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Meeting Children's Needs for Care and Protection

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Meeting Children's Needs for Care and Protection

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1. Overall aim of the seminar series

The core aim of the series was to draw together national and international knowledge and professional, policy and research expertise in relation to the management, evaluation and research of everyday multi-professional intervention to safeguard children. It comprised two linked elements. The first focused on the issues involved in using administrative data routinely collected on children safeguarded in the community to better inform planning and delivery and research. The second focused on the methodological issues in designing a longitudinal study that can effectively explore the complex and multidimensional nature of intervention taking account of contextual and process elements.

a. Leadership and participation

The organisation and delivery of the series afforded opportunities to identify leaders within the field and to open up possibilities for further knowledge exchange and collaboration. In preparation for the seminars, contact was made with a number of organisations and projects who are involved in innovative projects internationally and across the UK. The seminars themselves were well attended, and included participants from the academic, public and voluntary sectors who were working in practice, policy and research roles. The strength of the mix of participants and that they brought a multi-disciplinary dimension to the discussions together with multiple perspectives and complementary insights on the collection, analysis and use of data.

The programme team drew on and extended upon the research working group of the Scottish Child Care and Protection Network (SCCPN). SCCPN brings together stakeholders from the academic, public and voluntary sectors to work collaboratively to ensure that child care and protection practice is supported by the best possible evidence. SCCPN supports the dissemination of research evidence from national and international sources and promotes the generation of new evidence to fill gaps in knowledge. SCCPN is merging with the Multi-Agency Resource Service (MARS) to create a Scottish hub for child care and protection.

The series has resulted in fostering new links between different fields and networks in pursuit of improving data collection and use, in addition to widening opportunities for future collaborative research and development activities. See Table 2 for an overview of proposals and outputs, which includes information on links that have been made.

b. Main questions and objectives

The seminars addressed two overarching questions with associated objectives:

1. What needs to be in place to ensure that data that is routinely collected about children and families on a national and local basis can be collated, linked and used to improve operational decision-making and planning, and as the basis for longitudinal research into outcomes for children? Objectives to address this question were:
 - a. the production of a structured data-mapping and linkage model that will facilitate the maximum use of routinely collected data on children and families to gauge outcomes of intervention,
 - b. the development of a model for data-linkage on a national and local basis that will form the bed-rock for a number of research and internal evaluation projects,
 - c. the creation of an ethical framework that would be acceptable to health and social care ethical bodies.

2. What are the core constituents of a robust longitudinal design that would be fit for the evaluation of the efficacy of everyday professional intervention aimed at improving the lives of vulnerable children?

Objectives to address this question were:

- a. the distillation of learning from previous longitudinal studies to create the foundations of a robust design,
- b. the collation of information about the most appropriate measures to capture everyday intervention and child well-being,
- c. the development of a robust analytical package for a longitudinal study.

2. Seminar structure and content

Full details on all the agendas, speakers and topics covered, as well as links to the presentations and associated podcasts, can be found in Appendix 1. More detailed exploration of the content and discussion emerging during the seminars is captured in the later section on 'Emergent themes', on pages 11 to 17.

a. Seminar 1: Data linkage and mining: vision, possibilities and practicalities

The first question was the focus of a three-day seminar on March 9th, 10th and 11th - "*Data linkage and mining: vision, possibilities and practicalities*". This seminar considered the specifics of the Scottish context; achievements from other countries; and the methodological, ethical, legal and practical challenges of maximising the use of routine data collection. The aims of the days were to:

- bring together national and international experts in mapping and making effective use of existing data-sets relating to child well-being in a range of disciplines,
- explore practical and technical issues involved in cross-referencing data on a population-wide basis and in relation to vulnerable groups of children within the population,
- note the ethical issues involved in making use of routinely collected data for research and evaluation purposes.

The first day's programme - ***Creating a vision*** - was intended to stimulate discussion and consensus building regarding the *value* of administrative data for research and evaluation purposes.

Janice McGhee, University of Edinburgh, introduced the seminar, then **Fiona Mitchell**, Coordinator, SCCPN, drew together messages about the potentially positive Scottish context for increasing data linkage across agencies for research and evaluative purposes. It was highlighted that Scotland's scale - its population size, its geographical boundaries, and its relatively small number of administrative areas (32 local authorities; 8 police forces; 14 regional health boards) – represents an opportunity for dialogue and coordination of activity, as does the proximity that exists between central and local government. Recent Scotland-wide policy initiatives – the introduction of the *National Performance Framework*, *Single Outcome Agreements*, and *Getting It Right For Every Child* – also offer frameworks that can be used to unite different stakeholders' in their objectives and in their methods for the measurement of progress to achieve those objectives. Phil Raines, Head of Child Protection Policy Team, Scottish Government drew attention to our need to make sense of interaction of different issues in creating risk and vulnerability for children, and the interaction of agencies in meeting the needs of children and families, and its implications for the longer term in children, families and communities lives.

Mansoor Kazi, University of Buffalo, presented examples of using administrative data and linking data across agencies within a single administrative area: Chautauqua County in New York State. Using data from education and health agencies, he illustrated the potential for exploring the inter-relationship between outcomes, client demographics, client circumstances and services provided. He emphasised the importance of working closely in partnership with agencies to interrogate their data. This can increase the commitment to ensuring accuracy in the data and to the use of data linkage more generally.

Melissa Johnson Reid, Washington University in St Louis, drew on her experience of three large scale initiatives that have linked administrative data to illustrate possibilities for child protection research and to highlight factors to consider in the development of a data linkage project. She drew on examples of developments that connected existing information systems and those that constructed new integrated information systems for the purposes of data extraction, linkage and analysis. She highlighted a number of 'do's' and 'don'ts' to consider when developing or using data systems for multiple purposes.

Delegates discussed the levels of consensus and commitment to the development of a model of cross-sectoral data linkage and how progress towards that goal could be achieved.

The second day - ***The current state of play: garbage in, garbage out?*** – presented an opportunity to consider what data exists at local and national levels, and the value it has for strategic planning and evaluative purposes. **Paul Rigby**, Researcher, Glasgow City Council presented on the current data collection and linkage in Glasgow Child Protection Committee area, and highlighted the wealth of data that is available but under-used. **Morag MacNeil** and **Bob Stradling**, University of Edinburgh, reflected on the use that they had made of routine data during the course of the *Getting It Right for Every Child* Pathfinder evaluation, and presented a model for using case data for a number of purposes that reported on progress for children according to the GIRFEC well-being indicators. **David Derbyshire** and **Fiona Steel**, from Action for Children, explained the development of a national outcomes framework for monitoring and evaluation also based upon the GIRFEC well-being indicators. **Rikke Iversholt**, IRISS, presented on the development of a data visualisation tool to provide examples of displaying administrative data pictorially and graphically.

Delegates then mapped out what they considered to be the core data necessary for tracking outcomes for children and discussed what is available and what gaps need to be filled.

