples of bias to research samples, and of lengthy additions to timescales that inflated the costs of research studies, in ways that raised questions about appropriate use of public money. Relatedly, several respondents commented on the impact that gatekeepers within local authorities could have on the execution of research, even when it has governance approval. Again, they gave examples of delays to project timescales, and of sample bias.

#### Message 4: Quality assurance

Guidance should:

- (a) indicate 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; and
- (b) recommend oversight to ensure that studies which have the necessary research governance approval are able to proceed as agreed.

### 5.4 Proportionality and flexibility

Following on from the discussion above, proportionality and flexibility emerged as critical related themes. There is an evident need for flexibility in order to accommodate the diversity of existing arrangements within local authorities. In addition, local authorities differ considerably in their research governance needs. Thus, for example, a small unitary authority is unlikely to have the same needs or resources for research governance as a large County Council. Guidance needs to recognise this variation, and allow that one model of research governance will not fit all.

While many respondents were concerned to develop more rigorous and consistent arrangements across children's services, those with well-developed arrangements generally felt they worked well, and so guidance needs to accommodate established arrangements. At the same time, local authorities without formalised research governance panels were not necessarily lacking in systems of independent scrutiny. In one local authority, two senior managers in different divisions of the children's directorate operated a reciprocal system of 'external check and challenge', which was seen to work well; in another, the Director of Children's Services scrutinised proposed research. Respondents' feedback indicated that research governance was not dependent on particular systems of working; rather the key features of robust scrutiny were independence and relevant expertise, including methodological expertise.

This last point raises a question about the levels of independence and of expertise that are necessary to ensure robust, and appropriate, scrutiny. Given the diversity of children's services, and the variety of existing arrangements and of resources available, local authorities are likely to vary in the extent to which responsible staff have the necessary methodological expertise to make sensitive cross-disciplinary judgements, for example of research quality. This is problematic, not least, because of the tendency of discipline-specific conceptions of research quality to limit innovative or cross-disciplinary research (Research Councils UK 2006). But this point highlights a critical question – about the *purpose* of scrutiny. Arguably, the function of research governance is to ensure that assessment of research quality has been carried out (to agreed standards), rather than to replicate that assessment.

For example, if a study has been commissioned by competitive tender, and thus subject to independent review of quality, and is subject to independent ethics review (e.g. through a research organisation's

institutional systems), the role of local authority research governance should be to make sure that those external checks meet set criteria<sup>18</sup> – not to repeat the process of review. The local authority needs to make a separate judgement about whether they want to engage in the research, about whether the research is worthwhile and relevant to their needs, but is that research governance? Arguably, it is not. However, for other forms of research activity – such as internal local authority consultation – external checks may not be present. In those cases, there is a stronger need for internal local authority systems to incorporate independent review of the research, including ethics review.

Given our earlier arguments about the need for a broad definition of research in children's services, we recommend that proportionate systems should allow different levels of scrutiny – and different requirements for independence – depending on the nature and scope of proposed work. Many frameworks for research governance and research conduct, including the recently published ESRC Framework for Research Ethics, highlight the need to provide for 'light touch' or 'expedited' review for certain forms of research. This could be a useful model, not least because one particular concern raised by respondents was the failure of existing systems to 'capture' a substantial proportion of research in children's services. Respondents spoke of colleagues 'working the radar' of existing research governance or research commissioning systems, for example by classifying research-like activity as consultation. They also highlighted the difficulty of engaging more autonomous providers (e.g., schools, or voluntary sector provision) in local authority systems. Arguably, these difficulties would be exacerbated by the imposition of time-consuming systems which could be perceived to be overly rigorous, and which could actively erode communication, trust and compliance.