The third day looked at ***The possibilities and the practicalities***. **Beth Smith** (MARS) drew together key messages to have emerged from the previous days, including the need for a strategic approach, coupled with the involvement of front-line practitioners. She emphasised the importance of maintaining the momentum of this initiative. **Steve Pavis**, Information Services Division (ISD), NHS presented on the role of ISD and the development of the infrastructure for data linkage (administrative and research data) as part of the Scottish Health Informatics Programme (SHIP). SHIP, as it stands, provides a structure that allows for the safe linkage and the safe usage of multiple datasets from different sources. The programme has created an indexing process that protects the anonymity of data while also maximising accuracy in the matching of data from different systems. It has developed safeguards for data usage by putting in place parameters for the approval of researchers, by limiting access to data via 'dumb terminals' only and by checking the outputs of data analysis to ensure that anonymity is protected. **Graeme Laurie**, University of Edinburgh presented the governance framework for SHIP that takes account of ethical and legal implications of data sharing and data linkage for research and evaluation purposes. **Phil Anderson**, Australian Institute of Health and Welfare, drew on work undertaken to demonstrate the feasibility of linking different national administrative datasets. He described the key role that the Institute, as an independent body, can play in undertaking large data-linkage projects to enable data to answer important questions. Examples included

the analysis of data to understand the operation of (multiple) pathways to receiving help that children and families experience or the educational outcomes for different groups of children subject to child protection orders (see box). **Gary Sutton**, Scottish Government, described the Children Looked After Survey (CLAS) whereby aggregate local authority data returns on looked after children have been replaced by individual level collection. The inclusion of the Scottish Candidate Number (SCN) in the dataset allows 100% linkage with the national data return on children's education. There are plans, also, to eventually link CLAS with the planned national returns of individualised child protection statistics (see box).

Understanding educational outcomes of children on guardianship or custody orders

This project responded to a gap in knowledge about the educational outcomes of children placed in child protection services in Australia. It looked at the academic performance of children on guardianship/custody orders across 2003 to 2006, changes in their performance over this period and where possible compared the academic results of children on orders with those of other children. In addition to providing baseline data on children's participation and achievement of benchmarks in standard reading and numeracy educational tests, the study's utility to the development of policy and practice is evident in its presentation of the following key findings:

- Children on guardianship/custody orders performed worse than all children, with outcomes similar to the general population of Indigenous children.
- Children on orders experienced diverse academic pathways over time.
- Indigenous children on orders were half as likely to achieve benchmarks as other children on orders.
- Length of time on orders was not a significant factor in benchmark achievement.
- Older students were less likely to achieve national benchmarks.

The project involved interdepartmental linkage of data across multiple jurisdictions, and as such involved collaboration between the education and child protection departments within each of the five participating jurisdictions. Detailed state level data was also available for each jurisdiction.

Australian Institute of Health and Welfare (2011) Educational outcomes of children on guardianship or custody orders. Australian Institute of Health and Welfare, Child Welfare Series 49.

Educational outcomes for Scotland's looked after children

In line with a policy priority of the Scottish government, an annual statistical publication reports on looked after children's attendance, exclusion and attainment (based on an accumulative score of the different course levels and awards attained - Scottish Tariff points system). The first publication (issued 2011) about looked after children in 2009/2010 identified:

- The overall school attendance rate for looked after children was 87.8% compared with 93.2% for all school children. School attendance rates were lowest for those looked after at home.
- The overall exclusion rate for looked after children was 365 per 1000 looked after children, compared with 45 exclusions per 1000 pupils for all school children. Exclusion rates were highest for those looked after in a local authority home (866 per 1000 children)
- The average tariff score for looked after children who left school during 2009/10 was 67, compared to 372 for all school leavers. This is influenced by the fact that around 90% of looked after children who left school during 2009/10 were aged 16 years or under when they left school, compared to only 37% of all school leavers being aged 16 years or under when leaving school.
- At the time of the initial destination survey of school leavers, 59% of looked after children compared with 87% of all school leavers in 2009/2010 were in a positive destination. Whereas at the time of the follow-up survey, the percentage of school leavers in positive destinations dropped to 44% for looked after children and to 85% for all school leavers.

The analysis of these patterns has only been possible as a result of linking looked after children's data provided by local authority social work services departments with educational data provided by publicly funded schools, the Scottish Qualifications Authority (SQA) and Skills Development Scotland (SDS).

Scottish Government (2011) Educational outcomes for Scotland's Looked After Children, 2009/2010. Statistics Publication Notice, Health and Care Series.

In small groups delegates considered a strategy for overcoming barriers to enable the promotion of linkage of datasets and facilitating better use of data for the benefit of vulnerable children in Scotland.

b. Seminar 2: Design and methodology in longitudinal research: scope, approach and practicalities

The second two day seminar held on April 20th and 21st - "*Design and methodology in longitudinal research: scope, approach and practicalities*" moved the focus to longitudinal design. It considered methods for capturing the nature and intensity of routine practice, exploring what outcomes measures are required in addition to the routine data as explored in seminar one and discussed the practicalities of setting up and sustaining longitudinal research with vulnerable populations. The aims were to:

- bring together national and international experts in designing, implementing and undertaking longitudinal studies,
- engage in detailed exchange about the type and range of data that is required to capture fundamental aspects of everyday intervention and child well-being,

- learn from existing successful studies about effective statistical and analytical analysis of the impact of intervention upon outcomes.

The first day's programme - ***Longitudinal research: key design issues*** - explored methodological and practical issues in developing a longitudinal study of vulnerable children in state protective systems including consideration of intervention, services and child well being outcomes. **Brigid Daniel**, University of Stirling, introduced the day and outlined the potential of routinely collected data for longitudinal analysis of outcomes for vulnerable children while recognising the limitations including the lack of information that would allow a full picture of intervention and outcomes.

Paul Bradshaw, Scottish Centre for Social Research, the home of the Growing Up in Scotland Survey and **Stephanie Lalonde**, National Longitudinal Survey of Children and Youth (Canada) both outlined key lessons for longitudinal research design drawing on their respective experience. **Ruth Gilbert**, Institute of Child Health, University College London, illustrated the use of routine health care data to understand patterns of child maltreatment and the potential additional explanatory power of linking to cohort data. **Lucy Thompson**, Public Health Resource Unit, NHS Greater Glasgow and Clyde discussed the population wide use of a standardised tool, the Strengths and Difficulties Questionnaire (SDQ), as part of an evaluation of a parenting support programme.

In the workshop participants discussed the relevance of a longitudinal study of vulnerable children in state protective systems and explored the key elements in the design and management of such a study. Sampling frameworks, data to be collected on the child and family, practicalities in setting up and sustaining longitudinal research with vulnerable populations, ethics and consent, the extent of qualitative data collection and approaches to analysis were discussed.

The second day - ***Defining core elements to quantify routine intervention and measure child well being*** – provided an opportunity to begin to explore the definition of outcomes and the classification of routine multi-professional intervention. Lorraine Waterhouse, University of Edinburgh, outlined the purpose and aims of the day.

Lisa Calderwood, **Millennium Cohort Study**, provided an overview of design and methodology issues focusing on data gathered and child outcome measures utilised. **Emma McWilliam**, Social Care and Social Work Improvement Scotland (SCSWIS) outlined the multi-agency inspection methodology including the use of case files to analyse professional practice and interactive technology to gain children's views. The presentation highlighted the potential for inspection methodology to inform the design of longitudinal research (and *vice versa*) and for greater congruence between inspection and research activity. **Alison Jaconelli**, Strathclyde Police Public Protection Unit, explored strengths and barriers in gathering data on police interventions and outcomes. **Marian Brandon**, University of East Anglia, drew out key lessons from a longitudinal follow-up study of children living with significant harm. In the workshop participants discussed the most effective methods for capturing the nature, intensity and focus of routine multi-professional practice and measures of child well-being outcomes from multi-disciplinary perspectives.

c. Seminar 3: Consolidating collaborative partnerships: sharing and applying knowledge

The final two day seminar "*Consolidating collaborative partnerships: sharing and applying knowledge*" was held on June 21st and 22nd. Two briefing papers based on the earlier seminars were provided for the first day for discussion with an invited wider audience. This was followed by a full-day workshop for the team on June 22nd to identify next steps and action plans for wider dissemination of the knowledge captured.

Academics from other parts of the UK were invited to the first half of this meeting to discuss the potential for developing a UK-wide collaborative research project. The aims of this seminar were to:

- present examples of what has already been achieved in Scotland,
- set out a vision of what could be further achieved in Scotland with consensus to take forward a national strategy,
- begin to shape a strategic plan to promote better information and research for better child well-being in Scotland.

The seminar was introduced and chaired by **Jacqui Roberts**, the interim Chief Executive of Social Care & Social Work Improvement Scotland (SCSWIS) who, in her introductory remarks indicated that SCSWIS will be looking for robust and meaningful management information to be returned to them during the course of their scrutiny activity.

Steve Pavis, (ISD) returned and started by describing the National Information Strategy (NIS) for health and social care which is likely to run from 2012 – 2016. NIS is a national initiative to establish information priorities for health and social care to support service planning, performance management, research and audit. Steve again described SHIP in which there had been considerable interest at a previous seminar. SHIP provides a robust model for secure linkage of data from different datasets which is already answering questions in health and is beginning to address cross-sector issues. Most of the interest to date has been in older age but Steve considered some specific information priorities for children and young people and reminded us of key *Scotland Performs* high level outcomes for children, including:

- we have improved the life chances for children, young people and families at risk.

Nayha Sethi (Research Fellow, School of Law, University of Edinburgh) used SHIP as an example of a good governance structure in which, again, there had been considerable interest at a previous seminar - the guiding principles and best practices for SHIP governance are available from the SHIP website. Nayha emphasised the importance of proportionate governance. The aim is to balance the public interests that are served by data sharing with the protection of privacy and confidentiality.

Chris Dibben (Lecturer in Health Geography, University of St. Andrews) described the Scottish Longitudinal Study (SLS) which is a large-scale, anonymised linkage study designed to capture 5.5% of the Scottish Population based upon Census data, Vital Events data, National Health Service Central Register data, NHS data and Education data. As yet, SLS does not have access to social care data to enable 100% linkage.

Elaine Farmer (Professor of Child and Family Studies, University of Bristol) offered insights from a study of the reunification of looked after children with their parents (Farmer *et al.* in press; Farmer and Lutman, 2010). The findings on outcomes that Elaine presented gave a vivid illustration of what can be learned from longitudinal studies and their value for developing messages for policy and practice.

The final presentation was from **Fiona Mitchell** (SCCPN co-ordinator) and **Janice McGhee** (Senior Lecturer, University of Edinburgh). Fiona used the GIRFEC and Curriculum for Excellence combined model as a basis for mapping what data is already potentially available to shed light on child wellbeing on all indicators and where the gaps are. Janice synthesised the material from the previous seminars about longitudinal studies and identified the key design issues. Both identified the benefits of a national minimum dataset that could form a valuable core of data about child well-being.

Towards the end of the afternoon participants formed smaller working groups to discuss ideas for what could be done next to take the issues forward.

On the second day **John Devaney and Trevor Spratt** (Queen's University, Belfast) presented a summary of their ESRC funded study exploring the feasibility of linking census data with social care data. The objectives of their study is to assess: practicability of combining the datasets; the accuracy and quality of the data; and the applicability of combined dataset to addressing questions on long-term multiple and complex needs. It was agreed that there was huge potential in developing a four UK nation collaborative approach towards longitudinal research that builds on routinely collected administrative data, supplemented by additional data collection. This collaboration will be taken forward by the SCCN research sub-group.

3. Emergent themes

a. Administrative data and data linkage

i. Data consistency and utility

The seminars helped to distinguish between data flow and data collection. There has been a lot of activity aimed at improving data flow within and between agencies to support the delivery of services to individuals and to manage performance. For example, there are 14 data sharing partnerships in Scotland established to facilitate delivery of better services within the eCare framework. They have established a raft of protocols for sharing health and social care data about individuals to support service delivery. Similarly the *GIRFEC* team is developing a national information sharing protocol – the Inter-Agency Communication Tool (IACT) which is currently sitting with e-health. IACT also supports the exchange of information in relation to individual case management. At the moment, neither of these initiatives stores or captures data for use in evaluation or research, however, the ethical protocols and the practical mechanisms developed to enable different systems to 'talk' to each other in relation to individuals could provide helpful pointers for research.

The Improvement Service – a partnership between the Convention of Scottish Local Authorities (COSLA) and the Society of Local Authority Chief Executives (SOLACE) - was set up in 2005 to help improve the efficiency, quality and accountability of local public services in Scotland by providing advice, consultancy and programme support to councils and their partners. They aim to do this by:

- encouraging councils and their partners to work together and helping them reap the extra benefits that come good partnership working (collaborative gain);
- identifying and sharing best practice from the public, private and voluntary sectors in the UK and internationally;
- providing learning and development opportunities to elected members, senior management and officers and
- promoting the use of knowledge management within local authorities to support knowledge sharing, learning and business redesign.

The Improvement Service is likely to have a key role in promoting consistency and quality in the collection of (administrative) data that can support the evaluation of public service delivery.

Multiple factors influence what data is collected and retained, and how it is collected. Single agencies record data for different purposes, such as case management, operational planning and for national statistical returns. Software, and its lack of adaptability or the cost of adapting it, has an influence on what is collected, how it is collected and what use is made of it. Over the seminars there was a consensus that a wealth of data is collected but that it is not used as much as it could be - within single agencies or between agencies – at either local or national levels.

There are differences between, and diversity within, local authorities, health boards and police forces in their approaches to data recording, management and use. It is not evident that there is a shared sense of ownership and understanding of the value of data for learning about the effectiveness and efficiency of services. Too often data collection can be perceived to be a bureaucratic exercise. Contributors noted developments and the progress towards better data management within health agencies and the police forces and highlighted a need for a cultural shift within local authorities in particular. National projects and central government were identified as important players in promoting consistency of data collection within single disciplines.

That data is not used to its full potential can have a demoralising effect as the burden of recording appears to be disproportionate to the return. This in turn can influence the level of commitment to accuracy and consistency in data recording. Jacqui Roberts was very clear that SCSWIS would not add just another layer of data collection. Similarly, it was reported that the national convenor for Children's Hearings is also sympathetic to not gathering a wider range of data but making better use of what is collected. It was considered critical that practitioners and managers are involved in defining and developing the criteria and measurements for data recording and collection, and in interrogating and using the data for service design, development and evaluation. With increased understanding, it was argued that there would be greater ownership and commitment to improving the quality of data recording.

National data definitions may be a way to promote consistency and guide data recording across agencies and across geographical areas. Examples were shared of efforts to establish and maintain consistency of data collection across agencies and areas – Australia has an agreed minimum dataset and 'data dictionaries' that operate on a statutory basis across all services and states/territories (<http://www.aihw.gov.au/data-standards/>). A mandatory requirement for specific data, that is clearly defined, was identified as enabling. The progress achieved in relation to the evolution of the looked after children data return was cited as an example of how central government can positively influence data collection at a local level. In England June Thoburn is leading a project as part of the Munro review aimed at creating a core minimum dataset in relation to all children.

ii. Data linkage

Different agencies hold data that offers some information on different aspects of children's development, especially in health and education domains. However, in order to gain a more holistic picture of children's development these different datasets need to be linked. There are different ways to link datasets. Different agencies assign numbers to individuals, for example, for health services everyone is assigned a unique Community Health Index (CHI) number and for educational purposes all school children have a Scottish Candidate Number (SCN). Where two different datasets include the same unique identifier it is possible to make a 100% linkage, albeit with clear safeguards. For example, SHIP has a secure indexing service that can link datasets using the CHI number without releasing it to the researcher. Mansoor Kazi attained 100% by using a school identifier which is shared with the support service as long as parental permission is granted.