It may be more effective to introduce an approach based on key minimum standards, which could be implemented flexibly, with different levels of scrutiny depending on needs and contexts. This approach was evident in several governance frameworks, including professional codes of conduct; some guidance (and several interviewees) commented specifically on the impossibility of any document anticipating every eventuality. A number of recently developed codes – such as the BPS Code of Conduct and the ESRC Framework for Research Ethics – as well as other, longer established models (e.g. the BERA and BSA codes) specifically highlighted the need for principled approaches. As Hammersley (2009, p215) observed:

*'guidelines can only be guidelines not algorithmic rules that govern behaviour; and, as a result, there is always scope for reasonable disagreement about what is and is not, was or was not, acceptable behaviour in the circumstances.'*

In sum, flexibility was seen as important in order to ensure a proportionate system, to enable check and challenge, whilst accommodating the broad definition of research activity that respondents hoped guidance would encompass. They advocated recognition that different activities carry different levels of risk, but also have differing resources and timescales for their execution. Respondents from a range of perspectives warned that disproportionately stringent arrangements would have adverse consequences, in terms of:

- acting as a barrier to the development of a research culture within local authorities that are working hard to develop evidence-based strategy and services; and

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<sup>18</sup> An example might be the ESRC criteria for institutional ethics review.

- reducing the likelihood that any arrangements introduced would ‘capture’ the range of activity ongoing, since – as one respondent said – people would ‘work the radar’ to avoid governance arrangements that they saw as being inappropriately slow or demanding.

### Message 5: A flexible and proportionate approach

Guidance should specify flexibility and proportionality as key principles of 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. This may necessitate the development of sector specific guidance on research governance (e.g. guidance for voluntary sector providers and guidance for schools).

## 5.5 Children’s competence and vulnerability

Decisions about proportionality, and about the levels of scrutiny and of independence that are necessary for research governance in children’s services, depend in no small part on understandings of the potential vulnerability of children and young people in research. Earlier, we discussed the potential applicability of the Department of Health’s Research Governance Framework to children’s services. Aside from its potential value as an existing established framework, there is a question about its *relevance* to children’s services. The Research Governance Framework (RGF), as it applies to adult social care, is partly concerned to safeguard users of adult social services, a population that is seen, inherently, as potentially vulnerable. Is this also true of users of children’s services? The latter includes social care populations – such as disabled children and children in need – but it also includes children and young people in the general population, such as young people in schools – who may or may not have specified additional needs.

These differences in population raise a fundamental question. To what extent should users of children’s services – and children and young people in particular – be seen as inherently vulnerable? Following on from that point, it may be argued that their potential vulnerability depends not only on their circumstances, but also to their (relative) immaturity, and their legal status as minors. This implies a second question: to what extent can the governance of research involving children and young people start from an assumption of competence to give valid consent?

The answers to these questions are complex, and emotive, and are well-addressed in the academic literature. As Morrow (2008) observed, research involving children and young people necessitates particular considerations, in order to address:

- children’s competencies, perceptions and frameworks of reference;
- their potential vulnerability to exploitation in interaction with adults, and adults’ specific responsibilities towards children;
- the differential power relationships between adults and children; and
- the role of adult gatekeepers in mediating access to children.

At the same time, there is a danger that inappropriately protective discourses can undermine children's rights and voices. This point was highlighted in our review of the academic literature, and illustrated in the views of a number of those who took part in our research. It represents a significant concern for research governance in a policy context that prioritises attention to children's views as service users.

Rather than positioning children and young people as inherently immature or incompetent to make decisions, it might be more productive to argue that the responsibility lies with the researcher: to use methodologies that are sensitive to and respectful of children's competences, and to address the particular considerations of research with children and young people. As such, the function of research governance is to check that such considerations are adequately addressed, rather than to start from an assumption that research involving children and young people is inherently high risk, because of their immaturity and vulnerability. Other governance frameworks allow that research with children is not necessarily high risk<sup>19</sup>. A further useful parallel can be drawn with the legislative framework of the 2005 Mental Capacity Act, which advocates an assumption of capacity as a starting point.