Where there is no common unique identifier across the datasets it is possible to use 'probabilistic' linkage using demographic data, typically such linkages use date of birth, gender, and some letters from the surname and given name. Good percentages of linkage can be attained with this method. During the seminar potential shared unique identifiers were suggested – including the CHI, National Insurance numbers, and identifiers established by the work for the eCare Multi-Agency Store. There were perceptions that technical challenges are more easily surmountable than the ethical challenges relating to data usage and linkage. The work undertaken by ISD and the Scottish Health Informatics Programme on Guiding

Principles and Best Practices could provide the foundations for the linkage of data across different disciplines.

iii. Key gaps

Key gaps identified in existent administrative data were perceived to be the lack of consistent measurement of:

- the nature and intensity of services provided,
- children's development and well-being at regular intervals,

thus information to describe intervention and to gauge outcomes is sparse. Health and education data will include some information about treatment or services provided; but qualitative information is not routinely collected and social care information about service provision is limited. It may be possible to codify some aspects of service provision and incorporate this information within routinely collected data.

In relation to outcomes, it was agreed that Getting It Right for Every Child offered a framework for multi-disciplinary measurement of children's well-being in key domains. The evaluation of the Highland Pathfinder demonstrates an approach for collating existing data, incorporating well-being indicators, which can be operational at an individual (case management) and aggregate (evaluative) level. Voluntary organisations, including Action for Children and Aberlour, have developed frameworks for monitoring and evaluation that attempt to establish measurements for the GIRFEC wellbeing indicators as part of routine practice.

There were broader questions about whether what is collected anyway is the most useful for providing insights into the *onset* of potential problems for children, regardless of whether it is linked with anything else.

iv. Conclusion

Harnessing the knowledge of practitioners, managers, policy leads, researchers and analysts *together* will enhance the feasibility and functionality of data recording and collection systems, and reduce duplication of data collection and improve approaches to measuring and recording information about:

- the demographic characteristics and circumstances of individuals using services;
- service provision;
- the well-being of children in receipt of services.

All wish to understand better what works for whom, and in what contexts, so that service responses can better meet the needs of all children and young people. If consulted, practitioners and managers would be well best placed to identify *what* it is important to know for practice, and researchers can consider *how* to construct data fields and measurements that can be aggregated and used also to support evaluation and research.

It was clear from the seminar that there are some research questions that cannot be answered with routinely collected administrative data alone. Sometimes it will be necessary to supplement it with additional data collection, especially about the qualitative aspects of service provision. However, there was consensus that routinely collected data potentially offers a solid platform upon which to build.

b. Longitudinal design

i. The need for longitudinal research

A longitudinal study is required to track the journey of vulnerable children through formal systems of support and protection, explore short-term and longer-term outcomes and evaluate the efficacy of everyday multi-professional intervention aimed at improving children's lives. Researchers, policy makers and professional participants contributed to robust discussion of the relevance of, and methodological issues in, developing such a study. In relation to service provision, there was some consensus that much less is known about routine practice with children and families as opposed to specific, 'manualised' interventions. A longitudinal survey of children in state protective systems has the potential to evaluate the effectiveness and outcomes of routine practice or '*service-as-usual*' (i.e. everyday multi-professional intervention of all services involved with children known to social work) and in this way make a significant contribution to policy and operational evaluation and development.

There are core constituents that need to be considered in designing a longitudinal survey of this vulnerable population of children. These include a sampling and collection strategy: which data to collect, on whom, and when the data should be gathered. Decisions on depth (multi-method, intensive data collection) versus breadth (sample size and representativeness) of data collection are required. Resources (costs) as well as methodological considerations will influence these decisions. A robust analytic and statistical package needs to be incorporated into the research design from the outset. A minimum of three sweeps is generally required for a study to be classed as longitudinal. Defining the central question to be addressed by a longitudinal study is the starting point.

ii. Sampling frameworks

Sample size has to be sufficiently large to answer the central question and to deal with non-response attrition over longer time periods. A key decision is sample selection; given the porous boundaries of children's difficulties and their status in child welfare systems a wide sample of cases known/allocated to social work may be best. Whether non-allocated cases should be included as a comparison remains open for discussion. A longitudinal study of children in state protective systems is by definition a 'high risk' group and this points to a within groups analysis.

Comparison of an allocated and non-allocated social work cohort drawing on administrative data where there is some systematic variation between areas (local authorities, jurisdictions in the UK) could allow some exploration of the reasons for differences and may provide some information about intervention.

There may be some potential to compare developmental outcomes with sub-groups within other UK child cohort studies (the Millennium Cohort Study (MSC) strata of disadvantaged children was the 25% most poorest) while in the Scottish Longitudinal study at any one time there are around 5000 0-15 year olds in the most deprived 10% of data zones in Scotland.

iii. Attrition

Attrition is a significant problem. In child cohort studies, higher dropout is associated with social and economic deprivation, a common background feature of children involved in public child welfare systems. There was some discussion about these 'shadow' groups of the most vulnerable children who are the most likely to fall out of any data collection systems. The data cleaning system for SLS entails discarding cases where there are too many missing data fields, for example, if a child apparently disappears from a family –

these could be the individuals that we are most keen to know about. SLS, though, could re-consider this approach.

Potential solutions may include the utilisation of financial incentives (temporal incentives in particular) to support participation. There are other tried and tested methods to maintain interest in longitudinal studies – from birthday cards, competitions for children (e.g. to have a drawing in a calendar) to regular information bulletins. Literacy needs to be considered and easy-to-read formats can be used. A method to track closed cases needs to be built in from the start: the electoral register (and other administrative databases) or the use of ‘stable contacts’ has proven effective. Administrative data might provide a solution to exploring some outcome data on ‘non-returners’ and would also provide a retrospective ‘event’ history in system contact terms.

iv. Capturing Intervention

The term ‘intervention’ can be rather misleading because it is very broad and can conflate issues such as the delivery of specific services, the nature and quality of engagement and relationship-building, the adoption of a particular approach (for example, ‘solution-focused’ or ‘cognitive-behavioural approaches’) and the provision of a therapeutic programme (for example, ‘Incredible Years’). Elaine Farmer suggested that child and family characteristics may emerge as more powerful than services and case *management* variables may be more likely to be linked with outcomes than specific services. The typology of case management that they developed could be adapted for use in other studies. Having noted this, though, there were many encouraging pointers from the seminars.

There are trade-offs between depth and breadth and for a large longitudinal study broad categorisations should capture ‘service as usual’ sufficiently well for statistical analysis. Larger sample sizes offset some of the nuanced differences at individual level. Developing a straightforward tick-box/pro-forma survey form categorising services may be the most effective approach at the macro-level for quantitative analysis. Any categorisation needs to be informed by services known to be effective from current knowledge (including any randomised control trials, generally of manualised programmes). The nature and intensity of engagement needs to be captured alongside the focus of intervention (child, mother, father, sibling). These need to take account of the differing professional disciplines and context. Inputs and outputs including the use of formal legal and administrative authority (such as child protection registration) also need to be included in any data collection to provide the fullest picture. These may be most reliably accessed via administrative data.

Data collection from parents/persons with most knowledge about the child can provide good information about effective intervention (‘help’ was suggested as the better term) including assessment of the quality of relationships. This would also improve the collection of direct information about social and personal contextual variables.

v. Defining Outcomes

The term ‘outcome’ can also be somewhat misleading because it implies an endpoint, whereas development is continuous and cumulative. It is applied inconsistently to the short, medium and long term and it also implies, albeit subtly, a causal link with the service provided or under scrutiny. The discussions in the seminars helped to clarify that the key requirement is for access to information at regular intervals about children’s progress and well-being in all developmental domains. Child well-being measures need to provide a holistic perspective that captures the child in their social environment.