In practical terms, these discussions have two key implications. As noted earlier, the development of the Social Care Research Ethics Committee was in part driven by a concern that research organisations' ethics committees would not meet the Mental Capacity Act's requirements for independence (from the researcher). This emphasis on independence of ethics review reflected concerns about the vulnerability of research participants who lack capacity, under the terms of the Act. If (as we have argued) children should not be assumed to be inherently vulnerable or lacking in capacity, then research involving children and young people should not be assumed to be high risk. Guidance should start from a position of respect for individual competencies, and for children's rights to give or withhold valid consent. From this position, it should not be necessary for the governance of research with children and young people to require the degree of independence in ethics scrutiny that has been judged to be necessary for adults who lack capacity. Government guidance should make this clear. In doing so, it should state which frameworks or standards for ethics review are acceptable for research in children's services (see in Section 5.6).

Second, guidance needs to address specifically the relative priority attached to parents'/carers' or children's consent. There was evident disagreement about this question amongst respondents in the present study, highlighting a need for clarification. Respondents who prioritised adult consent for research with children expressed concerns in relation to parental responsibility, and adults' duty of care in protecting children and young people. Some also pointed to risk of parental complaints if their consent was not adequately secured.

Nonetheless, the reviews of the ethics of research with children, and of relevant governance frameworks clearly suggest that it would be appropriate for guidance to privilege children and young people's consent when they are participants in research activity. That is not to advocate neglect of the perspectives of parents and carers, or those with a duty of care or accountability to service users in children's services. However, as was argued by a number of respondents from a range of perspectives, there is a need to ensure that children and young people are recognised as individuals

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<sup>19</sup> See for example, the ESRC Framework for Research Ethics (ESRC 2010) and the recent guidance on 'material risks' for the NRES pilot of proportionate ethics review. See: <http://www.nres.npsa.nhs.uk/news-and-publications/news/proportionate-ethical-review-pilot/>

with rights within research governance arrangements. We recommend that this understanding is expressed in guidance in such a way as to ensure that:

- children's consent is not assumed on the basis of consent from adult gatekeepers;
- children who wish to participate are not prevented from having their voices heard because of the protective concerns of adult gatekeepers.

## Message 6. Hierarchies of consent

The guidance should not be age specific, but should specify that:

- (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).

## 5.6 Ways forward: principles and minimum standards?

The messages from the research summarised in this report are all about balances. There is a need to develop better scrutiny, and more consistency, in the governance of research in children's services. However, there is also a need to ensure flexibility – to accommodate and build upon the variety of arrangements that already exist, and to recognise the specific contexts and needs of integrated children's services, particularly given the relative autonomy of schools and early years provision, and of voluntary and independent sector providers. The integrated children's services agenda comes with statutory requirements for consultation and evaluation within Children's Trusts, and a strong desire to build a research culture within local authority children's services. The project also highlighted a fundamental tension between conceptions of the child as vulnerable, in need of protection and safeguarding, and a view of the child as an active agent, with a right to have her voice heard and to decide whether or not to participate in research.

These competing demands necessitate a broad definition of research, but also an approach to research governance that is proportionate and enabling. Guidance must be cognisant of the timescales and resources available for research and research-like activity, and of the variability of arrangements within and between local authorities. There is a need to avoid 're-inventing the wheel', but also to avoid setting standards for scrutiny that could act as an inappropriate barrier to research, or which could risk silencing children's voices, because of disproportionate concern about the views of adult gatekeepers. Above all, the project shows clearly that one size will not fit all.

As noted earlier, some research activity involving children's services will be subject to independent scrutiny outside of local authority research governance arrangements. This might simply include methodological scrutiny through the commissioning or funding process, and/or requirements for ethics review from research organisations, but equally – and notably, within the context of integrated children's services – external checks may well result from the involvement of other services in the research<sup>20</sup>. The potential implications of duplicating scrutiny, within an integrated service context, are of significant concern:

- First, a requirement for multiple approvals is likely to add considerably to the timescales for research involving integrated children's services. The concomitant implications for the likely cost of research projects raise a fundamental question about whether duplicated review would be a good use of public funds.
- Second, in light of literature that highlights the importance of inter-professional trust on the development of integrated working (e.g. Brandon et al. 2006; Horwath and Morrison, 2007; Edwards, 2009), it would be politic for government research governance requirements for children's services to accept scrutiny by other partner agencies, where appropriate.
- Third, there are practical consequences: if one scrutiny process requires changes (e.g. to project methods) it would effectively invalidate any existing approvals (and potentially, the contract with the research funder). At the very least, it would necessitate re-application to the original approval bodies, eroding trust and lengthening timescales, and running the risk that the original reviewers may not accept the proposed changes. Clearly, this circularity is not practicable.

Nevertheless, there remains a need to consider how research governance arrangements for children's services could operate to ensure that quality standards are met for research that is commissioned without any formal process of independent review, particularly if those who have reviewed the proposed project have a vested interest that could compromise research quality or integrity. An approach to research governance that is based on principles and minimum standards could be sufficiently flexible to apply across the variety of research-like activity ongoing in children's services whilst avoiding duplication of review, and confining requirements for formal review of research governance and ethics review to projects that are not captured by other recognised forms of scrutiny.

### Message 7. A principles-based approach

- (a) Research governance in children's services should be based on clear underpinning principles, to guide decision-making at all stages of the research process.
- (b) 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.
- (c) It should allow that the specifics of how principles should be applied may vary, whilst principles and minimum standards remain constant across domains.
- (d) 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.

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<sup>20</sup> Examples in the context of integrated children's services could include the Department of Health's Research Governance Framework requirements for research involving the NHS; the research governance requirements of CAF/CASS (the Child and Family Court Advisory and Support Service); and approval from the National Offender Management Service (NOMS) for research involving young offenders.

### 5.6.1 Key frameworks

Our review of frameworks of research governance highlighted a number of commonalities in the principles prioritised by different systems. All frameworks embed expectations of quality, although they vary in their expectations of how these should be assessed or defined. The competence and professional integrity of researchers and research organisations is related to ideas of quality, and is another recurring principle in many codes of conduct. Finally, independence is also highlighted in a number of codes, and often related to principles of professional integrity and to avoidance of conflicts of interest (for example, in the commissioning and conduct of research), as well as to requirements for independent review.

Given the need to avoid duplication of scrutiny, it would be useful – where appropriate – for the guidance to make reference to existing frameworks for research governance and ethics. Earlier, we highlighted questions about the extent to which the Department of Health’s Research Governance Framework, as a system designed for health and social care, might fit with the specific character of research in children’s services. However, we also noted that it is the most widely applied single system in local authorities responding to the survey, which suggests it has potential adaptability to the needs of children’s services. The Government Social Research Unit’s Ethical Sensitivity Checklist also provides a useful starting point, designed to be used during the commissioning process as a guide to the levels of scrutiny that a project should have.

The ESRC Framework for Research Ethics (FRE; ESRC 2010), whilst not designed for research in government, could be a particularly useful model for research involving children’s services. Published in January this year, the Framework has been reviewed and updated following extensive consultation. Its ethics principles (see Box 5.1) are designed to be cross-disciplinary in social science research and so aim to accommodate different methodological paradigms as well as rapidly developing areas such as online research and visual methodologies, which are very relevant to research with children and young people. Consequently, they are relevant to most research that is likely to involve children’s services, including secondary analysis and research with adult stakeholders (professionals and service users) as well as with children and young people. In addition, whilst differences exist, of course, the ESRC ethics principles are compatible with other commonly adopted guidelines, such as those of the Market Research Society or other professional bodies (including the Government Social Research Unit).