Existing data is accessible via administrative data and although somewhat rudimentary is useful, for example, giving information on school attendance, additional support needs, injuries (HES), chronic illness, mental health, health checks for all in looked after children (LAC) data. Such data can be supplemented by *standardised measures* and complement others studies, including the Strengths and Difficulties Questionnaire (SDQ) (this measure is used in the MCS and Glasgow Parenting Project); measures of cognitive development (assessments of numeracy, language, colours, such as the Bracken School Readiness Assessment); and physical growth and development measures. Any tests chosen need to be easily administered and scored. Self-completed questionnaires for children (pencil paper/computerised such as Viewpoint, which is used by a number of local authorities) can be effective. In-depth qualitative information can be captured from an *overall assessment* by practitioners of the child's well-being in broad terms.

These measures can provide a cross-sectional picture of how a child is at any point and, over time, can show changes. They can be used as 'scores' in statistical models to compare different types of service input or to consider relative wellbeing compared with what might have been expected with no service input. They can also form the basis for comparison between groups of children. Access to comprehensive information about children's well-being at regular intervals would also be enormously valuable for practitioners.

In addition data tends only to be gathered on citizens who receive services and this may not represent the community presence of problems (for example maltreatment); it is harder to capture positive outcomes, as there are no later system contacts; and data gathering primarily orients towards key performance and system indicators rather than specific outcome data. There is growing recognition of the potential to link longitudinal survey data with administrative data to populate gaps and to examine outcomes for children more comprehensively.

vi. Consent

There are two main forms of consent – 'opt-in' where potential participants are asked to actively agree to participate (used, for example, in GUS and MCS) and 'opt-out' where consent is assumed unless potential participants actively state that they do not consent to participate. Participation is achieved in child cohort studies through direct contact by the research team, generally via the provision of names and addresses to the team by public authorities (e.g. child benefit records). Consent also includes consent to access administrative records (for example health, education) of the child, parents and siblings. Linkage is not straightforward and all levels (deterministic, probabilistic and manual) are likely to be required. There is discussion as to whether consent needs to be continuously sought in longitudinal research rather than a one-off process. Children's consent to data-linkage raises temporal as well as ethical issues. Access to parental administrative data, such as health records, economic records or past involvement with state child welfare agencies would provide additional contextual information but may be difficult to gather due to confidentiality concerns without direct consent.

vii. Conclusion

There is a consensus that longitudinal research to evaluate the effectiveness and outcomes of 'service-as-usual' is important. Data-linkage of administrative data has some limitations and crucially cannot provide sufficient information on the nature, intensity and focus of service delivery and intervention more broadly. The general absence of data on intervention in child welfare services was a key theme to emerge from the seminar. There could be merit in linking a longitudinal survey with administrative data.

4. Next steps

The full set of recommendations and outputs to date are summarised in Table 2 at the end of this section.

a. Opportunity to maintain the momentum

During the course of the seminars we heard examples of what can be achieved in data linkage and in longitudinal design. Based on the presentations and discussion we are convinced that longitudinal tracking of the effectiveness of service provision to vulnerable children over the longer term for both research and operational purposes will be greatly facilitated by better use of existing routinely collected data, better linkage of different datasets relating to different aspects of well-being, greater commonality of data fields collected across all local authorities and the establishment of a national minimum dataset.

We are also convinced that there is now sufficient evidence from existing national and international models of governance, data linkage and longitudinal design upon which to build an effective model for Scotland. It is clear that a minimum dataset would not provide the evidence required to answer all the questions that might be asked in longitudinal research. However, if existing data can be used more effectively, research designs can then focus on what additional information is needed in relation to specific research and evaluation questions. Indeed, during the seminars there the view that it was a moral imperative to use data better was expressed.

It was evident from the seminars that there is an enormous amount of activity being undertaken in relation to both data management and longitudinal surveys. Some of these activities are linked and cross-referenced, but some appear to be operating in parallel. During the course of the seminars we identified some key data repositories, projects and activities of relevance to the aims, some generic and some child-specific. In our view, any further developments in relation to the specific needs of vulnerable children should be embedded within these wider initiatives; however, it is our observation that placing a sharp focus on the needs of children can help to explain the *point* of making better use of data. Whilst there is merit in developing projects at local level there was a clear view that there is also a need for a national approach.

We recommend the immediate formation of a small working group that would build on the momentum generated by the seminars. Ideally, the group would be chaired by Scottish Government, and comprise representatives from the range of relevant initiatives identified at the seminars. The group would *not* establish a new layer of data gathering, rather it would aim to map and refine current data collection activity.

b. Opportunities to build a core children's data-set

At a generic level the Improvement Agency is currently mapping what data is available to illuminate progress in relation to the national performance framework. This parallels some of the more specific mapping work that is being undertaken in relation to GIRFEC. The GIREC team are undertaking a mapping exercise, based on the one undertaken for the pathfinder evaluation, to identify available data in relation to the SHANNARI outcomes. Building on the concept developed by the GIRFEC evaluation team we have mapped what is currently available on a national basis against the GIRFEC outcomes and SCCPN will continue to develop this mapping process (see Table 1).

Table 1 Child-level data returned on a national basis

Indicator	Systematically collected
Safe	SCRA referrals and hearings data Children looked after return (CLAS)
Healthy	Health data returns and information systems
Active	Health data returns and information systems
Nurtured	SCRA referrals and hearings data
Achieving	School and pupil census School leaver destinations survey
Respected	
Responsible	
Included	School and pupil census School leaver destinations survey Children looked after return (CLAS)

There is, already, a core set of data about all children in Scotland contained within the local data collection systems of the universal services, some of which is also subject to national returns and collation. In particular the ISD health dataset contains a number of relevant fields, for example, information on antenatal care and on immunisations. SHIP has also established a robust model for data linkage based on a set of core principles. This existing data forms the basis of a minimum dataset about children. The 14 data-sharing partnerships have developed protocols for matching fields and linking data in relation to individuals for service planning and there could be useful learning from that project about ways to facilitate field matching.

We recommend that in Scotland we should consider building on this existing data, especially that held by ISD, to develop it into a consistent minimum core data-set. Ideally it would be helpful if there could be agreement to include the same unique identifier across health, education and social care.

The National Information strategy provides one opportunity to take this forward and following the seminars SCSWIS is now represented on the NIS strategic oversight group.

We suggest that there is merit in the Scottish Government liaising with the Munro review sub-project to consider opportunities for congruence with their activity.

SCCPN will continue discussions with ISD about possible case studies using SHIP to interrogate health information about that is available about chronically vulnerable children.

c. Opportunities in relation to children in receipt of significant support and protection services

Scotland has a hybrid child protection system that comprises the Children's Hearing system and the system of inter-agency procedures for investigation and case conferences. Children may be subject to either or both of these systems. Currently SCRA holds a national database in relation to referrals to Reporters and panel disposals and the Scottish Government holds the national child protection statistics in relation to referrals to local authorities, joint investigations and case conferences. These data sets use different identifiers. There is considerable overlap between these groups of children but it is not possible to gauge the exact number, especially because the child protection and SCRA statistics are not linked.

We recommend that once there is a national individualised (i.e. child level) child protection return it be linked with SCRA data. This could be done probabilistically, but would be more robust if a common identifier was used. The Scottish Government would need to take a lead on this.

This linkage would, at the minimum indicate how many children are subject to dual procedures. It would also allow an aggregate picture of the overall number of children in Scotland about whom there are protection concerns.

A key policy aim is to offer services to children and families before problems become entrenched and before children's development is compromised by chronic neglect. Many children and families across Scotland are provided with support by local authorities or referred for services from voluntary agencies (which are often funded by local authorities). However, because the number of referrals to local authorities and the number of children and families receiving support on a voluntary basis is not recorded consistently or collated on a national basis it will be difficult to gauge the efficacy of this policy. In England, there is an annual Children in Need statistical return which is a valuable source of data of which there is no equivalent in Scotland.