#### Box 5.1 ESRC Research Ethics Principles (ESRC 2010)

1. Research should be designed, reviewed and undertaken to ensure integrity, quality and transparency
2. Research staff and participants must normally be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved. Some variation is allowed in very specific research contexts.
3. The confidentiality of information supplied by research participants and the anonymity of respondents must be respected
4. Research participants must take part voluntarily, free from any coercion.
5. Harm to research participants must be avoided in all instances.
6. The independence of research must be clear, and any conflicts of interest or partiality must be explicit.

The ESRC's FRE has a further advantage in that it is widely recognised and accepted by Higher Education Institutions, independent research organisations that are eligible to receive ESRC-funding, and other funding bodies (such as the Nuffield Foundation and Joseph Rowntree Foundation) that sponsor research in children's services. It also sets out requirements for independent ethics review within research organisations, and has systems to check on ethics review in organisations that it funds. In a climate of limited resources to develop new arrangements, it seems likely that there would be benefits for DfE in recognising ESRC criteria for ethics review within its guidance.

The ESRC also accepts other systems of ethics review that meets its criteria (for example, independence of scrutiny and lay membership), and so avoids duplication with other systems, such as NRES. Consequently, the suggestion that DfE 'passports' ESRC-recognised ethics review systems is consistent with the objective of avoiding duplication. However, it does not address the question of how DfE and local authorities can ensure adequate scrutiny in research that is not subject to any kind of external review. This concern applies to internal research-like activity, especially that which has not been through any kind of commissioning process. It also applies to externally commissioned work (including work commissioned by DfE) that is carried out by independent consultants, or by small organisations in the voluntary or independent sector that may not have the resources or capacity to establish sufficiently robust or independent systems of review.

It is important that governance requirements do not act as a barrier to the engagement of these smaller stakeholders in research – the risk of failing to accommodate their needs is that this work will go ahead, but defined in such a way as to avoid governance scrutiny. In these cases, there is perhaps a responsibility on the part of the commissioning organisation to provide appropriate scrutiny, that is independent of the project commissioners and of the researchers. This kind of system could also be applied to internal research (and research-like) activity that does not entail any independent scrutiny – for example, by means of an internal panel that meets minimum agreed criteria.

#### **Message 8. A system of passporting**

- (a) The guidance 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 including:
  - GSRU guidance on research commissioning, and existing DfE and local authority guidelines; and
  - ESRC criteria for research ethics committees.
- (b) Guidance on passporting should specify accepted systems for:
  - external ethics review (e.g., NRES; organisational research ethics committees that meet ESRC criteria); and
  - independent scrutiny of research quality and competence (either through commissioning or through governance review, or through checks such as Criminal Records Bureau clearance).
- (c) Guidance should also specify minimum standards for independent scrutiny of research governance and ethics, for research activity which cannot be passported following external scrutiny.

## 5.7 Conclusions

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. Nonetheless, this guidance will come at a time when research in children's services – especially if broadly defined – takes on a vital importance, within a climate that prioritises evidence-based policy and practice, and which emphasises the rights of children and young people to have their voices heard.

- It seems critical that the guidance begins by highlighting the value of good research for children's services, 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.
- Moreover, in the context of the statutory requirements for consultation with service users within Children's Trusts, there is a need to ensure a broad definition of research, and for research governance arrangements to avoid defining children as inherent vulnerable, or lacking in capacity to consent – highlighting the researcher's responsibility to respect children's competences and so enable their participation. Research with children and young people necessitates particular considerations, but it is underpinned by core principles of research ethics that are common to any research.
- Research governance systems must be flexible and proportionate, to accommodate the variety of existing arrangements in local authorities, and the diverse needs of the stakeholders involved – researchers, research commissioners, and service providers – whilst ensuring that key governance principles of ethics, quality, independence and competence can be achieved.
- Concerns about quality must also accommodate the potential negative sequelae of disproportionate governance. The guidance should build on existing frameworks and guidance, and should explicitly require a system of passporting, to avoid duplication of review.
- It may be unrealistic to assume that any one system can be designed to capture the diversity of research and research-like activity, particularly given the relative autonomy of services such as schools, but a broad framework of minimum standards could offer a starting point that is adaptable to meet these diverse needs.

This report has drawn together information from a range of perspectives, encompassing the views of a variety of different professional stakeholders alongside academic and other literature. However, the main conclusions from this work are clear. To develop a coherent and transparent system of research governance that can be applied across the diverse, and increasingly integrated climate of children's services necessitates a simple, and flexible, approach – one that is based on clear principles, but which is flexible in its implementation around key minimum standards. New guidance may unlikely to capture every form of research-like activity involving children's services, and it should allow that 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 – for research in this field. As such, the development of guidance is a welcome beginning, and not an end-point.

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# Appendix 1: Information sheet and survey (MS Word version)



department for  
**children, schools and families**



Leading education  
and social research  
Institute of Education  
University of London

## RESEARCH GOVERNANCE ARRANGEMENTS FOR CHILDREN'S SERVICES

DCSF is developing guidance for the governance of research in children's services, and has funded research to inform that guidance, through scoping and consultation with key stakeholders. The project has Ministerial approval, and the support of the Association of Directors of Children's Services.

This survey is for Directors of Children's Services in local authorities. It addresses two key areas:

- information about your authority's existing arrangements for the governance of research in children's services;
- your views on the development of research governance for children's services.

For the purposes of this survey, research governance is defined as follows:

- (i) the principles, requirements and standards that apply to work defined as research;
- (ii) the arrangements to define and communicate those principles, requirements and standards;
- (iii) the delivery mechanisms to ensure those arrangements are met; and
- (iv) the arrangements to monitor quality and assess adherence to standards.

The aim of research governance is to improve research and to safeguard the public by: enhancing ethical awareness and scientific quality; promoting good practice; reducing adverse incidents and ensuring lessons are learned; and forestalling poor performance and misconduct.

(From Department of Health Research Governance Framework for Health and Social Care)

The survey represents an important opportunity to make sure that your views are taken into account in the development of research governance arrangements. It should not take more than 15-20 minutes to complete, but please contact the researchers directly if you have any questions or wish to comment in more detail on the planned developments. All survey responses and feedback from local authorities will be treated as confidential. Survey data will be stored safely and securely, and will be destroyed following the end of the project. All responses will be anonymised in feedback to DCSF. You can complete the survey on paper or securely online.

### RESPOND BY FRIDAY 13 NOVEMBER 2009

#### RETURN PAPER COPIES TO:

Dr. Janet Boddy, Senior Research Officer, Thomas Coram Research Unit, Institute of Education

Email j.boddy@ioe.ac.uk

Telephone 020 7267 3669

#### SECURE ONLINE VERSION:

[https://www.surveymonkey.com/s.aspx?sm=9PqMSGcVT\\_2figNE3klrW6hQ\\_3d\\_3d](https://www.surveymonkey.com/s.aspx?sm=9PqMSGcVT_2figNE3klrW6hQ_3d_3d)

## A. Your local authority

1. Name of local authority

2. Name of Director of Children's Services

Contact email:

Telephone:

3. Name of person completing form

Role in local authority:

Contact email address:

Contact phone number:

The next phase of work will involve in-depth consultation with stakeholders in four case study local authorities (selected to represent different authority types, geographical areas, and levels of research activity). Case study authorities will be anonymised in feedback to DCSF and other outputs from the study.

4. Would you be willing for your authority to take part in the case studies?

Yes

No

## B. Research in your local authority

The Department of Health Research Governance Framework defines research as 'the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods'. We would like to know more about research involving children's services in your local authority.