We recommend that local authorities consider collaborating to agree on one consistent method of recording information about all referrals for additional support and / or protection and that work be undertaken to develop a consistent set of data fields across local authorities. If this is not feasible at the minimum a map of equivalent fields in different authority databases would be helpful. A national return would not be required as long as the data could be made available in a consistent form for research, evaluation and service planning purposes.

d. Opportunities to improve support for looked after children

The project to undertake a 100% linkage of CLAS with education data using the SCN is a key development. The Scottish Government Analytical Services, Children and Families is also leading a project to link CLAS data with health data. This linkage would mean that in time for all looked after children in Scotland there will be information about their educational attainment and their health. This dataset could then be used for comparative analysis with population norms for education and health outcomes (perhaps using *Growing up in Scotland* and *Scottish Longitudinal Survey*). The data offers the opportunity for both cross-sectional and longitudinal research into efficacy of services and intervention if supplemented by additional data

collection. If CLAS also included information about the Pathway Plans it would also enable the study of transitions to independent living. Once the new child protection statistical return is available it will also be linked with CLAS.

We recommend that an on-going dialogue be maintained with academics in SCCPN, the Looked After Children Research Network and other stakeholders to ensure that this burgeoning dataset is used to full capacity for research and evaluation. SCCPN will take the lead in maintaining the momentum.

A project to gather looked after children's views via Viewpoint is rolling out across Scotland such that there is an increasing database of information from the young people concerned themselves.

We propose that this dataset be linked with the basic looked after children database, and, in due course, with the enhanced dataset. This could be lead by the Viewpoint project.

e. Opportunities from inspection activity

SCSWIS aims to avoid the introduction of an additional layer of data-collection, and shares the aspiration that existing data be used more effectively to support self-evaluation and external scrutiny activity aimed at improving services. SCSWIS will now have direct input to NIS. SCSWIS also works closely with the Improvement Service to ensure that their activities are congruent and do not entail parallel data collection activities.

SCCPN will continue to liaise with SCSWIS to explore the potential for use of inspection data for research purposes with a view to informing quantitative data with qualitative data from across Scotland inspection. There would also be exploration of the potential for piloting methods for capturing information about service provision and intensity.

It was evident from the consideration of research methodology that rich, qualitative data is required in order to make sense of the range of variables that can impinge on children's development and well-being. The methodology SCSWIS that uses for the joint child protection inspections yields this kind of data. Data protection issues, of course, need to be considered, however, there is an opportunity for a convergence of inspection and research activity.

SCCPN will engage in discussions with SCSWIS to discuss opportunities for greater congruence of inspection and research activity for the next round of integrated child protection inspection.

f. Opportunities to improve knowledge about vulnerable children using existing survey data

In GUS and the SLS, Scotland has two valuable and rich sets of longitudinal information about children. Neither would provide sufficient numbers of children receiving social work support nor sufficient detail about service provision and social and emotional well-being to give a full answer to the question about the effectiveness of intervention. However, both provide potential contextual and comparison data. There are also potential opportunities to supplement the data on existing members of the datasets with more in-depth material, and /or to introduce additional samples using similar methodology.

SCCPN will continue discussions with GUS and SLS to explore the feasibility of developing a research proposal to focus on the issue of children in receipt of significant levels of services.

g. Opportunities for UK wide collaboration and beyond

The seminars enabled SCCPN to identify an international network of experts in data-linkage and / or longitudinal research. Participants in the seminars and potential participants who were not available to present expressed great interest in the aims of the seminars and were keen to remain in contact and to develop collaborative proposals for further work.

SCCPN is co-ordinating a symposium for the BASPCAN national conference drawing from the presentations at the seminars.

The research sub-group of SCCPN, in the first instance, will develop and outline summary for a proposal for a UK-wide project that will take the research ideas from the seminars forward.

The research sub-group of SCCPN will also maintain links with the wider network of experts with a view to developing international comparative studies.

h. Opportunities to share knowledge obtained

SCCPN will maximise the sharing of the knowledge obtained during the course of the programme.

All materials developed – including the programmes, the introductory and summary briefings developed for each seminar, and the presentations (including audio recordings and slides) produced by the speakers – have been uploaded to the SCCPN website. SCCPN and MARS network communications have highlighted their availability. A full list of materials and links is provided in Appendix 1.

A synthesis of the key findings from the programme will be written up as an academic journal paper.

The programme team will meet with representatives from the Scottish Government to present an overview of the programme, share the knowledge obtained and the next steps identified.

Table 2 Summary of proposals and outputs.

Proposals and outcomes	Recommended Lead and partners	Start-time
<i>Opportunity to maintain the momentum</i>		
Establishment of a small data collection and linkage working group.	Scottish Government with NIS, the Improvement service and in collaboration with all relevant stakeholders	Autumn 2011
Explore the feasibility of developing a core minimum dataset.	The established working group.	Spring 2012
Representation of SCSWIS on the NIS strategic oversight group.	NIS	In place

Liaison with the Munro review sub-project on data.	Scottish Government	Autumn 2011
Exploration of possible SHIP case studies in focusing on vulnerable children	SCCPN with ISD	Autumn 2011
Representation of SCCPN the iACT.	SCCPN with iACT	In place
Response to the consultation on the The Public Records (Scotland) Act 2011.	SCCPN	Within consultation timeframe.
<i>Opportunities in relation to children in receipt of significant support and protection services</i>		
Link individualised child protection return with SCRA data.	Scottish Government and SCRA	Once individualised CP return is in place (2012)
Consideration of developing one consistent set of data fields across local authorities.	The established working group	Autumn 2011
<i>Opportunities to improve support for looked after children</i>		
Ensure that the research and evaluation opportunities of the CLAS dataset and its linkages are fully developed.	SCCPN, the Looked After Children Research Network, the New Centre for Residential Care and Scottish Government	Spring 2012
Link the Viewpoint data with CLAS.	Viewpoint project with CLAS project.	Autumn 2011
<i>Opportunities from inspection activity</i>		
Explore the potential for use of inspection data for research purposes.	SCCPN in partnership with SCSWIS.	Autumn 2011
<i>Opportunities to improve knowledge about vulnerable children using existing survey data</i>		
Explore the feasibility of developing a research proposal to focus on the issue of children in receipt of significant levels of services drawing on GUS and / or SLS data.	SCCPN with GUS and SLS	Discussion commenced
<i>Opportunities for UK wide collaboration and beyond</i>		
Co-ordinate a symposium for the BASPCAN national conference drawing from the presentations at the seminars.	SCCPN with seminar contributors	Abstracts all submitted to BASPCAN

Develop an outline summary proposal for a UK-wide project that will take the research ideas from the seminars forward.	SCCPN with academic partners across UK	Outline distributed, follow-up meeting to be held in Autumn 2011.
Maintain links with the wider network of experts with a view to developing international comparative studies.	SCCPN	Following meeting with UK-wide group.
<i>Opportunities to share knowledge obtained</i>		
Audio-record presentations for listen-back by those unable to attend	IRISS and SCCPN	Uploaded to IRISS Learning Exchange and linked to SCCPN web pages specific to the programme
Develop repository of all materials developed for the programme	SCCPN	Website page developed and live
Academic journal paper reporting on key findings of the programme	Programme team	Under development
Meeting with Scottish Government Representatives	Programme team and SUII	Under discussion

References

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Farmer, E.; Sturgess, W.; O'Neill, T. and Wijedasa, D. (in press) *Achieving successful returns from care: What makes reunification work?* London: BAAF.

The Academy of Medical Sciences (2006) *Personal data for public good: using health information in medical research*. London, The Academy of Medical Sciences.