**5. Which of these research activities have taken place, involving children's services in your authority, IN THE LAST 12 MONTHS? (tick all that apply)**

- Analysis of individual case files
- Analysis of aggregated data
- Collecting information from users of services delivered by the local authority
- Collecting information from users of services contracted by the local authority (e.g. PVI services)
- Collecting information from relatives or friends of service users
- Collecting information from staff employed by the local authority
- Collecting information from staff employed by agencies or services contracted by the local authority (e.g. PVI services)
- Other desk research (give details)

**6. In the last 12 months, has your local authority been involved in any other research activities involving children's services, not included in the list above? (please give details)**

**7. Who has carried out research involving children's services in your authority, IN THE LAST 12 MONTHS? (tick all that apply)**

- Local authority staff
- Students based in local authority services (e.g. student social workers or teachers)
- University research staff
- University students (not based in local authority services) (e.g. psychology students)
- Researchers from independent organisations (e.g. market research or survey organisations)
- Independent consultants
- Don't know
- Other (give details)

**8. Who has funded research involving children's services in your authority, IN THE LAST 12 MONTHS? (tick all that apply)**

- Local authority
- Central government (e.g. DCSF)
- Other external bodies (e.g. charities)
- Other (give details)
- 

## C. Current research governance arrangements

Children's services are very diverse, and it is recognised that the division of children's services varies between local authorities, and so we want to learn more about how that works in relation to the governance of research involving children's services.

**9. Are there currently any systems of governance applied to research involving children's services in your local authority? (please tick one only, and give details below)**

- No current systems
- No routine systems – arrangements are specific to the service involved in the research (give details)
- Children's Services Directorate apply adult social care research governance systems
- Whole local authority research governance arrangements (e.g. local authority research unit)
- Other (please give details)

**10. Do any systems of governance apply to research involving independent (PVI) sector children's services that receive local authority funding (e.g. childminders, private nurseries, independent sector residential homes)? (please tick one only, and give details below)**

- No current systems
- No routine systems – arrangements are specific to the service involved in the research (give details)
- Same arrangements as described in Q9 above.
- Other (please give details)

**11. When a new piece of research is being undertaken involving children's services in your directorate, is there a named individual (or individuals) who would be notified?**

- Never
- Sometimes
- Always
- Not known

**12. If someone is notified (sometimes or always), then who would that be?**

- Specific to the service or providers involved in the research
  
- Named individuals responsible for each area of children's services (e.g. early years, schools, children's social care)
  
- Named individual(s) responsible for research governance in Children's Services Directorate as a whole
  
- Named individual(s) responsible for research governance in local authority as a whole
  
- Not known
  
- Other (please give details)

**13. Do the same arrangements apply to all kinds of research in children's services? (please give details)**

- Yes                       No                       Don't know

**E. Requirements for research ethics approval**

**14. Do you set any local authority requirements for ethics approval of research involving children's services?**

- Not known
- No current systems
- No routine systems – ethics approval requirements are specific to the service involved in the research (give details)
- Whole Children's Services Directorate requirements for ethics approval
- Whole local authority requirements for research ethics approval
- Other (please give details)

**15. What requirements are set for ethics approval of research involving children's services (please tick all that apply and give details below).**

- In-house ethics review systems
- Requirement for commissioner to check that independent ethics review has been carried out (e.g. by another institution's committee, such as a University ethics committee)
- Ethical issues considered as part of research commissioning process
- Not known
- Other (give details)

**16. Do the same ethics review requirements apply to all kinds of research activity? (please give details)**

Yes

No

Don't know

**F. Your views on the development of research governance arrangements for children's services**

**17. Is there anything you would like to change about current systems or processes in your local authority, specifically in relation to research governance for children's services? (tick all that apply, and give details below)**

- Timescales for research governance approval are too long
- Insufficient rigour in current arrangements
- Too many processes involved in current arrangements
- Too much variability in arrangements across the directorate
- Other (give details)