Thomas, R. and Walport, M. (2008) *Data sharing review report*. Report for the Justice Secretary.

McGhee, J. and SCCPN (2011) 'Longitudinal research on children in state protective systems: creating a robust design for a complex multi-professional environment.' Stirling University: SCCPN

Mitchell, F. and SCCPN (2011) 'Data linkage and mining: vision, possibilities and practicalities.' Stirling University: SCCPN.

Appendix 1: Background material and documentation of the workshops

Material	Author	Format
<i>Seminar briefings</i>		
Introductory briefing	Brigid Daniel and SCCPN	
Data linkage and mining: vision, possibilities and practicalities.	Fiona Mitchell and SCCPN	
Longitudinal research on children in state protective systems: creating a robust design for a complex multi-professional environment	Janice McGhee and SCCPN	
	Brigid Daniel and SCCPN	
<i>Speakers presentations</i>		
The Scottish context: scale, scope and potential (slides)	Fiona Mitchell, Scottish Child Care and Protection Network	Audio-recording and slides (pdf)
Collating and connecting multi-sector data for evaluation purposes	Mansoor Kazi, University of Buffalo Slides	Unavailable
The Scottish context: gaps in understanding what's effective in meeting children's needs for care and protection (slides)	Phil Raines, Head of Child Protection Policy Team	Audio-recording and slides (pdf)
Developing multi-sector longitudinal databases (slides only)	Melissa Jonson-Reid, Washington University in St Louis	Slides (pdf)
Current data collection and linkage in Glasgow Child Protection Committee area (slides)	Paul Rigby, Glasgow City Council	Audio-recording and slides (pdf)
Making use of routine data: lessons learned from the Getting It Right For Every Child pathfinder evaluation (slides)	Morag MacNeil/Bob Stradling, University of Edinburgh	Audio-recording and slides (pdf)
Developing outcomes framework for monitoring and evaluation (slides)	David Derbyshire, Action for Children	Audio-recording and slides (pdf)
Visualising data	Rikke Iversholt, Institute for Research and Innovation in Social Services	Audio-recording
Developing a child level minimum data set for 'children in need' and 'looked after' in England (slides only)	June Thoburn, University of East Anglia	Slides (pdf)

Linking national health services data: ISD and the Scottish Health Informatics Programmes (slides)	Steve Pavis, Scottish Health Information Service, ISD	Audio-recording and slides (pdf)
Good governance in data sharing and data linkage for research and evaluation purposes (slides)	Graeme Laurie, University of Edinburgh	Audio-recording and slides (pdf)
Assessing the feasibility of linking datasets (slides)	Phil Anderson, Australian Institute of Health and Welfare	Audio-recording and slides (pdf)
National statistical data returns: linking individual data for looked after children (slides)	Gary Sutton, Analytical Services Unit, Scottish Government	Audio-recording and slides (pdf)
Key messages from the seminar one (slides),	Beth Smith, Director, MARS and Chair person for the seminar	Slides (pdf)
Key issues for longitudinal research design: lessons from Growing Up in Scotland (GUS), (slides)	Paul Bradshaw, Scottish Centre for Social Research	Audio-recording and slides (pdf)
Using routine healthcare data for longitudinal analyses	Ruth Gilbert, Director, Centre for Evidence-based Child Health, Centre for Paediatric Epidemiology and Biostatistics and MRC Centre of Epidemiology for Child Health, University College London - Institute of Child Health	Audio-recording.
Key issues for longitudinal research: a view from overseas, the National Longitudinal Survey of Children and Youth - NLSCY (Canada), (slides)	Stephanie Lalonde, Chief, NLSCY (Canada)	Audio-recording and slides (pdf)
Glasgow Parenting Support Framework Evaluation: school readiness and longitudinal trajectories using the Strengths and Difficulties Questionnaire (SDQ) and linked health data, (slides)	Lucy Thompson, Public Health Resource Unit, NHS Greater Glasgow and Clyde	Audio-recording and slides (pdf)
Survey design issues and child outcome measures in the Millennium Cohort Study, (slides)	Lisa Calderwood, Senior Survey Manager, MCS	Audio-recording and slides (pdf)
An Inspector's view: quantifying intervention and outcomes, (transcript)	Emma McWilliam, Her Majesty's Inspectorate for Education	Audio-recording and transcript (pdf)
Police Analytic Services – capturing intervention, (slides only)	Alison Jaconelli, Strathclyde Police Public Protection Unit	Slides (pdf)

Social work perspective: a longitudinal study of children at risk of significant harm, (slides)	Marian Brandon, University of East Anglia	Audio-recording and slides (pdf)
An example of what can be achieved in data-linkage - SHIP, (slides only)	Steve Pavis, Head of Programmes, Information Services Division (ISD) of National Health Services Scotland	Slides (pdf)
An example of a good governance structure – SHIP, (slides only)	Nayha Sethi, Research Fellow, School of Law, University of Edinburgh	Slides (pdf)
An example of what can be achieved with data linkage and longitudinal research - SLS, (slides only)	Chris Dibben, Lecturer in Health Geography, University of St Andrews	Slides (pdf)
Insights from a study of the reunification of looked after children with their parents, (slides only)	Elaine Farmer, Professor of Child and Family Studies, Centre for Family Policy and Child Welfare, University of Bristol	Slides (pdf)
Better information and research for better child well-being - a vision for Scotland, (slides only)	Fiona Mitchell and Janice McGhee, SCCPN	Slides (pdf)

Appendix 2: List of participants

<i>Seminar 1: Data linkage and mining: vision, possibilities and practicalities</i>	
Alison Jaconelli	Strathclyde Police
Andrea Lockhart	Dumfries and Galloway Council
Anthea Springbett	NHS NSS Information Services Division
Beth Smith	Multi-Agency Resource Service (MARS)
Brian Yule	Grampian Police
Caroline Hand	East Dunbartonshire Council
Catherine Nixon	Medical Research Council
Catriona Laird	Multi Agency Resource Centre
David Blair	Scottish Government
David Derbyshire	Action for Children
Donald Lamb	Scottish Children's Reporter Administration
Gillian Henderson	Scottish Children's Reporter Administration
Fiona Steel	Action for Children
Frank Popham	University of St Andrews
Gerry Higgins	Fife Council
Gillian Buchanan	Scottish government
Graeme Laurie	University of Edinburgh
Graeme Mitchell	ACPOS Information Management Project
Ian Barron	University of Dundee
Ian Milligan	Scottish Institute for Residential Child Care
Jeremy Akehurst	The Moray Council
Jillian Russell	North Ayrshire Child Protection Committee
June Thoburn	University of East Anglia
Lawrie Elliott	Edinburgh Napier University

Lisa Bennett	Scottish Children's Reporter Administration
Louise Hill	University of Edinburgh & NSPCC
Mansoor Kazi	University of Buffalo (The State University of New York)
Marian Martin	HMIE
Marion Macleod	Children in Scotland
Mike Palmer	Scottish Government
Morag MacNeil	University of Edinburgh
Nadine Dougall	University of Stirling
Paul Bradshaw	Scottish Centre for Social Research
Peter Traynor	ACPO(S) National Information Management Project
Phil Anderson	Australian Institute of Health and Welfare
Philip Raines	Scottish Government
Rikke Iversholt	Institute for Research and Innovation in Social Services
Robert Stradling	University of Edinburgh
Rod Harrison	Scottish Governemnt
Stephen Pavis	Information Service Division, NHS
Stuart Osborough	City of Edinburgh Council
Trisha Hall	Aberlour Child Care Trust

Seminar 2: Design and methodology in longitudinal research: scope, approach and practicalities