**18. What do you see as being the key strengths of your current arrangements for research governance in children's services?**

**19. What do you see as being the key barriers to research governance in children's services in your local authority?**

**20. How could these barriers be addressed in future?**

**21. What do you see as being key areas for further development in research governance in local authority children's services (nationally)?**

**22. What advice would you give DCSF about the development of research governance arrangements for children's services?**

**23. In developing arrangements for the governance of research in children's services, what would be your PREFERRED approach? (Please explain).**

**24. Any other comments?**

**Thank you for your help with this important project**

Please contact us if you would like to add any further comments, or if you have any questions about the work:

**Dr. Janet Boddy**  
**7612 6248**

**Email** [j.boddy@ioe.ac.uk](mailto:j.boddy@ioe.ac.uk)

**Telephone 020**

## Appendix 2: Case Studies Stakeholder Interview Topic Guide

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### Introduction:

- **Purpose of research:** Follow-up in more depth on survey, and learn from their views/experience. Not evaluating their arrangements, but aim to make sure that recommendations are sensitive to local authority contexts.
  - **Confidentiality:** Local authorities not named to DCSF. Will be written up as anonymised case studies. Offer to send interview note to participant to check.
  - **Outputs:** Report to DCSF with recommendations; DCSF will go on to develop guidance.
  - **Permission to record and data protection information.** (data stored safely and securely, separately from identifying information).
- 

### 1. Interviewee background

- Job title (from survey)
- Role and responsibilities: general, and in relation to research governance
- How long in role?

### 2. Research governance arrangements in your local authority

- More detail on survey description of current arrangements
  - Staffing and resourcing
  - Timescales and procedures
  - Probe for information about gatekeeping
- How much research and research-like activity those arrangements capture?

### 3. Managing the diversity of children's services

- How do those arrangements apply to:
  - **Different sectors** of children's services: education, early years, social care, anything else?
  - **Different providers** of children's services: local authority, voluntary sector, private providers?
  - **Integrated/cross-agency children's services/cross-agency working:** e.g. involving health.
- Is anything missed? What counts/does not count as research for those arrangements?

### 4. Examples of projects

- Can you give me some examples of research projects involving children's services in your local authority, and the governance or approvals they have been subject to?
- *Probe for:*
  - Ethics review/checks
  - Other research governance approval or review
  - Examples from different sectors of children's services, including integrated services
  - Challenges, as well as what works well.

### 5. Key issues in research with children

- How much of a priority is research with children in your local authority?
  - *Probe for examples*
  - What do you see as the **key barriers and facilitators** in relation to research involving children's services in your LA?

- Does your local authority have any systems – or use research – to include children’s views in the development or delivery of services?
    - *Probe for examples*
    - What do you see as the **key barriers and facilitators** in relation to including children’s views in the development or delivery of services?
  - What do you see as the **key challenges/concerns in relation to ethics** of research with children.
    - *Probe for how that applies across different sectors (e.g. education, social care)*
  - What do you see as the **key challenges/concerns in relation to other aspects of research governance** (e.g. quality, proportionality, gatekeeping).
    - *Probe for how that applies across different sectors (e.g. education, social care)*
6. **Advice to DCSF on development of arrangements for children’s services**
- Go over survey responses and probe for more detail:
    - Challenges and strengths in your local authority and what you would like to see change
    - Advice for DCSF
7. **Potential contacts for other interviews**
- Refer to survey responses about other organisations involved in research:
    - representatives of universities and/or independent research organisations that have been involved in research in your local authority.
  - Contacts in local authority:
    - local authority managers with responsibility for schools, early years provision, children’s social care, and/or parenting and family support;
    - representatives of settings/service providers that have hosted research in your local authority – e.g., schools, early years provision, children’s social care, and/or parenting and family support;
8. **Any other comments or issues?**

*Record interview duration and anyone else present*



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