Alison Jaconelli	Strathclyde Police
Anthea Springbett	NHS NSS Information Services Division
Autumn Roesch-Marsh	University of Stirling
Bob Stradling	(retired)
Catherine Nixon	MRC/CSO Social and Public Health Sciences Unit
Cherilyn Dance	Tilda Goldberg Centre for Social Work and Social Care

Dr John O'Dowd	NHS Greater Glasgow and Clyde
Emma McWilliam	Social Care and Social Work Improvement Scotland – SCSWIS
Euan McKay	East Dunbartonshire Council
Gary Sutton	Scottish Government
June Thoburn	University of East Anglia
Lucy Thompson	NHS Greater Glasgow and Clyde
Marian Brandon	University of East Anglia
Marian Martin	HM IE
Morag MacNeil	(retired)
Paul Bradshaw	Scottish Centre for Social Research
Philip Raines	Scottish Government
Rebecca Brown	Centre for Child and Family Research, Loughborough University
Stephanie Lalonde	Statistics Canada
Steven Dalton	Scottish Government
Trisha Hall	Aberlour Child Care Trust
Wendy VAN RIJSWIJK	Scottish Government

Seminar 3: Consolidating collaborative partnerships: sharing and applying knowledge

Gary Sutton	Scottish Government
Alison Jaconelli	Strathclyde Police
Marion Macleod	Children in Scotland
Maggie Mellon	Scottish Child Law Centre and NHS Health Scotland
Kirsty Markie	Improvement Service
John Devaney	Queen's University Belfast
Donald Forrester	Tilda Goldberg Centre
Konrad Zdeb	The Improvement Service

Lucy Thompson	NHS Greater Glasgow and Clyde
Nadine Dougall	University of Stirling
Philip Raines	Scottish Government
Marian Martin	HMIE
Stephen Pavis	NHS, Information Services Division
Peter Traynor	ACPOS
Catherine Nixon	MRC/CSO Social and Public Health Sciences Unit
Caroline McConnell	East Dunbartonshire Council
Jean Soper	Loughborough University
Louise Hill	University of Edinburgh & NSPCC
Brigid Daniel	Stirling University
Cherilyn Dance	University of Bedfordshire
Mansoor A. F. Kazi	University at Buffalo (The State University of New York)
Clare Lushey	Centre for Child and Family Research, Loughborough University
Emma McWilliam	Social Care and Social Work Improvement Scotland
Anthea Springbett	NHS NSS Information Services Division
Robert Wilmot	Glasgow Children's Panel
Mark McAteer	The Improvement Service

Appendix 3: List of useful resources and sources of further information

The Administrative Data Liaison Service (ADLS)

The Administrative Data Liaison Service (ADLS) is funded by the ESRC to support administrative data based research in the UK. The ADLS does not hold administrative data. Its function is to act as an intermediary between academic researchers and data holding organisations to provide information, aid with communication and promote the use of administrative data. <http://www.adls.ac.uk/>

eCare Programme

There are various reports documenting the development of the eCare programme available on the Scottish Government website:

<http://www.scotland.gov.uk/Topics/Government/PublicServiceReform/efficientgovernment/DataStandardsAndeCare>

Of particular relevance is the specifications developed for the eCare Multi-Agency Store (MAS) Data Model, with the latest report Version 2.9 available online:

<http://www.scotland.gov.uk/Resource/Doc/82980/0059166.doc>

Evaluation of the Highland pathfinder for Getting it right for every Child

An evaluation report of the development and early implementation phases of *Getting it right for every child* in Highland 2006 - 2009. Full report: <http://www.scotland.gov.uk/Publications/2009/11/20094407/0>

Executive summary: <http://www.scotland.gov.uk/Publications/2009/11/20094457/0>

Briefing 5:

<http://www.scotland.gov.uk/Topics/People/Young-People/childrenservices/girfec/publications/Briefing5>

Briefing 7:

<http://www.scotland.gov.uk/Topics/People/Young-People/childrenservices/girfec/publications/Briefing7>

Scottish Health Informatics Programme (SHIP)

SHIP is an ambitious, Scotland-wide research platform for the collation, management, dissemination and analysis of Electronic Patient Records (EPRs). The programme brings together the Universities of Dundee, Edinburgh, Glasgow and St Andrews with the Information Services Division (ISD) of NHS Scotland. SHIP is funded by the Wellcome Trust, the Medical Research Council and the Economic and Social Research Council. The programme of work is centred around a core set of four generic activities (C1-C4): provisioning of datasets for research (C1); governance (C2); engaging researchers (C3); and engaging the public (C4). These activities will develop the infrastructure for inter-organisational data sharing in Scotland and build capacity to provide a sustainable future for EPR research

<http://www.scot-ship.ac.uk/>

http://www.scot-hip.ac.uk/sites/default/files/Reports/Guiding_Principles_and_Best_Practices_221010.pdf

Scottish Collaboration for Public Health Research and Policy (SCPHRP)

The Scottish Collaboration for Public Health Research and Policy (SCPHRP) is a public health consortium of members drawn from research, policy and practice. It has been tasked with creating strategies to tackle Scotland's poor health record. The Collaboration is dedicated to identifying opportunities to develop novel public health interventions that will equitably address major health problems in Scotland.

<https://www.scphrp.ac.uk/>

Social Care and Social Work Improvement Scotland (SCSWIS)

Scottish Ministers are taking the lead in developing a more systematic and proportionate approach to performance management in children and young people's services. They have also asked Social Care and Social Work Improvement Scotland (or SCSWIS), working with other scrutiny bodies, to develop an improved way of scrutinising children's services in Scotland. The first stage of the process identifies what the new system will cover, setting out the policy framework and required outcomes in terms of information gathering and policy implementation. It is being led by the Scottish Government, with input from the scrutiny bodies. The aim is to have this stage completed and agreed by the SCSWIS Board and signed off by Ministers by end July 2011.

<http://www.scotland.gov.uk/Topics/People/Young-People/childrenservices/girfec/publications/scswis>

Growing Up in Scotland Study (GUS)

GUS is tracking the development of a large sample of children across Scotland from infancy through to adolescence. The aim is to provide information to support the development of policy and to plan services for children and their families www.crfr.ac.uk/gus/index.html

The Millennium Cohort Study (MCS)

MCS is a multi-disciplinary research project following the lives of around 19,000 children born in the UK in 2000/1. The Economic and Social Research Council (ESRC) commissioned it and a consortium of Government departments and the Wellcome Trust has supplemented funding. The study aims to provide a better understanding of the social conditions surrounding birth and early childhood and potentially resolve many of the issues about their long-term impact. These include issues of central policy interest such as the foundations of social capital and cohesion.

www.cls.ioe.ac.uk/text.asp?section=000100020001

National Longitudinal Survey of Children and Youth (NLSCY)

NLSCY is a long-term study of Canadian children that follows their development and well-being from birth to early adulthood. The study is designed to collect information about factors influencing a child's social, emotional and behavioural development and to monitor the impact of these factors on the child's development over time.

www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=4450&lang=en&db=imdb&adm=8&dis=2

National Survey of Child and Adolescent Well-Being (NSCAW)

NSCAW 1997-2010 is a sample of more than 5,501 children (ages 0 to 14) from 97 child welfare agencies nationwide. It was drawn from cases investigated/assessed by local child protective services (CPS) agencies, and includes both opened and unopened cases. It includes children at home and in out-of-home care and is designed to allow in-depth analyses of subgroups of special interest (e.g., young children or adolescents in foster care) while providing national estimates for the full population of children and families entering the system. The core sample is supplemented by a sample of 727 children who have been in foster care for a longer period, to allow additional analysis of issues related to this group.

www.acf.hhs.gov/programs/opre/abuse_neglect/nscaw/